

**DIRECT SUPPORT PROFESSIONALS' PERSPECTIVES
AND ROLE PERCEPTIONS IN THE FIELD OF
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

by

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GLOSSARY

Ableism- a set of discriminatory attitudes, practices, and beliefs that systematically assign inferior value or worth to disabled people

Access need- the needs we have to access a space; to live, move and be in a space well.

Activities of daily living- daily self-care activities including bathing, dressing, toileting, medication, etc.

Adaptive skills- a collection of skills learned and performed in everyday life

Day program- center-based care that provides clients with supervision, social support, and support with activities of daily living

Direct support professional- someone who provides primarily non-medical hands-on supports, training, and supervision, and personal assistance to adults with intellectual and developmental disabilities

Group home- a home where a small number of unrelated people in need of care, support, or supervision live together and receive services

Intermediate care facilities- long-term care facility of 4 or more beds that provides nursing and supportive care to residents

Independent living- a philosophy, social movement, and governmental program that says every person, regardless of disability has the potential and right to exercise individual self-determination

Interdependence- a consensual, mutual reliance on others of giving and receiving care and meeting each other's access needs

Instrumental activities of daily living- type of activity of daily living related to independent living including preparing meals, managing money, doing laundry, etc.

Person-centeredness- a model of service-providing that focuses on the disabled person in every aspect of planning and providing services

Person-directed- services designed by the person, where that individual can decide what services they will receive, and who, when, where, and how those services will be provided.

Pre-vocational support- center-based services intended to teach general work skills and concepts in preparation for work

Self-determination- belief that all people must have opportunities and experiences that enable them to exert control in their lives and advocate on their own behalf

Sheltered workshop- segregated work environment and institution intended to keep disabled employees “safe” and learn job skills to prepare for competitive employment

Supported employment- services provided individually in the community to support a person in obtaining and maintaining competitive employment

Waiver- a state-specific Medicaid program that allows for services to be provided outside of nursing homes

LIST OF ABBREVIATIONS

ADLs- activities of daily living

CNA- certified nursing assistant

DSP- direct support professional

HCBS- home and community-based services

IADLs- instrumental activities of daily living

ICF- intermediate care facility

I/DD or IDD- intellectual or developmental disability

LTSS- long term supports and services

NADSP- National Alliance for Direct Support Professionals

NCI- National Core Indicators

NLCDD- National Leadership Consortium on Developmental Disabilities

PCA- personal care assistant

ABSTRACT

The systemic failure in the long-term services and supports sector for adults with intellectual and developmental disabilities (IDD) is characterized by a multi-decade long period of disinvestment in the field of direct support. Direct support professionals (DSPs) continue to be in high demand, while efforts to recruit, train, and retain these professionals pose challenges. As the field is evolving, the roles and responsibilities of these professionals are essentially shifting as well. During this crisis, DSPs have specific needs in order for them to succeed and promote quality outcomes for the people they support. This study examines the perspectives and role perceptions of direct support professionals who work directly with adults with intellectual and developmental disabilities, to answer two primary research questions: 1) How do the role perceptions of direct support professionals differ between agencies across the spectrum of service providing? and 2) What is needed in the field to better support direct support professionals?

While many studies track changes in the role responsibilities of direct support professionals with the evolution of service delivery from traditional, congregate control towards supporting self-determination, this project calls into question how those roles are defined. It recognizes and appreciates the knowledge of direct support professionals around their own profession and aims to understand how role perceptions might vary and thus impact the quality and nature of the supports provided to adults with IDD. This research will also examine what these professionals need from their supervisors to improve the quality of supports and services they provide, and to address the incredible rates of turnover and vacancy in the field.

This qualitative research study consists of case studies at five agencies and a national DSP survey disseminated by the National Alliance for Direct Support Professionals (NADSP). The results of the study find that role perception does change across the spectrum of service providing, with DSPs from more traditional agencies often maintaining more traditional role perceptions, specifically an emphasis on activities of daily living (ADLs), health and safety, and dispensing medications. DSPs at more innovative agencies tended to have more innovative role perceptions, including an emphasis on self-determination, choice, and non-locational or not task-based uses of community. The study identified six support needs for DSPs including: improved access to training opportunities, reliable and quality staffing, reasonable job expectations, fair compensation and recognition, quality and participatory management practices, and adequate funding for basic needs. The implications of this research can impact how role perception is conceptualized in DSP selection, training, and evaluation and the need for service providers to adopt evolving role definitions to improve quality of services. Additionally, this research can support the discovery of alternatives to address the DSP workforce crisis by centering the voices of direct support professionals themselves.

Chapter 1

A NOTE ON TERMINOLOGY

Throughout the course of this paper, I will be using a variety of terminology that I would like to provide a note on in advance. My primary objective in doing so is to: 1) use the definitions to provide a common basis of understanding about such terminology; 2) provide context to historical terms; and 3) add to the discussion about language currently used in the field. The changes in service-providing and societal expectation towards disability spur continued changes in the language used to discuss or describe disability. A variety of terms and acronyms used in this paper are commonplace within the field today or are used from a historical context. Many of those terms are defined and explained in the glossary and in the list of abbreviated terms, and this section provides context and discussion to those definitions. Some language I use in the course of my paper is also in support of a contemporary approach to language around disability that is not agreed upon in the professional or academic communities.

First, the term *intellectual and developmental disability (I/DD)* is the current, most accepted term to describe this population. An intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) as “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, as expressed in conceptual, social, and practical adaptive skills. The disability originates before age 18” (2010, pg 1). *Adaptive skills*, one of the areas identified as an area of limitation for people with intellectual disabilities, are

simply a collection of skills learned and performed in everyday life (AAIDD, 2010). A *developmental disability*, on the other hand, is an umbrella term that encompasses intellectual disability as well as other disabilities that occur during childhood. It is defined as

a severe, chronic disability of an individual 5 years of age or older that (a) is attributable to a mental or physical impairment or a combination of mental and physical impairment; (b) is manifested before the individual attains age 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency and (e) reflects the individual's need for a combination of special, interdisciplinary, or generic service, individualized supports, or other forms of assistance that are lifelong or of extended duration and are individually planned and coordinated (Developmental Disabilities Assistance and Bill of Rights Act of 2010, PL 106-402; 102(8)(a)).

Often the terms intellectual and developmental disability are used together to represent the wide-array of people who have disabilities that were acquired in childhood. In the course of this paper, I will use the terms together and interchangeably.

The term intellectual and developmental disability has not always been the term used to refer to people with I/DD. Instead, terms like “simpleton,” “feble-minded,” “idiot,” “moron,” “mentally retarded,” “mentally challenged,” and others have historically referred to the I/DD community. These terms, while seen as

harmful and offensive slurs today, were well-used in their times and were considered the commonly accepted term by families of persons with disabilities and the medical community. In the course of this paper, I will most often use the term “person with an intellectual or developmental disability,” though in sections relating to the historical foundations, I may use terminology that was appropriate or widely used in the time period being referenced. The language is to reflect the historical foundations and is not intended to cause offense to the reader. At this time, I will also call attention to the potential that future readers of this paper might find offense in the language I am using as the field continues to shift. My hope is this background will provide context to the language I am using as it relates to the current accepted terminology, and that we all can look at how language can be reflective of thought and broader society values.

In the course of my paper, I will most likely alternate between *person-first language* and *identity-first language*. Person-first language puts the person before the disability, describing what that person “has” not who a person “is” (Snow, 2001). This language practice eliminates many stigmatized words and phrases, like “the handicapped”, “suffers from...”, “mongoloid”, etc. and hopes to recognize the humanity of each person. Many disabled people however, prefer identity-first language. Jim Sinclair is often attributed with coining the idea of identity-first language, which recognizes that disability is inextricably linked with the person and is central to disabled people’s identities and lived experiences (Sinclair, 2013). Since I will be using both interchangeably, I may refer to “people with disabilities” (person-first) or “disabled people” (identity-first) throughout my paper.

The professional community is not in agreement as to appropriate terminology, however in my personal life, I prefer the use of “disabled people” to reflect a support

for the voices of the disability community who understand disability as central to their identities and beings. I often avoid “person-first language” since many disabled people see it as an act of violence towards their body-minds, essentially removing their disability from their being. Many disabled people see “person-first” language as an erasure of their experience, that when someone for instance says a “person with autism” they are basically saying, “it is unfortunate and an accident that a person is Autistic...[and that] Autism is detrimental to value and worth as a person” (Brown, 2011). “Person-first” language puts disability as a malady people have and not something to be embraced as part of one’s identity. Professionals, especially non-disabled professionals, as well as many parents of disabled people, might disagree with my choice to use identity-first language. However, it is with conscious intent that I choose to use this language and stand in solidarity with politically-organized disabled people. However, to vary sentence structure throughout my paper and with a belief that alternating these approaches most likely will not cause harm, I will use both interchangeably.

The focus of this study is on the *long-term services and support sector* (LTSS). Long term services and supports refer to the services and supports used by individuals with functional limitations who need assistance to perform activities of daily living (ADLs). *Activities of daily living* can include bathing, dressing, grooming, preparing meals, household chores, and administering medications. ADLs typically refer to the activities focused on personal care, that of dressing, grooming, toileting, etc. *Instrumental activities of daily living* (IADLs), a subtype of ADL, focus on activities that are instrumental to someone’s life without relating to direct physical care, including telephone use, managing finances, household chores, laundry, or preparing

meals (Jefferson, Paul, Ozonoff, & Cohen, 2006). In the United States, Medicaid, Title XIX of the Social Security Act of 1965 (PL 89-97), is the primary funder for LTSS in a variety of settings.

This study is particularly interested in direct support professionals who are providing the long-term services and supports. *Direct support professionals* (DSPs) are operationally defined for this study as: “1) someone who provides primarily non-medical hands-on supports, training, and supervision, and personal assistance to adults with intellectual and developmental disabilities; 2) is at least 18 years of age; and 3) works either full-time or part-time as a direct support professional.” This definition excludes direct support professionals that have additional duties related to administration or shift supervision (often referred to as “coordinators,” “lead staff,” and “house managers”).

DSPs are often referred to more colloquially or operationally as “caregivers,” “aides,” “teachers,” “job coaches,” “inclusion specialists,” and a variety of other titles. Their work currently falls primarily under three standard occupational codes in the Bureau of Labor Statistics: 1) personal care aides (PCAs), 2) home health aides, and 3) certified nursing assistants (CNAs). *Personal care aides*,

assist the elderly, convalescents, or persons with disabilities with daily living activities at the person’s home or in a care facility. Duties performed at place of residence may include keeping house (making beds, doing laundry, washing dishes) and preparing meals. [Personal care aides] may provide assistance at non-residential care facilities [and] may advise families, the elderly, convalescents, and persons with disabilities regarding such things as nutrition, cleanliness, and household activities (U.S. Bureau of Labor Statistics, 2017c).

Home health aides have a slightly different job description and are defined as people who,

provide routine individualized healthcare such as changing bandages and dressing wounds, and applying topical medications to the elderly, convalescents, or persons with disabilities at the patient's home or in a care facility. [Home health aides] monitor or report changes in health status [and] may also provide personal care such as bathing, dressing, and grooming of patient (U.S. Bureau of Labor Statistics, 2017a).

Lastly, *Certified Nursing Assistants* (CNAs), “provide basic patient care under [the] direction of nursing staff. [CNAs] perform duties such as feed, bathe, dress, groom, or move patients, or change linens” (U.S. Bureau of Labor Statistics, 2017b).

The three job roles share various elements and have similar responsibilities and purposes.

Direct support professionals, while often captured within these codes, are inadequately understood through these titles. While sharing some similarities to PCAs, home health aides, and CNAs, DSPs occupy a unique and particular field in supporting adults with I/DD. The role of direct support professionals is of unique interest for the purpose of the study and will be further discussed throughout the paper, but at this time, it is helpful to present an operational definition of the term direct support professional, as well as the terms of the three job categories that DSPs currently fall under. The primary reason for this is to create a point of comparison and differentiation as well as to substantiate some of the claims and critiques made of the role definitions of direct support. There are significant implications of the refusal of

the Department of Labor to create a separate category for DSPs under the Bureau of Labor Statics, that will be discussed in a future section.

There are a variety of terms that are used throughout the field to describe values-based beliefs and current approaches to disability service providing that might be useful to have defined here as well. The field refers to a variety of terms, in no particular order, such as 1) person-centered supports; 2) self-determination; 3) independent-living; 4) interdependence; 5) integration; and 6) inclusion.

Person-centeredness refers to a model of service-providing that focuses on the disabled person in every aspect of planning and providing services. In an aspirational form, the person is the main priority and all services and supports revolve around and are specified to that individual, their strengths, needs, dreams, and ambitions. Person-centered supports differ from *person-directed supports*, where the supports are not just designed around the person, but are designed by the person, where that individual can decide what services they will receive, and who, when, where, and how those services will be provided. Person-directed services and supports are usually person-centered; however, some supports that are defined as “person-centered” aren’t always person-directed.

Self-determined behavior is defined as “volatile actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). Self-determination means that people get to live the lives they choose to live for themselves, and that decision-making and agency rests in the hands of the individual. Truly great lives are ones that are self-determined, which is an instrumental component to building quality services. Throughout the course of

the paper I will discuss self-determination and how direct support professionals have the potential to serve as promoters of self-determination.

Independent-living is both a federal program, a historical movement, and a philosophy/ideology. As a program, independent living centers are cross-disability, community-based non-profits that are created and operated by disabled people (Administration for Community Living, n.d.). These centers can connect people to services and supports that help them to live in their communities. I will briefly discuss the independent living movement in a later chapter about disability history. The independent living movement was during the process of deinstitutionalization where people with significant disabilities for the first time were able to live free and independent lives. This movement was a civil rights movement for people with disabilities and the philosophy gained influence and served as the basis for the passage of the Americans with Disabilities Act of 1990 (PL 101-336). As a philosophy, the independent living movement accentuates consumer control over services and the centering of disabled voice in decision-making especially in regard to services that impact their livelihood and independence.

Some critique the concept of *independence*, instead calling for a societal shift towards truly *interdependent* societies. Independence, some even label as rugged individualism, focuses on living as a monolith without the support of others and centers “overcoming” in order to do things on one’s own. It’s a term that is embedded throughout the disability services field, emphasizing the accomplishment of tasks including accomplishing ADLs and IADLs on one’s own. This emphasis on overcoming reinforces capitalistic and ableist ideals that productivity and self-sufficiency are the ultimate goal. Ableism is a set of discriminatory attitudes,

practices, and beliefs that systematically assign inferior value or worth to disabled people and is often imbedded in the pursuit of independence and the requirement of disabled people to “overcome” their disability to attain value in our society.

Independence also focuses on the notion that seeking care essentially makes you weak or less than. It definitionally ignores the active role of care-giving and care-receiving that all people are a part of. With an emphasis towards independence, the necessity of direct support professionals in building the ideals of community access and self-determination is ignored.

Interdependence, however, is bidirectional about mutual reliance that is a valuable and celebrated part of society. It recognizes people as having access needs that can only be met through other people and supports. Interdependence allows for supports to exist and doesn't require any form of “overcoming” to reach independence. Judy Heumann, one of the founders of the Independent Living Movement once said, “To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a normal body” (cited in Stoddard 1978, 2). Ultimately, this rings true to the concepts of the more modern term, interdependence, which recognizes that part of the human experience requires a reliance on others. I argue this idea lives in line with the ideals and philosophy of the so-called independent living movement.

The last two terms, *integration* and *inclusion* are related but have critical distinctions of note. Integration is the incorporation of individuals from different groups, for instance, disabled and non-disabled people occupying the same space. This term was often used in the civil rights movement calling for the integration of blacks and whites and an ending of Jim Crow-era segregation. Integration alone is not

sufficient for building meaningful, thriving, and cooperative communities or relationships. Inclusion takes integration a step further, focusing on the role of disabled people as equally participating and valued neighbors and citizens. People are not just occupying the same physical space but are also interacting as equal members in society. Inclusion International, an international network of people with intellectual disabilities and their families, defines five principles of Inclusion in their “Statement of Unity”. They define that inclusion:

1) supports people with intellectual disabilities to have control over their lives and to make choices and decisions in their lives; 2) requires that people with intellectual disabilities be accepted as full and equal members of their family and community; 3) requires the removal of social, cultural, economic and political barriers that prevent people with intellectual disabilities from full and equal participation in all aspects of community life; 4) is about full and equal participation in using mainstream services and is not consistent with segregation or segregated facilities; and 5) celebrates diversity and equality, as the key to building stronger and better communities”(Inclusion international, n.d.).

These pillars recognize other themes important to the field, like self-determination, defined earlier, and community access.

Some argue however, that the term “inclusion” while a commonly used ideal today, is not sufficient. Inclusion still maintains a power-dynamic that allows groups in power to choose to include or exclude. It doesn’t dismantle oppression, and often tries to make people “appear equal” or “appear normal” rather than actually disrupting the systems that seek to exclude and punish difference. As a term, it doesn’t fully

capture long histories of segregation and marginalization, and the long path towards building just, anti-ableist spaces, that also destroy other forms of oppression. In addition to dismantling the systems that seek to exclude, inclusion alone doesn't consider people's life outcomes and the way they build interactions between others and their community. Sense of belonging research pushes past just including people to understand how people belong to their communities. A group of researchers examined the intersections of faith, flourishing, and disability. They developed dimensions for belonging, that while tied to fostering belonging in church congregations, can be extrapolated to broader disability outcomes. The dimensions of belonging include: 1) to be present; 2) to be invited; 3) to be welcomed; 4) to be known; 5) to be accepted; 6) to be supported; 7) to be cared for; 8) to be befriended; 9) to be needed; and 10) to be loved (Carter, 2016). These dimensions are possibilities for considering outcomes for disabled people that go far beyond integration or inclusion.

Ultimately, this note on terminology calls on the importance of language in shaping ideas and thoughts. It also serves to clarify the approach I, as a researcher, am taking on these issues. I recognize disability issues to be social justice issues, as are the rights and just treatment of direct support professionals. I envision a world where people belong to their communities, where their gifts and talents are celebrated, and where everyone's access needs are met. This envisioning is integral to the work of disability justice, that reimagines the body-mind and that seeks for equity across the many identities we all hold. This note on terminology, serves as a way to position my project in light of an ongoing social movement, and to present my approach to this work and the necessary impact that has on my research.

Chapter 2

INTRODUCTION

The intellectual and developmental disabilities (IDD) service sector is constantly changing in the United States. In 2015, an estimated 895,690¹ adults over 21 years old and 1.4 million total individuals with intellectual and developmental disabilities were receiving or formally waiting for publicly funded long term supports and services from their state IDD agencies (Larson et al., 2017). Many rely on these services in order to access the community and live self-determined lives. The supports are vital to the health, wellbeing, and equitable access to opportunities for many disabled people.

2.1 Historical Framework

To understand disability service providing in the United States, one must understand the history of the sector. Historically individuals with intellectual and developmental disabilities, formerly referred to as mentally retarded, were “treated” in large state institutions. In the 1950s and 1960s, institutionalization of the mentally retarded began to grow tremendously, often attributed to the post WWII baby boom. Medical professionals encouraged parents to place their children into state institutional care. In 1950, 148,209 people lived in state operated facilities of sixteen or more people and this population peaked in 1967 with 228,500 people living in state operated IDD facilities (Larson et al., 2017). From 1970 on, each five-year interval exceeds a

¹ The caseload total includes people with IDD who receive services, are waiting for services or are known to but not receiving services under the auspices of the state IDD agency.

reduction of 3% in large state IDD facilities (Larson et al., 2017). This period is known as deinstitutionalization and represents a transformation in service provision. This shift is instrumental in understanding the role of contemporary direct support professionals (DSPs) and the direction of the field. In addition, this shift is necessary to evaluate how services are still institutional in nature and how to create systems-change in the way services are provided in the U.S.

The large reductions in institutionalized populations were driven by a variety of major events spurred by the efforts of organizers and policymakers. In 1966, Blatt and Kaplan released “Christmas in Purgatory” an expository photojournalistic essay that ties together photos Kaplan took undercover in an institution. The images reveal the horrible conditions within state institutions, including people stripped of their clothing, sitting idle all day. Similarly, Geraldo Rivera’s documentary, *Willowbrook: The Last Great Disgrace*, was released in 1972, exposing the realities of the worst state institution in New York. Similar documentaries and exposes were released throughout the deinstitutionalization of many institutions in the United States. They are horrific to watch and are often cited as major events and motivators for the process of deinstitutionalization.

Alongside the work of parent organizers, disabled activists were demanding change. Pressure from activists enabled the implementation of Section 504 of the 1973 Rehabilitation Act (Rehabilitation Act of 1973, PL 93-112) which was the first civil rights protection for disabled people in the U.S. The Rehabilitation act declares that individuals with disabilities have a right to: “a) live independently; b) enjoy self-determination; c) make choices; d) contribute to society; e) pursue meaningful careers; and f) enjoy full inclusion and integration in the economic, political, social, cultural,

and educational mainstream American society” (29 USC 701(a) (2)). Section 504 specifies that any entity which receives federal dollars cannot discriminate against people with disabilities. It is important to note that while these ideas and protections were put into law, that did not translate to what actually happened in the service sector.

Within this context, Wolfensberger and others asserted a concept of normalization (1972) which argued that disabled people deserve access to a normal rhythm of the day, routine developmental experiences and economic standard, as well as the chance to make choices and to live, work, and play in their community. This was a major bolster in the independent living movement and played a significant role in deinstitutionalization. It serves as a basis for future developments toward self-determination and the push for equitable, self-directed services. Some of the concepts Wolfensberger uses (Wolfensberger, 1972) can be found in the mission statements of many agencies around the country today.

A series of lawsuits challenged institutional care in the 1970s also contributing to deinstitutionalization and a shift to community-based services. In 1971, *PARC v. the Commonwealth of Pennsylvania* (1971), mirrored the *Brown v. Board* decision in Kansas (*Brown v. Board of Education*, 1954) to include people with disabilities in accessing education. *Wyatt v. Stickney* (1971), a court case tried in federal court in Alabama, required institutions to treat or educate their residents. In *Mills v. Board of Education of District of Columbia* (1972) the courts linked the language of *Brown v. Board* (1954) to include people with disabilities, reasserting the right that all children have to a free and appropriate public education. Another court case was filed in response to the inhumane living conditions at Willowbrook State School (*New York*

State Association for Retarded Children, Inc. v. Rockefeller, 1973). Collectively, the work of disabled activists, parent groups, court cases and legislation, led to a shift in services, moving to deinstitutionalize people with intellectual and developmental disabilities and promote community access. With people leaving institutions, a new wave of service providing emerged.

2.2 Medicaid

Medicaid is an individual entitlement program that is the primary provider of health insurance for people with significant disabilities. Medicaid is jointly funded by state and federal governments and for every \$1 expended by a state, the federal government matches at least \$1 (42 CFR§ 433.10(b)). States run their own programs within federal requirements. Those requirements are very broad, so states maintain significant flexibility and can add additional services or beneficiary categories. Medicaid remains a significant part of the U.S. budget each year. Medicaid is actually the largest portion of a state budgets depending on how they finance public education.

Most persons with disabilities who receive Supplemental Security Income (SSI), a Federal income supplement program funded by general tax revenues, are eligible for Medicaid. Medicaid is often confused with Medicare, a federal health insurance program. Some disabled people are dually eligible for both Medicaid and Medicare. The modern wave of service-providing is often based off of funding from Medicaid reimbursements. Since many service-providers rely on Medicaid funds to operate their services, those that receive Medicaid funding are also required to live by the standards and rules Medicaid establishes.

2.2.1 HCBS Rule

The Home and Community Based Services Waiver is one of the major funders for disability services. A waiver program is a state-specific Medicaid program that allows for services to be provided outside of nursing homes. In 2014, the Center for Medicare and Medicaid Services (CMS) released a new rule, that its waiver funds cannot be used on settings that isolate people. The HCBS Settings Final Rule (CMS 2249-F/2296-F) set out a series of specific quality requirements for agencies in order to continue receiving state and federally funded HCBS funds. These new standards are experiential and are more about the qualities of the setting than previous guidelines. The requirements are incredibly lengthy, and many agencies currently do not adhere to the new guidelines. The timeline for implementation of the rule has been extended, now allowing states until March 17th, 2022 to reach compliance (HCBS Advocacy Coalition, 2019). It is one of the most influential rules impacting the disability community and is encouraging change within many agencies, incentivizing truly person-centered models of support. The implementation of the final rule unfortunately has also led organizations to attempt to get around the regulations or try to “appear compliant” rather than actually adjusting and changing their services. There has been major push back to the rule itself and what it represents. The HCBS rule represents the shift of service providing from more institutional frameworks towards truly measuring what is a “home and community based” service and serves as a major step in the right direction for service quality.

2.2.2 Waiting Lists

Unfortunately, there are huge waiting lists to receive funding for services in many U.S. states. Attacks on Medicaid and Medicare could further increase waiting

lists and deny access to services for many disabled people. In 2017, the Kaiser Family Foundation calculated that are currently 707,000 people waiting to receive Medicaid-funded HCBS services and that waiting times averaged around 30 months across all waivers with waiting lists (Kaiser Family Foundation, 2019). Ultimately, this means that disabled people are going without needed supports to live their lives. Often, due to long waiting lists, people are forced into institutional care, in order to receive any services from the state. The system is still set up with an institutional bias in Medicaid services, that prevent people from living the lives they want in their communities. About half of Medicaid dollars go towards nursing homes, and nationally people with disabilities are currently only entitled to receiving nursing home services and can receive home-based care usually only if their states have special waivers (Gleckman, 2013). Home and community-based options are underfunded, face long waiting lists, so often people are still forced into institutional care.

Recognizing how many agencies are funded primarily through Medicaid, is also important to understanding the issues direct support professionals (DSPs) face in receiving fair and equitable compensation. As will be discussed, DSPs face historically low wages, and this is often due to the low reimbursement rates set by Medicaid for HCBS settings.

2.3 Workforce Crisis and Systemic Failure in Service Providing

The changing policy landscape around disability service providing, with a shift from institutional, congregate care towards increasingly home and community-based services, materialized a need for a widened direct support workforce with broadened competencies. There is a great and increasing demand for direct support professionals (DSPs) while a lagging ability to recruit, train, and retain skilled individuals. Persistent

low wages and benefits (Bogenschutz, Hewitt, Nord, & Hepperlen, 2014), poor training, supervision, and lacking opportunities for advancement and professional development (Bogenschutz, Nord, & Hewitt, 2015), have resulted in a multi-decade long period of high turnover and poor retention (President’s Committee for People with Intellectual Disabilities, 2017). The current state of the direct support professional workforce has been coined a crisis, but some argue that this is far too ongoing and persistent to be considered so any longer: “A 30-year crisis is not a crisis; it is a systemic and pervasive failure in the long-term services and support system in the United States” (Hewitt, Macbeth, Merrill, & Klesit, 2018). This systemic failure is characterized by multiple decades of disinvestment in the direct support professional workforce and poor attention from policymakers, researchers, and agencies to the needs and perspectives of these professionals. Stakeholders agree that the lack of qualified employees is a major barrier to providing high quality supports and promoting person-centered services (Larson & Hewitt, 2005).

2.3.1 Size of Direct Support Workforce

There is no way to officially measure the size of the DSP workforce because the Bureau of Labor Statistics does not classify direct support professionals in a unique category—which is just one of the institutional ways it denies the professionalization of this career. Instead, direct support professionals are identified in three primary standard occupational classifications of the Bureau of Labor Statistics: 1) personal care assistants (PCAs); 2) home health aides; and 3) certified nursing assistants (CNAs). As of May 2017, there are 2.035 million personal care aides, 820,960 home health aides, and 1,453,670 certified nursing assistants (U.S. Bureau of Labor Statistics, 2017c). Direct support professionals are thus estimated to be around

4.5 million professionals (Espinoza, 2017a; PHI, 2013) and some estimate the number is even higher due to the complex nature of job titles for direct support professionals, indicating some people may have been miscounted or not included in these three domains.

Services for the elderly and people with disabilities are projected to grow by 98.1% from 2010-2020 (PHI, 2013). This increase in demand is partially created by the growing elderly population (President’s Committee for People with Intellectual Disabilities, 2017). Often the competing demand for DSPs between the I/DD field and the elderly communities, creates even greater pressure on the DSP workforce. The growth of DSPs required is far outpacing population growth. Average growth rate is about 7 percent, while PCAs and Home Health Aides have a 41% growth rate from 2016-2026, creating 1.8 million jobs (U.S. Bureau of Labor Statistics, 2019). Home care is projected as the fastest growing occupation between 2016 and 2026 (PHI, 2018).

It is important to note that the roles and responsibilities of direct support professionals are distinct from the position they are currently categorized under in the Bureau of Labor Statistics. With a changing service sector and demands for an evolving definition of “quality,” the tasks and responsibilities of DSPs need to change. Distinctions among roles is necessary in the movement towards professionalizing this career and improving the quality of services provided to people with IDD.

2.3.2 Broadened Competencies

Beyond the needed growth of the direct support professional workforce due to increased demand for services, the shifts in the policy landscape requires broadened competencies of professionals in the field. When providing services historically in

congregate and segregated care, tasks required were institutional in nature, often called “custodial care”. Direct support professionals were only required to provide for the basic health and safety of the people they served. With a shift in ideology and service providing, the role of direct support professionals has necessarily evolved. Role definitions themselves are an object of consideration for this study, however it is broadly accepted that the tasks, skills, and competencies required for this professional field have broadened and are still broadening with the shift in services (Hewitt & Larson, 2007; President’s Committee for People with Intellectual Disabilities, 2017).

Direct support professionals are often seen as part of a “secondary” labor market (Hewitt & Larson, 2007, p. 180; Hewitt et. al, 2008), indicating they are a low-skilled, entry-level occupation. However, the professionalization of the field and the changing role of direct support staff requires significantly more skills than other “secondary” labor and low-wage positions (i.e. janitorial staff, fast food workers, etc.) Care-work is difficult work. It requires emotional and physical investment and a wide array of skills to support the variety of complex needs human beings have. Unlike jobs of equal status or pay in our society, DSPs serve a wide facet of roles and perform a wide-variety of tasks. Since the field has moved from the low expectations of simply meeting health and safety needs, to promoting the self-determination and community access of the people they support, DSPs are now being asked to do much more than they have ever been. The tasks of serving as a community connector, supporting people to build relationships and foster a sense of belonging within communities, takes skill and time. The role of advocate and supporter of self-determination are not jobs that can be done, or at least done well, without training, time, effort, and commitment. This adds complexities to the recruitment within the workforce as well as the training

obligations of service providers. There are significant skills gaps within the workforce recruits of the direct support field, with employers believing they cannot be as selective as they once could (Larson & Hewitt, 2005). The assumption of low-skilled work, lack of visibility of the direct support professional field, and historically low wages, contribute to the skills gap and many of the other issues of turnover and retention.

2.3.3 Systems of Oppression Impacting Care Work

Before discussing the assumptions of low-skilled work and the historically low wages of the field, one must evaluate the impact of systemic oppression on the field of direct support. The field is often occupied by womxn with an assumption that they automatically know how to do “care work”. 86% of the DSP workforce is estimated to identify as female in 2015 (U.S. Census Bureau, 2016) . In addition, many researchers often compare the growth rates of the sector, described previously, to the specific growth rates of female adults. Thus, the direct support workforce continues to perpetuate its feminized role.

This history of devaluing work that is “feminized” is based on systems of sexism that are tied up with other forms of oppression. Women’s labor and work is often devalued, as demonstrated in randomized control studies including studies about gender bias in publications (Knobloch-Westerwick, Glynn, & Huge, 2013), in hiring practices (Moss-Racusin, Dovidio, Brescoll, Graham, & Handelsman, 2012), and in a study by the Institute for Women’s Policy Research and Oxfam America that explores the gender divide in low-wage work (Shaw, Hegewisch, Phil, Williams-Baron, & Gault, 2016). A disproportionate number of low-wage workers are not just women, but immigrant, Black, brown, working-class, poor, undocumented peoples. Histories of

racism have often tied these communities to working for free, such as during slavery, colonization, and in prison-work. These complex histories are some of the factors that influence how care workers are treated in American society today. They are overworked, underpaid, and their work is undervalued.

Additionally, our individualistic and capitalist culture often pushes towards eliminating dependency. Since disabled people rely on caregiving, both care and the caregiver are stigmatized because of this dependency (Kittay, 2011). This stigma impacts caregivers' wages and benefits, as well as their valuation in our society and within organizations. Since our society is forcing a focus on "independence" where dependency is looked down upon, these attitudes make care work invisible, in turn oppressing one group in order to alleviate oppression of another (Kittay, 2011). The erasure of care as work, oppresses the workforce of direct support.

The voices of direct support professionals in a society that devalues and even erases their work, are often ignored in research and policymaking, and most importantly in organizational management. Professionals often see direct support staff as uneducated, unworthy of study, or incapable of being contributors to our collective knowledge base and decision-making. These assumptions are often shaped by class systems that continue to perpetuate disparities and hierarchies of power and privilege. Taking a step back to recognize the systems within our society that are at play, this research aims to take a stance towards recognizing direct support professionals as within a larger social justice movement. It works towards promoting worker's rights, especially of people of color and immigrant workers, and values the voices of DSPs as important towards promoting solutions to this multi-decade long crisis.

2.3.4 Wages and Benefits

The median hourly wage of direct support professionals in 2016 is estimated to be \$11.41 an hour (National Core Indicators, 2018). This workforce has actually seen a decline in real wages over time (PHI, 2015) and are projected to be the fastest growing low-wage work (PHI, 2013). Studies revealed that there is also significant discrepancy in wages for direct support professionals working for private versus public providers (Carman, McComb, Mccollum, & Schroeder, 2009). It was found that in 2010 over one third of direct support professionals working for privately operated providers were receiving annual gross entry-level wages below the Federal Poverty Level for a family of three [\$18,310] (Carman et al., 2009). Public providers are predominantly institutional in nature, and the discrepancy in wages is an illustration of the lack of value for more integrated, community-based work, as well as the bias towards traditional services and institutional placements in the delivery of services. It also illustrates how state legislatures take care of their employees but only provide private providers with meager or even zero annual increases. In addition, providers of more integrated or community-based services, were found to pay their direct support professionals less than in more traditional day programs and segregated settings (Bogenschutz et al., 2014). There is a disincentive for movement towards community-based options for direct support professionals who are paid and thus valued less than their institutional counterparts.

Another issue with wages comes from the argument that providing services in the community is cheaper than providing services in institutional care (National Council on Disability, 2012). While that can be true, it often comes with the consequence of paying people in the community less. Instead, policymakers need to

value quality outcomes for people with disabilities and pay direct support professionals fair wages.

In addition to the low wages, direct support professionals often have few benefits. Many direct support staff work in part-time capacities, and often part-time workers cannot access fringe benefits (Bogenschutz et al., 2014). Due to the low wages, three out of five direct support professionals in the United States rely on public benefits (ie. food, medical, and housing assistance) (PHI, 2015) even with some working full time. The National Core Indicators surveyed agencies nationally to capture benefits that DSPs receive. The study found that on average only 68.5% of agencies were found to offer pooled paid time off to at least some of their employees, with only 35.2% of agencies providing pool paid time off to all DSPs (National Core Indicators, 2018). 44.7% of agencies on average were found to provide paid sick leave to at least some of their DSPs, and 49.8% of agencies offered paid vacation time to at least some of their DSPs (National Core Indicators, 2018). Additionally, 80.5% of providers on average offer health insurance benefits to at least some of their DSPs, 78% offer dental insurance to at least some of their DSPs, and 67.6% offer vision insurance to at least some of their DSPs (National Core Indicators, 2018).

Lower wages and benefits have been found to produce poorer quality of life and service outcomes for adults with intellectual and developmental disabilities receiving services. This is due to the fact that lower wages are correlated with higher levels of turnover and vacancies, which also lead to poorer outcomes for the individuals being supported (Carman et al., 2009). Wage differentials between public and private providers as well as between more innovative, community-based services

and traditional day habilitation programs, disincentivize a shift to more community-based services.

2.3.5 Training and Competencies

One of the major challenges in retaining and preparing direct support professionals, are issues in training and competency development. Currently, many trainings are often described as standard, repetitive, and outdated, meeting the needs of a few while ignoring the needs of many direct support professionals (Larson & Hewitt, 2005). Shifts in service providing, with changing the roles and responsibilities of direct support professionals, prompt a need for updated and improved training. At the same time however, shifts in service providing have created additional barriers to providing for updated and quality training. The shift from congregate care to individualized community services have led to dispersing the direct support professional workforce and varying the working hours of those professionals. Direct support professionals often cannot afford the additional travel costs to meet at a common location, and often do not have the time or coverage to take off work for a training (Larson & Hewitt, 2005).

Complex state and federal regulations for training requirements also serve as barriers to providing quality training. Each state has its own mandated minimum training requirements for DSPs. For instance, in Pennsylvania, program staff are mandated to have 24 hours of training annually and DSPs are trained in the “areas of intellectual disability, the principles of integration, rights and program planning and implementation” beyond extensive training in fire drills and safety, first aid, Heimlich techniques, and CPR (Pa. Code §6400.46). In Delaware, home health aides are required to complete an orientation program that includes topics such as agency

basics, patient care philosophy, patient rights, and job descriptions, the completion of seventy-five hours of training, as well as 12 hours of continuing annual development with more advanced topics including assisting self-reliance in activities of daily living, meal planning, maintaining a healthy environment, verbal/non-verbal communication, and patient rights (Del. Code§4406.5.7). Maryland has its own staffing requirements, calling for training in a variety of basic topics including “seizure disorders, principles of behavior change, management of disruptive behaviors, medication administration, and the aging process and the special needs of the elderly” (COMAR, 10.22.02.11) States can vary in their requirements for the content DSPs receive or the amount of time they must spend in training and continuing education. Many states focus on the health and safety training, and significant work is needed across states to address the developing of competencies for DSPs and their various roles.

Competency-based trainings are designed to develop people’s knowledge, skills, and attitudes in their work, as opposed to only focusing on one aspect. The trainings are usually a combination of classroom learning and on-the-job training. It has been noted that with competency-based trainings, states can decrease turnover and increase service quality of DSPs (Bogenschutz et al., 2015). Overtime, there have been a wide variety of DSP competency sets developed including the Community Support Skills Standards, a tiered competency model from the U.S. Department of Labor, CMS Core Competencies, and the National Alliance for Direct Support Professional’s competencies. The 15 NADSP competencies include: 1) participant empowerment; 2) communication; 3) assessment; 4) community and service networking; 5) facilitation of services; 6) community living skills & supports; 7) education, training & staff-development; 8) advocacy; 9) vocational, educational &

career support; 10) crisis prevention and intervention; 11) organizational participation; 12) documentation; 13) building and maintaining friendships and relationships; 14) provide person centered supports; and 15) supporting health and wellness (NADSP, 2016). Quite distinctly, there is a variety of competencies needed for the field of direct support, each of which are vital to providing quality services.

2.3.6 Turnover and Retention

High rates of DSP turnover are one major issue that impacts the quality of services and supports that people with intellectual and developmental disabilities receive. The turnover rate for DSPs nationally is reported as ranging from 38.2% (Carman et al., 2009) to around 45.5% (National Core Indicators, 2018) with some studies citing turnover rates as high as 76% (President's Committee for People with Intellectual Disabilities, 2017). DSPs often leave their agencies shortly after being hired and onboarded. 38.2% of DSPs that left their agencies were employed for less than 6 months, and 59.2% of DSPs that left their agencies were employee for less than a year (National Core Indicators, 2018). This poses particular issue for agencies since a lot of resources are used to train DSPs, and after investing into training DSPs, many will turnover soon after. With high turnover, a lot of agencies also face high vacancy rates, where they are operating with less staff than they need. National Core Indicators reports an average of 9.8% vacancy rate for full-time positions and an average of 15.4% vacancy rates for part-time positions (2018). Oftentimes high rates of vacancy in agencies, leads to significant need for overtime from retained staff. The cost for agencies nationally on overtime expenditures is estimated at \$206,276,508 (Hewitt, Taylor, Kramme, Pettingel, & Sedlezky, 2015).

In studies about direct support professional turnover, turnover was almost always observed as a hindrance (Woltmann et al., 2008). High rates of turnover can lead to poorer outcomes for the people being supported (Bogenschutz et al., 2015; Woltmann et al., 2008). Having a constant influx of new DSPs can be harmful to people with complex medical needs and can prevent progress in relationship building and self-determinant goal setting for the people being supported. Beyond harm to the outcomes of people being supported, turnover hurts providers' bottom lines as well as that of federal, state, and local governments. The national cost for turnover in long-term care for government payers is roughly \$2.5 billion (Seavey, 2004).

Studies suggest there are a variety of factors that impact turnover. These include: work/job satisfaction, job strain, lack of respect, inadequate management, work or family conditions, poor social and supervisory support, role ambiguity, and high stress with low autonomy (Acker, 2004; Bogenschutz et al., 2015; Gray-Stanley et al., 2010; Hatton et al., 2001; Mittal, Rosen, & Leana, 2009). There are a variety of stressors that DSPs face in their jobs from heavy workloads, unrealistic expectations, lack of involvement in decision making, and client care (Gray-Stanley et al., 2010). Additionally, studies have linked together wages and turnover rates. The 2009 ANCOR wage study found that "for every \$1 increase in entry-level wages, turnover is predicted to decrease by 3.61%" (Carman et al., 2009, p. 13). Wages in isolation can't realistically address turnover in the field and may not be reasonable solutions, so agencies need to give attention to the multitude of factors that impact turnover in order to create turnover reduction and promote staff retention.

Beyond looking at what causes turnover, a notable study examined what actually promotes retention. This study found that DSPs stay for a variety of reasons,

including “(a) being “called ” to service, (b) patient advocacy, (c) personal relationships with residents, (d) religion or spirituality, (e) haven from home problems, and (f) flexibility” (Mittal et al., 2009, p. 623). A variety of research studies also suggest that building supportive job conditions can help retain workers (Kim & Stoner, 2008), developing social support and supervisor support was found to lead to less turnover intention (Nissly, Barak, & Levin, 2005), as well as informing workers of the realistic parts of their work can help prevent role conflict and dissatisfaction (Acker, 2004). The literature overall suggests that organizational conditions can play an important role in preventing turnover, promoting retention, and developing job satisfaction.

2.3.7 Professionalization of Direct Support

In order to address the challenges of recruitment and retention and in order to create quality, the field of direct support needs to be professionalized. The National Alliance for Direct Support Professionals discusses that professions have 1) evolving bodies of knowledge, 2) validated core competencies, 3) a set of ethical or professional standards and values, 4) universally recognized and portable certifications, and 5) affiliations with professional organizations. These universal components of professions elevate positions into viable careers, and recognizes the specialized skills needed to perform the job responsibilities. To recruit young people into the field, there needs to be recognition of the profession and of the availability of jobs in the sector (President’s Committee for People with Intellectual Disabilities, 2017).

NADSP serves as a national professional organization for DSPs and works to accomplish all five elements of the professionalizing of this career. NADSP enhances

the status and recognition of DSPs, provides opportunities for training and education, and advocates on the behalf of DSPs and issues important to them. Their work established a code of ethics, a credentialing program, as well as a group of core competencies, all essential portions of professionalizing the field of direct support. They also advocated for the occupational title of “Direct Support Professional” and though ignored by the Bureau of Labor Statistics, continue to work towards its distinct inclusion in the occupational codes (NADSP, n.d.-a).

Direct Support Professionals also need their profession to be recognized as a viable career path, both to attract future talent, as well as to appreciate the work of DSPs in the U.S. DSPs are nationally recognized in September for Direct Support Professional Week (President’s Committee for People with Intellectual Disabilities, 2017). NADSP also has efforts to appreciate and recognize exemplary professionals in the field. However, a week of recognition is not enough, and more needs to be done to elevate the role of direct support and to appreciate the complex nature of this career in more substantial ways.

2.4 Scope of Research

In the face of the evolving roles and outcomes of direct support and in light of the systemic and pervasive failures in the long-term services and supports system, researchers, organizations, advocates, and policymakers are searching for solutions to improve quality in the field. John F. Kennedy Jr. wrote in 1996 that “quality is defined at the point of interaction between the staff member and the individual with a disability” (cited in NADSP, n.d.-b). Direct support staff are the necessary piece towards promoting quality outcomes for the people they support. However, in this

process, direct support professionals themselves are rarely consulted in designing solutions for the crisis.

The goals and aims of this study were to answer two primary questions of interest to the field:

- 1) How do the role perceptions of direct support professionals differ between agencies across the spectrum of service providing?
- 2) What is needed in the field to better support direct support professionals?

The first question is precipitated by the need to better define the evolving role of direct support. The issue with the “workforce crisis” at its core and best should consider the outcomes of people being supported. The crisis is about the inability to recruit, train, and retain skilled professionals, and in recognizing that direct support staff are the key to quality, the crisis is really about a failure of a system to promote quality outcomes for the people being supported. When the definition of quality shifts to people getting to live the lives they choose to live, out within and with their community, and is focused on the relationships and access to life experiences of people being supported, the definition of direct support shifts too. The first question aims to explore this change in role definition and explore the implications of differences in role definition.

The latter question seeks to provide voice to a workforce that is often silenced, in order to recognize direct support professionals as experts in their own experience. In order to address the workforce crisis, this study qualitatively explores the perspectives of DSPs on their own support needs. Recognizing these professionals as knowledgeable about their profession, the study sees potential solutions arising from the voice and ideas of the staff themselves.

In order to answer the research questions outlined above, Nancy Weiss, Caitlin Bailey, and I met to design the data collection tools. Weiss, Bailey, and I decided that it was imperative to center direct support professional (DSP) voices throughout the study. We designed an online survey in collaboration with the National Alliance for Direct Support Professionals (NADSP). To contextualize the survey, we also developed semi-structured interview questions to interview DSPs at a variety of agencies, while also collecting data about their agency from online websites and observations on site. The protocol was submitted to the University of Delaware Institutional Review Board (IRB) and all researchers completed Human Subjects Research training. The study was deemed exempt from review by the Institutional Review Board.

The case studies (primarily DSP case interviews, with additional website data and observational field notes) and the national survey disseminated by NADSP, served to answer both research questions.

Chapter 3

METHODS

This study used qualitative research methods to evaluate the research questions. The study had two major components: five case studies—consisting of interviews with direct support staff, website data, and observational field notes—and a national online survey of direct support professionals (DSPs) promoted by the National Alliance for Direct Support Professionals (NADSP). Both components provided information about role perception and support needs of DSPs.

The interviews conducted for the case studies and the responses taken from the DSP survey are inclusive only of direct support professionals' perspectives. The study operationally defines direct support professionals as: “1) someone who provides primarily non-medical hands-on supports, training, and supervision, and personal assistance to adults with intellectual and developmental disabilities; 2) is at least 18 years of age; and 3) works either full-time or part-time as a direct support professional. This definition excludes direct support professionals that have additional duties related to administration or shift supervision (often referred to as “coordinators,” “lead staff,” and “house managers”).” In order to participate in the study, research participants had to verify they meet the criteria of a DSP as defined. Compensation for research participation was not included, however direct support professionals who participated in the survey or in the interviews were given the opportunity to be entered into a raffle for ten \$50 gift cards. All direct support professionals who participated in the study were given informed consent documents either at the beginning of the survey or to be signed before each interview began. The study protocol was submitted to the

Institutional Review Board (IRB) and all researchers completed Human Subjects Research training. The study was deemed exempt from review by the IRB.

3.1 Case Studies

The first component of the project was a series of case studies from five agencies in Delaware and Maryland. The five organizations serve as distinct cases to better understand the broader field of direct support (Gerring, 2004). The cases also serve as a way to demonstrate some of the outcomes of the second half of the study, the national DSP survey.

The goal of the recruitment phase was to gather an illustrative sample of agencies to deeply explore. Agencies were not chosen randomly since often random selection in such small sample sizes can result in non-representative samplings. Rather, an approach to select for diversity (Seawright & Gerring, 2008) was used to consider the range of service-providing along a continuum. Since disability service providing is continuous and not distinctly categorical, efforts were maintained to select representative cases within distinct portions along the continuum of services from more traditional services such as sheltered workshops, group homes, and day programs, to more innovative agencies with services such as independent-living, supported employment, and person-directed services. All agencies that were sent a recruitment letter were also selected due to their proximate location being in Delaware, Maryland, or Pennsylvania.

The National Leadership Consortium on Developmental Disabilities (NLCDD) sent requests for participation in the research study via email to the leadership of eight agencies. NLCDD has an accepted values-orientation that leads many of the “graduates” of their Leadership Institutes to be more innovative in their service

delivery. Due to this, the research team decided to also recruit other agencies to represent more traditional service providing. Thus, an additional agency was contacted through personal connections by the interviewer and a ninth agency was cold-contacted for the sake of representing some of the most traditional service-delivery in the region. Responses were received from all but two of the agencies, one of which included the cold-contact agency. Due to scheduling restraints, not all eight agencies that responded eventually participated in the study.

The outcome of the recruitment phase resulted in five agencies representing unique places along a continuum of services being provided in the region. For the sake of anonymity for the direct support professionals being interviewed and the agencies being represented, each of the agencies and DSPs have been given pseudonyms in place of actual names. The five agencies will be thus referred to as: Hope Homes, Change Inc., Excellence in Direct Support, Community Connections, and ABC Center.

3.1.1 DSP Recruitment

At each agency, the contact person operationalized the request to recruit DSPs. At Hope Homes, the interviewer attended a DSP training at the agency's headquarters. The contact person announced the study to the DSPs in attendance and people were permitted to step out of the training to interview. For Change Inc. and Community Connections, agency leadership internally recruited for the interview slots and scheduled interview participants. Change Inc.'s leadership mentioned they had hand-selected DSPs to represent the wide-variety of services from more traditional to more innovative that they provide. Community Connections did not mention how the DSPs were selected for the interview slots. Agency leadership from Excellence in Direct

Support provided a list of sixteen direct support professionals from its agency, and DSPs were recruited from that list. Nine of the sixteen responded to the initial recruitment letter that was emailed to them, expressing interest in participating. Due to scheduling constraints and participants dropping out of the study, only three DSP interviews were eventually conducted at Excellence in Direct Support over the course of two days. Lastly, the recruitment of DSPs for interviews from ABC Center was less clear. DSP interviews were either pre-arranged into a schedule by the leadership of ABC Center—however no such list or schedule was provided to the interviewer—or the contact person announced the study to the DSPs working at the day program in the adjacent rooms who were permitted to voluntarily step out during the day to interview.

Twenty-four DSPs were interviewed in total. The breakdown of interviews included four DSPs from Hope Homes, seven DSPs from Change Inc., three DSPs from Excellence in Direct Support, four DSPs from Community Connections, and six DSPs from ABC Center.

3.1.2 Semi-Structured Interview Protocol

The interviews with the direct support professionals had a semi-structured format. The goal of using a semi-structured approach was to 1) provide consist format and direction for the interview itself, 2) allow for comparison across agencies, 3) provide significant flexibility in the interview to explore new ideas that the study had not initially considered, and 4) ask follow-up questions about the content the subjects shared. The schema for the semi-structured interviews is provided (see Appendix B). The interviews each lasted between twenty and thirty minutes and collected information about the agency both directly and indirectly. Interviews all took place in private rooms, without the observations of other DSPs, agency staff, or service-users.

The interview data was maintained through handwritten notes by the interviewer. All DSPs were informed their information would remain confidential and that their name and their agency name would be redacted from the final report. The interviews centered on job responsibilities, training, evaluation, retention factors, and support needs from the agency. The analysis for the purpose of this thesis will focus primarily on the research questions identified: 1) How do the role perceptions of direct support professionals differ between agencies across the spectrum of service providing? and 2) What is needed in the field to better support direct support professionals?

3.1.3 Additional Data Collected for Case Studies

In addition to the interviews conducted with direct support professionals from each of the agencies, additional data was collected for the purpose of the case study analysis. Observational field notes were taken from the site visits to focus on the observations of the physical structures where interviews were being conducted, notes on conversations with any staff the interviewer interacted with, and general observations from any services observed or brochures or other materials provided during the visit.

After the interviews were all conducted, agency information from the five agencies' public websites was also collected. The information collected included the mission/vision of the organization, the description of the types of services provided to adults with intellectual disabilities, and job descriptions for direct support staff. The additional information from the agency's websites and from the field notes taken were considered in developing the case study for each of the agencies.

The leadership or other staff from the agency were not interviewed for the purposes of this study. It was noted if leadership asked to be interviewed or asked to have their non-DSP staff interviewed.

3.1.4 Case Study Analysis

The research uses case studies to examine the two research questions and the data was analyzed using thematic analysis (Braun & Clarke, 2006). DSP interviews were considered both independently as well as grouped by agency. The thematic analysis focused on two portions of the interview: 1) role descriptions and 2) changes to better support staff.

The thematic analysis first began in the transferring of handwritten interview notes to typed versions. The act of transcribing the notes refreshed the interviewer's memory of the encounters and was the first cursory view of the interviews for potential codes relating to role description and agency changes. Following transcribing the interview notes, the researcher approached the analysis in two parts to address both questions.

To answer the first question about role descriptions, the researcher reviewed the notes to explore for all potential role tasks identified by the interview notes. All role tasks identified were then grouped into potential larger categories to understand role perception. The documents were then coded for identification of particular role categories within individual responses and grouped by agencies. The researcher then documented as case notes, any patterns between DSPs of a particular agency or any notable discrepancies between DSPs at a particular case agency.

Following coding for specific role descriptions, the researcher reviewed the surrounding notes of each of the interview notes, outside of particular responses made

about role descriptions. This wider review of the interview notes explored broader themes that were case-specific or DSP-specific. These patterns or discrepancies from within an individual case were documented by the researcher. In addition to coding job responsibilities, additional data from the agency's website and from the field notes taken on site, were then considered within the overall case notes. Examining the case notes, or the themes that were identified within a particular agency, the additional information gathered from the agency was compared to the thematic findings to add to the compiled case notes.

In comparing the cases, the case agencies were placed along a theoretical continuum of services from more traditional to more innovative. DSP responses, agency website information, and field notes, were used to capture the nature of the agency. The analysis considered the range of services being provided, language used in any website data collected, and any field notes about observations on site, to place the agency along the continuum.

In examining the sections about changes to better support staff, the data was looked at as a whole rather than solely by agency. The data was coded for specific themes relating to identified support needs. These individual codes were grouped into broader themes of what direct support staff need more of in their agencies to feel supported. The themes were checked for alignment with the same coding process used on national survey data (described below). The results about staff support from both the case studies and national survey will be included together.

3.2 DSP Survey

In addition to the direct support professional interviews and corresponding case studies, a national survey was developed, disseminated, collected, and analyzed,

for the purpose of this study. The survey instrument consists of fourteen questions and is provided for reference (see Appendix B). The instrument was designed based on the research question to focus on role perception and support needs of DSPs. The survey also addressed other questions of interest to the field including about evaluations and retention factors. The retention factor options provided were developed and expanded from Mittal, Rosen, & Leana's 2009 study about retention factors in direct support work. The six major themes were summarized and condensed into five retention factors to include: "a haven from home life," "flexible hours," "you are an advocate for the people you support," "personal relationships with people you support," and "religion and/or spiritual calling." Four additional retention factors were added as potential other reasons people stay in the field of direct support.

The major focus for this analysis was to answer two primary research questions: 1) How do the role perceptions of direct support professionals differ between agencies across the spectrum of service providing? and 2) What is needed in the field to better support direct support professionals?

To capture role perception and answer question 1, DSPs were asked to a) describe their job and the purpose of their role in three sentences or fewer and to b) list the three most important things they do in their job.

To capture support needs and answer question 2, DSPs were asked a) what would help them do their job better and how their supervisor or organization could better support them to do their job well.

The survey instrument was reviewed by leadership of the National Alliance for Direct Support Professionals (NADSP) to make edits for readability as well as to capture other ideas or language important in the field of direct support. These edits

encouraged changes to some of the retention factors, adjusted the language for asking about role perception, and modified other categories to include options to indicate a lack of knowledge on a particular topic.

3.2.1 Survey Dissemination and Response Rates

The survey was created using Qualtrix and disseminated through NADSP's social media networks. Direct support professionals are difficult to reach since there is no list of DSPs nationally and only one national professional organization. There is no accurate count of the total population, though it is estimated that there are around 4.5 million direct support professionals in the U.S. (Espinoza, 2017b; PHI, 2013). Social media through the only national organization for DSPs, served as a way to capture more professionals. NADSP posted about the survey on social media a few times in their DSP Facebook group. They also emailed the survey link to members of their organization multiple times alongside other parts of their e-newsletter. The deadline for the survey was extended an extra month due to a low number of responses. A final reminder email that centered the study, sent directly to member DSPs from NADSP, significantly increased the number of responses in the last twenty-four hours.

1,190 responses were recorded to the survey, inclusive of all partial responses and blank submitted forms. Responses marked as completing less than 97% of the survey were not considered for the purposes of the study since no response marked less than 97% completed up to at least question eight regarding role purpose, an essential component for this research study. Upon removing responses that were less than 97% complete, 910 responses remained. 71 respondents marked they did not qualify for the study as they were not DSPs as defined and were taken to the end of the survey. These responses were thus not included. Some responses marked as "100%

completed” are not necessarily full and complete responses. Since the survey allows DSPs to skip questions, “100% completed”, simply indicates that the respondent submitted the survey upon reaching the last question. Respondents that reached the end of the survey but did not complete up to at least question eight regarding role purpose, were also not considered resulting in 486 responses remaining.

After the initial coding, 46 respondents were marked as ineligible to participate, after their responses indicated they held a role that does not meet the criteria for a DSP as defined by the study. Examples include identifying in a response as a “house lead,” “group home manager,” “lead staff,” “assistant manager,” “program administrator,” “OT/PT specialist,” “staff development trainer,” or even in one case, a “CEO”. These responses were not considered in the analysis since they do not meet the definition of the requirements to participate in the study. In removing entirely blank responses and excluding ineligible respondents or insufficient responses, 440 DSP responses remain and were included in the analysis.

3.2.2 Thematic Analysis in Survey Responses

The data from the survey responses were analyzed using thematic analysis (Braun & Clarke, 2006) to answer the two research questions. To examine role perception, open coding was used on two of the survey questions: 8) Please explain your job and the purpose of your role in three sentences or fewer, and 9) What are the three most important things you do in your job? The data for both questions was read through in its entirety before establishing specific ideas to code for.

The data was then coded for 22 specific codes, essentially keywords, that were found from the initial read through of responses. During the process of coding the data, two terms in particular stood out that were found in a wide variety of DSP

responses: community and self-determination. In considering their context, it was determined that both keywords needed to be analyzed further to better understand their meaning and use. The keywords were tagged for their different uses. In addition to this further analysis of two specific keywords, responses were recoded an additional time to ensure the keywords best fit the responses.

At this time, each response, considering the keywords and boarder context, was rated a particular color to describe the overall role perception. Role perceptions were rated one of three colors: red, yellow, and green. The colors represent role perceptions as “more traditional” (red), “transitioning” (yellow), and “more innovative” (green). This process was done to supplement not to supplant the keyword analysis. The advantages of a color-rating allowed for the keywords to be considered in broader context, recognizing that keywords could sometimes be used as “buzzwords” and could not capture the subtleties of an overall response. The disadvantages of the color-rating are potential for inconsistency in the categorizing based on rater perception, values, and bias.

The rater considered keywords/ideas such as employment, self-determination, connecting to community as more “innovative” and keywords/ideas of health and safety, medication, and skill development as more “traditional”. Green ratings centered consumer-voice, autonomy and agency, focused on outcome-oriented measures such as employment or community connection, and/or moved beyond simply meeting people’s basic needs. Yellow ratings had responses that indicated conflicting elements in their role descriptions, lacked progressive value and practice alignment, or failed to provide enough information to adequately rate either as green or red. Red ratings solely focused on traditional roles such as ADLs, health and safety,

skill development and medication, considered community only as a location, focused on activities to keep people busy rather than focusing on outcome-oriented measures, and/or exhibited elements of power and control over people's lives such as in setting what is and is not "appropriate".

The keywords and color ratings were then compared across agency type. In order to do so, each response entry was grouped into three categories to represent more innovative, transitioning, and more traditional agency types. Respondents indicated on the survey where they provided services to include as many as ten different service settings. Each setting listed in a response was assigned one of three colors: red, yellow, and green to indicate if the service setting was more traditional (red), intermediate (yellow), and more innovative (green). Since DSPs can provide multiple types of services, DSPs could have a combination of assigned colors. Those combinations were then grouped into predominantly "green", predominantly "yellow", and predominantly "red" based on the combination of services they provide. The sorting schema is provided (see Appendix C).

Innovative/green settings included: 1) supported employment and 2) services in individual's home.

Intermediate/yellow services included: 1) services in family homes, 2) shared living/ host homes/ adult foster care, and 3) community-based day supports.

Traditional/red services included: 1) residential group homes, 2) center-based day programs, 3) pre-vocational support, 4) sheltered workshops, and 5) ICF residential facilities.

The more innovative agencies represented services that are provided in the community and that are found to promote higher quality outcomes for the people

being supported. Less innovative agencies represented services that are more institutional in nature, and often have poorer outcomes in terms of self-determination, work, relationships, and community inclusion. Intermediate agencies represented services that fell somewhere in between on the continuum of service-providing.

Examining the National Core Indicators data by setting type served to help determine the types of settings that fall under each category. The National Core Indicators are a set of standard measures used voluntarily by public developmental disability agencies to assess the outcomes of services across a variety of participating states. While the data has limitations in sample size and from participating states, it is one of the most reliable measures in the field to assess outcomes of developmental disability services. The indicators cross a variety of domains to evaluate quality services including employment, rights, self-determination, community inclusion, etc. For instance, an indicator like “choosing a housemate” can serve as a measurement of choice and self-determination. Of the people living in their own homes or apartments, 61% were found to make the choice for their housemates compared to only 11% in a group home or 5% in an Intermediate Care Facility (National Core Indicators, 2016). These indicators helped differentiate between progressive, intermediate, and more traditional services. In general, group homes, day programs, prevocational work, and sheltered work promote lower levels of choice and control, community inclusion, and work outcomes.

Services such as community-based day supports and supports in family homes were harder to place on the continuum of services. Community-based day supports can often describe a wide variety of supports offered. Some are truly person-centered and individualized, focusing on authentic decision-making and control, while others

maintain the same structures of day programs, with simply “outings” into the community. Due to the diverse ways that community-based day supports are provided, they are included in intermediate service settings to capture both the more progressive and less progressive services. On a similar note, while many see services in family homes to be ideal placements providing the best supports for people with intellectual and developmental disabilities, these settings are not across the board promoting outcomes that allow for authentic community connection and decision-making and control. While families are a vital part of the service-provision process, with an estimated 58% of people with IDD who receive publicly funded long term supports and services in their family homes on June 30th of 2015 (Larson et al., 2017), outcomes in family homes are not across the board as positive as services provided in an individual’s homes. In looking at an indicator of “choosing your daily schedule” for instance, there is a discrepancy between individual’s homes versus family homes that is notable; 78% of people in their own homes versus only 52% of people in family homes choose their daily schedule (National Core Indicators, 2016). Other indicators demonstrate similar findings, such as the ability to date, 82% in their own homes versus 65% in family’s homes, and in terms of choosing how to spend their money 74% in their own homes versus 52% in family’s homes (National Core Indicators, 2016). Due to this, services in family’s homes are considered as an intermediate service setting.

In total, 440 responses were collected. Of those 440 responses, 70 were from innovative (green) agencies, 128 were from intermediate (yellow) agencies, and 242 were from traditional (red) agencies. Role descriptions were not determined by every

response since some survey responses were too short or nonspecific to determine an overall description (as traditional, intermediate, or innovative) or to flag keywords.

To answer the second research question, the survey question about supports from DSPs' organizations was coded for themes. The data was reviewed in its entirety to capture all new ideas to code for. These codes were grouped into larger themes and the data was reviewed again to ensure the themes captured the data adequately. The support needs were not grouped by agency type but were examined holistically to capture direct support professional voice overall. The themes and codes were compared with the case study data results to promote an overall summation of support need findings.

Chapter 4

Results

This chapter will display the results of my analysis of the survey data and case studies. To review the purpose of this study is to answer two primary research questions:

- 1) How do the role perceptions of direct support professionals differ between agencies across the spectrum of service providing?
- 2) What is needed in the field to better support direct support professionals?

Each question is approached distinctly from the other, so this section will examine each question separately. However, the findings from both questions are significantly interrelated. The results examine the key themes resulting from the analysis of the survey data and will include quotes from the surveys to demonstrate the findings. Excerpts from the interviews will also serve to illustrate and corroborate findings from the national survey. Lastly, the cases themselves will be presented as narratives in light of both questions collectively.

4.1 Role perceptions of direct support professionals

The data from both the interviews and surveys revealed a list of roles direct support professionals (DSPs) typically take on. These aggregate lists of roles include: being a health advocate, dispensing medication, providing physical care (i.e. hygiene, showers, assisting in bathroom, feeding, turning in bed, etc.), keeping home (i.e. laundry, buying groceries, making dinner, cleaning); supporting emotional needs or being a listening ear, promoting safety, promoting wellness and happiness, being a teacher (e.g. teaching activities of daily living (ADLs) and instrumental activities of daily living (IADLs), socialization skills, pre-vocational prep, job skills), being a

community connector (i.e. taking on outings, planning a social calendar, keeping them occupied, parties, vacations, etc.), clerical/professional tasks (documentation, transportation, professional development activities), promoting self-determination, or serving as a connector to relationships and sense of belonging. This aggregate list of roles sourced from the study was used to consider all of the ways that DSPs identified their job tasks within the course of the study.

These aggregate roles, however, oversimplify the nature of the tasks that actually represent a wide-variety of perceptions of the role. For instance, being a connector to community can mean a lot of different things for particular DSPs and can be used in a variety of ways. Additionally, certain professional/clerical tasks that continued to come up (i.e. transportation or documentation) have very unique positions within organizations that can be representative of the nature of services, and thus might require separate analysis. Important differentiations are where power and control rests on these tasks, what the purpose for the role is, and what the intended outcomes are.

To examine some of those differences, the aggregate roles were translated into 23 particular keywords to analyze the survey results. The keywords considered the actual task/role as well as the intended outcome of the role, as direct support professionals described them. The 23 keywords were 1) health & safety; 2) activities of daily living or ADLs (inclusive of IADLs or instrumental activities of daily living); 3) medication; 4) providing activities; 5) independence; 6) reaching full-potential; 7) developing or teaching skills; 8) serving as an advocate (both in rights and in health); 9) building relationships; 10) meeting goals; 11) being a cheerleader; 12) employment; 13) having a meaningful day; 14) having a meaningful life; 15) transportation; 16)

providing choice; 17) emotional support; 18) sheltered work; 19) trying new things; 20) being person-centered; 21) self-determination; and 22) community.

After coding, the keywords for self-determination (21) and community (22) were further examined to better understand the context and meaning. The keyword “self-determination” was separated into four distinct meanings, including 1) supporting someone’s wants and needs; 2) supporting someone’s goals and dreams; 3) supporting someone’s decision-making; and 4) supporting someone to live a self-determined life. The keyword “community” was flagged for two distinct meanings. When DSPs used the word community to reference a location, for instance “going out into the community” or “taking people on outings”, that was flagged as a “locational” use of the word community. Additionally, “community” was flagged when DSPs used the term to reference authentic connection and contributions to and from a community. For instance a DSP mentioned the second most important thing they do is “involve them in the community” or another DSP mentioned that the third most important thing they do is “helping them to learn what all is available to them in their community and help them to utilize what it has to offer along with meeting old and making new friends.” The keyword “community” was thus seen as whenever community was referenced, as well as disregarding any “locational” uses of the term and capturing any “community connection” uses of the term.

The breakdown of keyword uses and relative keyword uses broken down by agency type are included in Appendix D. The most commonly used keyword was “ADLs” with 52.3% of DSPs mentioning ADLs in their descriptions, followed by “health & safety” with 38.9% of DSPs mentioning it in their descriptions. Many keywords ultimately had small percentages of DSPs including them in their

descriptions, including “full potential,” “cheerleaders,” “meaningful day,” “choice,” “emotional support,” “sheltered work,” “trying new things,” and “being person-centered” having less than 5% of DSPs (or less than 22 DSPs) mentioning that in their role description.

The keywords were considered broken out by each of the setting types: innovative, intermediate, and traditional. When considering the highest relative percentages of the use of keywords, seven keywords were eliminated from the results since the range from highest to lowest was no greater than 4%. The seven keywords that were eliminated from the results section on relative representation in role perceptions were 1) full potential, 2) advocate; 3) cheerleader; 4) meaningful day; 5) meaningful life; 6) sheltered work; and 7) person-centered. The designation of a 4% range was determined by the researcher analyzing, and future expansions of the study would consider applying a NOVA analysis on each keyword to calculate the significance of the differences by grouping. For the sake of this study, the significance in differences was not analyzed, but rather fairly close ranges of relative percentages were eliminated from reporting results by grouping.

More traditional agencies (colored red) had the highest relative uses of the following keywords: health & safety, ADLs, and medication. They had the lowest relative uses of the following keywords: developing skills, supporting relationships, trying new things, reaching goals, supporting employment, transportation, self-determination, and community (both with locational uses and without locational uses).

The intermediate agencies (colored yellow) had the highest relative uses of the following keywords: providing activities, developing skills, supporting relationship building, meeting goals, transportation, emotional support, trying new things, and

community (but only when locational uses were included). They had the lowest relative uses of the following keywords: independence and choice.

More innovative agencies (colored green) had the highest relative uses of the following keywords: independence, employment, choices, self-determination, and community (only when locational uses were removed). They had the lowest relative uses of the following keywords: health & safety, ADLs, medication, providing activities, and providing emotional support.

| Agency Group | Highest Relative Usage | Lowest Relative Usage |
|--------------|---|--|
| Innovative | Independence Employment Choices Self-determination Community (excluding locational) | Health & safety ADLs Medication Providing Activities Emotional Support |
| Intermediate | Providing Activities Developing Skills Relationship Building Meeting Goals Transportation Emotional Support Trying new things Community (including locational) | Independence Choices |
| Traditional | Health & Safety ADLs Medication | Developing Skills Relationship Building Trying new things Meeting Goals Employment Transportation Self-determination Community (both) |

Table Figure 1: Relative Breakdown of Keywords by Agency Groupings

The overview of these placements of keywords mirrored responses from DSPs that were interviewed, aligning often with the placement of the services they individually provide on the continuum of services, as well as looking at their agency more holistically. The most interesting of the examples is at Change Inc. Change Inc. represents a transitioning agency, and interviews were conducted with seven DSPs there from a variety of service-settings. They collectively identified a variety of role descriptions and isolating them by the service-setting provides interesting illustrations of the keywords and will be discussed in the case study section as well as in the discussion section.

At Excellence in Direct Support, one of agencies that provides traditional services in group homes, the role descriptions were fairly traditional. One of the DSPs first statements when asked about their role, was to “check in with the ladies, are they wet?” Ultimately Excellence in Direct Support serves as a great example of how to support DSPs, but as far as their role descriptions, the examples provided by their DSPs were focused primarily on physical direct care, and when discussing community focused on locational aspects of community, or community as a task or activity.

At Hope Homes, the DSPs shared role descriptions that were traditional in nature, emphasizing “serving as the extension of the nurse” and focusing on hygiene, dispensing medication, and completing chores. Three of the four DSPs interviewed mentioned the phrase “meet all of their needs” some emphasizing that as the most important part of their job. The phrasing was unique to just Hope Homes with no other DSPs interviewed using that phrasing.

Community Connections, the most innovative of the agencies used as a case study, also reflected more forward-thinking role descriptions. These included

descriptions to “treat them as adults,” “give people a chance to make mistakes,” “let them make their own choices,” “have a meaningful day” and “help them establish relationships and feel included.” The way these DSPs discussed their roles was distinct from the other agencies.

Lastly, ABC Center, the most traditional of the case agencies, had a lot of traditional role descriptions. The most descriptive and shocking of the role perceptions was when the DSP quickly described their role as “I wipe butts and do activities.” Many of the staff describe wanting to “keep people occupied.” These descriptors were what one might expect from a more traditional agency.

However, the results also found a lot of people using “community” based keywords in their role descriptions, even at higher rates than case agencies that provide more innovative services. These role descriptions are unique and of importance to the discussion of ABC Center as a case example. DSPs mentioned that their job was to “get them out into the community,” “take them fishing,” “have parties for them,” “go to the YMCA every week,” “take them to parks,” and “provide activities.” Without further analysis, those descriptions could stand in contradiction to the results of the survey keyword analysis, where the least progressive case agency had more innovative keywords. However, with context included in the results, these significant use of “community” codes in the role descriptions of ABC Center can be discussed further, as was completed with the keyword analysis. Particular attention is given to considering power and control in relation to the use of community keywords and will be discussed further in the ABC Center case study section and in the discussion.

Looking at an overall rating of the role perceptions—as either innovative, transitioning, or traditional— it is found that more traditional settings tended to have overall more traditional role perception ratings. More innovative settings tended to have higher relative rates of innovative role perception in comparison to other settings. However, it is important to note that more progressive settings, while having higher relative innovative perception ratings in comparison to other settings, had a fairly even relative split of different role perceptions. Only looking at the innovative settings, around 30% of DSPs had each type of role perception.

4.2 Support Needs of DSPs

To examine DSP support needs, both the survey and interview data ask DSPs what they needed from their agencies to do their jobs better. DSPs identified six significant support needs replicated in both the survey and interviews. The results found that in order to best support DSPs, agencies need to: 1) enhance access to training opportunities; 2) promote reliable and quality staffing; 3) maintain reasonable job expectations; 4) provide fair compensation and recognition; 5) ensure quality, participatory management practices; and 6) adequately fund basic needs. One DSP describes that agencies need to “treat DSP's with respect and stop making things unnecessarily complicated” which seemed to be a resounding call from many of the DSPs interviewed and surveyed.

4.2.1 Access to Training Opportunities

The results from the survey found that DSPs are craving access to training and professional development opportunities. Specific items that came up included desiring

ongoing training and higher quality training. Many suggested having more online options as opposed to in person trainings, including one DSP commenting

“Having a universal training for all agencies that can be accessed via computer would be very helpful. Especially when you take a day off of work to go to training and they have you watch YouTube videos!”

DSPs suggested a variety of topics they would be interested in learning more about including about IDD specifically, dealing with families and conflict, dual-diagnosis, mental health, behavioral training, communication, and dementia. Many suggested they are bored of the repetitive nature of the trainings they are required to take and wish that advanced topics were more available. Many also wish they could have more training in regard to directly supporting the people they work with before jumping in. One DSP mentioned that they were frustrated at how little training there was and wished that they needed to demonstrate their competency on the topics before the training stops and that new people were expected to work after just three days of training regardless if they had demonstrated competency in the training materials. They exclaimed “3 days is not enough!” Ultimately, direct support professionals are desiring more training, improved quality of training, and competency development.

4.2.2 Reliable and quality staffing

DSPs in the surveys and case studies described the harmful impacts that staffing shortages and skills gaps had on their lives and the way they performed their jobs. They wished that their organizations hired more reliable and quality staff. Some mentioned that there were not enough managers in their group home or that they lacked enough substitute staff to actually take time off. DSPs were calling for their organizations to “stop creating more residences when the agency can't even staff the

ones they have”. DSPs were really impacted by the rates of turnover, asking that their agencies invest in lessening turnover and vacancies. Many discussed working multiple jobs and working 80+ hour weeks. The vacancies and turnover really impact them, with a DSP mentioning that the “sudden staff dips place more demands on staff that remain and causes work to encroach on personal lives more”. Another shared that the short staffing “effects the effectiveness of how well we can provide person-centered support”. These impacts on direct support staff were mirrored throughout the data, with staff mentioning how much shortages and turnover impact their jobs.

A common theme also showed that the staffing shortages focused mostly on direct care workers and frontline workers, and that the issues were reversed for supervisors and administrators, with staffing surpluses. DSPs mentioned that there are too many supervisors and not enough direct care staff. One even mentioned that their organizations should “spend less money on ‘administrators’ who languish behind desks all day and occasionally slither out to condescend to people who are actually doing direct care”. Direct support professionals feel strongly that they are not being valued for their difficult and essential work, and that people who are being paid more are often being ineffective.

4.2.3 Reasonable job expectations

DSPs were concerned about their workloads and unfair job expectations. Many are asking for lessened caseloads, calling for more staffing but also reasonable expectations for the number of people they are supporting and the actual job responsibilities they are being asked to perform. One finding that was well-described by multiple DSPs was the issue of strong DSPs being overworked to make up for lacking quality in their co-workers. Instead of rewarding good DSPs, many felt like

they were being punished by adding job responsibilities without matching compensation. Many DSPs recounted having their tasks and expectations increased without additional time or compensation to match. DSPs are mentioning how they are overworked, and many would request less work, not simply more overtime. For example, a DSP interviewed mentioned wanting to not be paid to work through lunch, but actually have the opportunity to eat their lunch. They described how the “higher ups” wouldn’t even think about something like this but how DSPs really just want to have a break sometimes.

Some DSPs also suggested that managers shouldn’t add extra responsibilities outside of one’s job description, and especially should not do so without appropriate compensation. Adding responsibilities outside of the job description without formally changing the description or adjusting the pay scale, forces other DSPs to have increased expectations far beyond what they initially signed up for. This is unfair to all DSPs involved, and is a contributor to turnover issues according to some DSPs.

A DSP provided an interesting example of when their caseload and work expectations were not just unreasonable but were changed and dictated without their control or input. One DSP even reported,

[my role description] says ‘workout schedule directly with person supported’ [but] despite this, my supervisors routinely changed my schedule without the consent of myself or the people I support. This has had a detrimental effect on my customers and my own mental health. I want them to understand that they do not get to pay talented people low wages and shove their schedules and caseload around at will. It's one or the other. Not both.

Direct support professionals across the board were also discussing issues about documentation. In both the interviews and the survey results, this theme was touched on in a variety of ways and in multiple interactions. DSPs felt overwhelmed by the amount of paperwork required of them. Many wanted the paperwork to be moved online, and some mentioned if moved online, that the agency needed to provide more computers to make the online paperwork accessible at work. DSPs are also calling for overall less paperwork and documentation. Particularly around documentation that is repetitive, when documenting changes alone would be more effective and efficient for resource usage.

Ultimately, DSPs want clear and reasonable expectations for their work and the time they have. They currently feel overworked and underappreciated.

4.2.4 Fair compensation and recognition

The largest outcome of the study was DSPs describing in detail the desire and need for fair compensation and simple recognition for the work they are doing. In both the surveys and particularly in the interviews, this finding was extremely salient. DSPs discuss wanting simple recognition for their work, and not just on “DSP days”. Sometimes they just want a simple thank you from their agencies for all of the work they do. Particularly, DSPs who are doing a great job, as mentioned in the finding before, do not feel as though they are appreciated, and instead get additional work which feels like punishment.

There is an overall theme that DSPs feel underappreciated, overworked, stressed out, and stretched thin. They feel like the people who supervise them are taking advantage of them, and even sometimes dehumanizing them. One DSP shared that they wanted to “feel as if we were somebody and not just a body to suffice their

needs”. This sentiment is found throughout the case interviews and the survey data, where DSPs are feeling ignored, underappreciated, and undervalued. They feel like their supervisors have little to no appreciation for their lives outside of work and have unfair expectations of their time and tasks.

DSPs discuss a significant need for fair and appropriate compensation. The obvious of which is improved wages and just raises, however appealing benefits, allowing for time off, more vacations, and “referral pay” were also suggested as needed compensation for vital work. Lastly, DSPs are desiring career growth opportunities. Many DSPs mentioned wanting their agencies to support their professional development, connected often with their desire for more training. DSPs that were interviewed also mentioned wanting more opportunities for upward mobility in an agency, stating the lack of career mobility as a determinant for turnover in the field.

4.2.5 Quality and participatory management practices

Many of the DSPs in the surveys and interviews mentioned aspects of management that could better support them in their work. What came out of those responses, was a call for what I’ve labeled as “quality and participatory management practices”. Many of these findings are supported in talent management and strategic human resource management literature, which will be discussed further in the discussion section.

DSPs were looking for management to invest in them. They desired opportunities for professional development and career trajectory opportunities. DSPs often desired productive performance evaluations, so they could receive feedback about how they were doing and how they could improve in order to better to support

the people they work with and to promote upward mobility. DSPs mentioned their desire for performance evaluation, with many commenting that their scheduled monthly or annual evaluations were not actually happening.

DSPs recognized that they thrived better when their supervisors were motivated to be there. Many discuss the relationship with their supervisor as either a positive reason they stay, or one of the things they wish they could change. Some wish their manager would stop micro-managing them and would build trusting environments that allow them to thrive. A DSP put it this way: “Trust that those people working in the trenches with the people we serve know what we're doing.” DSPs throughout the study mention how “higherups” do not trust DSPs expertise or recognize the unique input they can provide as front-line workers.

DSPs in the survey also complained about policies being unfairly enforced. With transparency and fairness, DSPs would feel more respected and appreciate coming to work. Tied to transparency, DSPs desire improved communication from their agencies (both management and co-workers). Often poor outcomes were due to a lack of communication in the workplace, and many DSPs wished that their supervisors were clearer in their communication and more available to communicate with their direct support staff. They want to better understand the “why” behind decisions that are made.

DSPs also were frustrated with a lack of team-building on the behalf of management. Some DSPs desired more opportunities created by management to interact with their co-workers, learn from and collaborate with one another, and improve the agency culture by creating team-building activities and opportunities to interact. One DSP described this as “there is little interaction between coworkers.

This can drive a hard workplace environment. We do provide support to each other and communicate regularly through phone and email, but nothing can replace person-to-person interaction.”

One of the greatest takeaways relating to quality and participatory management is that DSPs want their voice to be heard and respected. Responses mentioned wishing their supervisors would listen to them, would take their suggestions, and would actually include them in decision-making. Some DSPs recalled monthly meetings where nothing came from their suggestions, and some were not even sure there were mechanisms to provide feedback on management or their co-workers. DSPs wish that management would “listen to what staff is saying rather than assuming you know the answers because of your title”.

The last aspect of quality management practices includes a section about common sense practice. Some DSPs mentioned concerns about things that seemed really straight-forward and only complicated by unnecessary bureaucracy that is not in the best interests of the people being supported. An example came from a DSP describing a rule the agency had put in place that bans cellphones from the agency. However, the DSP mentions that technology could allow them to teach the person they support how to have more independence and be able to call their own paratransit services. This senseless rule does not make any sense to the DSP or the person being supported, and a quality manager would be in contact with these frontline staff to recognize this ineffective policy.

4.2.6 Adequate funding for basic needs

Direct support professionals often mentioned that they understood many of the limitations that managers are facing. The feedback based in good intentions, including

discussions of understanding a bit of why things are the way they are. The last major finding is that DSPs really just wanted basic needs to be met. Many were frustrated by how under-resourced their programming is. Many advocating on behalf of the people they support, wishing that more resources could be allocated to the actual people receiving services.

Two big topics included transportation and technology. DSPs were asking for mileage reimbursements instead of stipends for transportation costs, and others requesting more company vehicles instead of using personal ones. For technology, DSPs were requesting more current technology be used, as well as adequate computers or cell phones to be able to complete documentation, including while within the community. DSPs were often finding that billing concerns were being put over the needs and what's best for the people being supported. While recognizing budgetary constraints are a reality, many DSPs were concerned about the complete lack of budget items for things that are really important to the people that are being supported and to promoting quality person-centered services.

4.3 Case Studies

In order to illustrate and support the findings about role perception and support needs, the following will describe each of the case studies as an entrance into the discussion of findings. The case studies will be presented to include the most relevant information, addressing role perception and/or support needs. Ultimately, the case studies serve as illustrations and lead into a further discussion of the findings of the study.

4.3.1 Hope Homes

Hope Homes appears to be a typical, more traditional agency that provides group home services. The findings from this organization were the least substantial due to limited number and time of interviews. Four interviews were conducted at this agency, and additional website data and limited observational notes were also examined to better understand this agency and the experience of the DSPs interviewed there.

The DSPs were interviewed at a DSP training the agency was holding. All four DSPs interviewed focused on traditional roles at least in the initial part of their descriptions. They empathized “serving as an extension of the nurse,” “focusing on hygiene,” “dispensing medication,” and “chores” as vital parts of their roles. Three of the four DSPs mentioned the phrase “meet all of their needs” with some DSPs emphasizing this as the most important part of their job. This phrasing was unique just to Hope Homes with no other DSPs using this phrasing.

In determining the agency was more traditional, one particular interview stood out. The DSP mentioned that “the person I support feels like he doesn’t have control; anyone could walk in the door to come support him”. This finding describes one of the ways that administrative action described by many DSPs in regard to changing up schedules, can actually take away power and control from the person being supported.

DSPs had conflicting reports about feeling appreciated by the agency. One DSP mentioned they had been working there for years but while the agency always has appreciative awards dinners, she had never been nominated. She feels underappreciated and excluded and thinks that people who stay for a while in the job deserve to be appreciated. In contrast, another DSP mentioned having received a lot of awards for her creativity and in “DSP excellence” which really matters to her. One of

the findings found that DSPs are generally feeling underappreciated. Clearly, Hope Homes had done some work to appreciate their staff, but managers need to recognize who is being nominated for those award dinners, and how they are making people who have been with their agency for a long period of time feel appreciated.

The interviews at this agency were conducted during a DSP training session at the agency's headquarters. The researcher didn't get to observe the residential placements themselves, but instead observed the beginning of the DSP training. The content for that particular training was very procedural, focused on utilities and infrastructure of the homes themselves. While the researcher did not observe the entire training, it ended early and the handouts provided only included basic logistical facilities information. The handout did include the mission/vision of the agency, an effort clearly demonstrating the work of management to make sure that the mission/vision was present in everything they do, but the training itself seemed to mirror survey findings: trainings were boring, repetitive, and not actually focused on personal outcomes of the people being supported.

4.3.2 Change Inc.

Change Inc. was one of the more interesting case agencies. Change Inc. is an agency in transition, and DSPs were interviewed from a variety of departments across the continuum of services they provide. DSPs from the most traditional settings at the agency had significantly more traditional role descriptions. One DSP worked to support a cleaning crew contracted by different state agencies and the other worked in a graphics department, running an embroidery machine. The two DSPs described their jobs being first about the actual task of cleaning or embroidery. One mentioned first that her job was picking up the cleaning supplies, and only later mentioned that the

cleaning came secondary to supporting the people in her enclave group. She also mentioned being a good driver as important and lastly to make sure the people had a good day. The other discussed her job as sorting and folding, as well as winding bobbins. Her job was first and foremost about the embroidery machine and not the people she was supporting. Her language discussed the importance of safety and teaching people to be timely, clean, and ready for work. The women in the graphics department even mentioned some of the people she supports have “mild MR, some have Downs” and they’ve been here for a long time. These role descriptions stood in contrast to the other more moderate or progressive departments.

Three of the DSPs interviewed worked in what were essentially group homes within the community. They had mixed responses of role descriptions. Two maintained very traditional understandings of their roles with some infusion of more innovative role descriptions. One described her job as being to build a better quality of life for the people she supports including providing “outings, functions, parties.” She emphasized some of the ideals of the “changes” happening at Change Inc. as people having their own space, their own room, their own bills, etc. However, when asked what the three most important things she does for her role were, she still listed medication, documentation, and physical care. The other mentioned phrases about independence of the people she supports. She focused on taking people “out and about in the community” and about people’s busy social calendars. However, her role was also combined with an adherence to a schedule. Her interview, like many of the interviews at the other agencies, used language of “taking people out to the community” as though it were a task to be done and less about genuinely connecting people to their communities or fostering a sense of belonging.

The last of the three group home DSPs surprisingly had the most forward-thinking of descriptions, describing how her job was to help give the people she supports a better life. She talked about people doing their own things in their own way and allowing the people she supports to make their own decisions. The “mixed bag” of role descriptions is reflective of the changes happening within the agency, trying to make the group homes more focused on open, person-centered, community living. There is an infusion of language that is more progressive, but still existing within traditional frameworks, has limitations to how much meaning it actually holds.

Two DSPs from two different departments were also interviewed. One DSP was part of a new department called “community development” and he discussed how his job was to get people out and his biggest role was to create a calendar board. Imbedded in his responses were still focused on building skills and keeping people safe. The department he was working for was one of the new ones that was being focused on with the “changes” happening within the agency. Yet still, those more traditional descriptions persisted with an infusion of some more community-based ideas. The second DSP was from the “supportive employment” department. She discussed the changes in expectations for her role with the “changes” of the agency. Before she had to “get the guys volunteering at jobs, but now I need to get them working at a job.” She focused her role as going with people’s unique style and pace, knowing the person, and learning about the job they have. Her focus was on building a relationship with the people she supports. Her description represented more progressive approaches, which live in line with being a part of the most progressive of the departments at the agency.

4.3.2.1 Dealing with Changing Times

The most interesting theme that came from the interviews and the site visit was the focus on the “changes”. Every DSP mentioned the “changes” and had their own unique perspective on them. According to each of the DSPs interviewed, the “changes” meant it was not okay to just have people out in the community, but they needed to have jobs that were for competitive wages. DSPs reactions to this were varied. Some were struggling to see those outcomes saying that at first some people were actually losing income and could not find jobs. Many felt these changes were unrealistic for a small number of people, but many acknowledged that a lot of the people they supported were capable of meeting the requirements of the changes. Some wished that things would stay the way it has always been, since “right now they [the people being supported] are protected”. DSPs mentioned that many parents were upset with the changes. Some DSPs were overwhelmed at first but admitted that it wasn’t as bad as they thought it would be. Many acknowledged that these changes would be great for the people they support. One even described how “people used to pack gumballs for vending machines, but now they get to actually enjoy in the community”.

DSPs admitted that many DSPs choose to leave the agency because of the changes. Many who had been there for years didn’t want things to change, so they just left to agencies that were doing things the traditional way. Many DSPs felt like it was bad for the individuals since they were used to being together all the time, but now they hardly would be.

DSPs discussed a lot about how management has handled and was handling the changes. The biggest complaint was the lack of communication. There hadn’t been trainings or communication about the changes, or ways to support individuals in working through these transitions. Many didn’t really know what was going on with

the changes or what the timeline was, because of poor communication from management.

The changes were also evidenced in the site observations. The researcher was able to walk through the old parts of the facility with the executive director of the agency. Throughout the mini-tour of the buildings, there was emphasis placed by the CEO on the physical infrastructure. The old parts of the property used to be houses for the “students” at the facility. The rooms were no longer in use as the shift towards community placements were encouraged. However, even with the changes, there was still a lot of emphasis on the buildings themselves. Talking with different staff (the receptionist, some DSPs, and even the CEO) they kept mentioning how large and beautiful the property was. They discussed how the buildings were maintained after years from when it was first established. The agency is very old, and thus structurally holds parts of its past. As an organization that is seeking to evolve and change, these historical structures are representation of one way they are being held back.

4.3.3 Excellence in Direct Support

Excellence in Direct Support represented a more traditional agency that provides group home services. All three DSPs interviewed had fairly traditional role descriptions, supporting the findings of the survey role analysis. One DSPs first statement when asked to describe their job mentioned they need to “check in with the ladies, are they wet?” Overall, the findings from their role descriptions were not incredibly interesting or different than a traditional role description of custodial care and safety. However, what was most interesting about this agency, was the way they support their DSPs

4.3.3.1 DSP Support and Management Practices

By far, Excellence in Direct Support had the best supports in place for direct support professionals and serve as a leader in the region for supporting DSPs in terms of appreciation, compensation, and participatory management. All three DSPs were raving about working for Excellence in Direct Support, which was not found in any other DSP interviews.

DSPs identified the quality communication, substantial support from supervisors, thank you notes even from the CEO himself, appreciation picnics, quarterly raises specifically for direct support staff, quick responses from supervisors and program director, and professional development training, as major components of their quality work experience. This left one DSP discussing how Excellence in Direct Support was “the best company I have worked with.”

Many pointed toward the efforts of the CEO. The CEO had actually been a DSP in his past work, which his staff mention as one of the reasons he may be so successful and supportive of his direct support staff. One DSP mentioned how,

there was an event with our neighbors and the CEO... came up to the event and was super helpful. He was willing to do the hands-on work. I walk over and see [him] in the dirt, taking out the trash. He even stayed after the event to help clean up.

The DSPs mention his hands-on approach and how much it mattered that he was a constant welcoming and helpful presence who was willing to do the direct support work himself. One DSP also mentioned how the CEO would sometimes come by the houses and discuss disagreements with the residents that lived there. He even wrote letters with one of the people his agency supports.

Another DSP just kept listing and listing the bonuses, values, and appreciation tokens that they received at this agency. The list went on and on and was also present on the agency's website. Obviously, this agency values supporting its employees. One of the most impactful bonuses was that the CEO was willing to pay for her to take classes while she was an employee with them. At one point there was an issue with the amount of credits she was taking, and he was even willing to be flexible with her and cover more credits that one semester. Another mentioned the bonus check every six months as well as raises. Another valued the agency's flexibility and willingness to help you take time off or even encourage you to. The CEO was also a believer in second chances. A DSP mentioned that he rarely fires people because he "that's not what this is about". That DSP really valued second chances and the opportunities the CEO made for them to learn, grow, and develop as an employee.

Interestingly, there was some overlap in employees between this agency and ABC Center, described below. One of the DSPs at Excellence in Direct Support previously worked at ABC Center and a DSP at ABC Center also worked at Excellence in Direct Support. This overlap was coincidental but provided really interesting data for comparison. One DSP who also worked at ABC Center provided negative examples from their experience at ABC Center that were not issues at Excellence in Direct Support. The most profound example was on a day when they were,

attacked while driving to job training. Someone threw a trashcan at my head and I stopped in the road. I had 9 people with me. I called my supervisor at ABC Center but they weren't available. It took one hour to help them calm down. The director wouldn't know what to do.

In contrast at Excellence in Direct Support they mentioned how the supervisors all used to be DSPs and were responsive to calls. That mattered a lot to this DSP.

4.3.4 Community Connections

This agency was the most innovative of the ones visited. Two of the DSPs in particular had the most forward-thinking role perceptions of all the DSPs interviewed. They included discussions like “treat them as adults,” “give people a chance to make mistakes,” “let them make their own choices,” “have a meaningful day,” and “help them establish relationships and feel included”. These positive descriptions were not without more traditional tasks about well-being and care, which are essential to the role, but demonstrated a concrete difference between other DSPs descriptions.

The other two DSPs at the agency that were interviewed had more transitioning descriptions, but evidence that they had elements of the broader message and values of the agency throughout their responses. They included things like “take on vacations” or “support their goals” but it was unclear if the alignment to forward thinking values that exists in the leadership of Community Connections has transferred to all of the DSPs specifically in their role perception. However, they noted that “the people we support have their own goals and we need DSPs who will listen, be patient, and help them reach their goals.” Overall, every DSP at this agency spoke about their role very differently than any of the other DSPs interviewed across all the other agencies.

4.3.4.1 Need for Quality Business Practices

Despite the more innovative role descriptions and overall quality of services, DSPs made it evident that the agency still needs quality business practices. DSPs

mentioned feeling unseen by their agency and needing more pay and recognition. One DSP mentioned “I don’t like the dry group meetings of our supervisors. And when I call my supervisor, I often don’t get a response when calling. DSPs need attention and communication from supervisors.” DSPs, while supported in some ways by the agency, with access to trainings and conferences for some, wanted more support from their supervisors. They wanted people to be responsive and to communicate well, mirroring findings nationally. A DSP suggested

when you reach out to a supervisor, they need to get back to you sooner. For example, sometimes they don’t respond to you until six hours later, but you need the information right then and there. The protocol says you should call them, but they don’t respond, so what do you do?

DSPs were feeling frustrated that the policies dictated one thing, but reality made it impossible for them. They had to decide whether to break protocol to try to take actions to best support the people they work with or abide by protocol and not work in the best interests of the people they support. This goes against the real intent of the protocol, and DSPs either want more flexibility, or more importantly, responsive supervisors.

DSPs at this agency also wanted “room to rise in the company.” Many recognized they had no room for upward mobility and were basically set to be a DSP with the agency forever. While a DSP mentions that “they are always willing to give you more training” and that “I have a great supervisor who cares about my personal life and work-life balance” DSPs feel like they aren’t allowed room to grow within the agency itself. While some feel “like I am a part of [Community Connections] and want it to prosper” many others feel like they aren’t getting what they need to succeed.

Clearly, Community Connections is making its changes, but some are not fully translating. A DSP mentioned that Community Connections needs to get the concept that it's about the individuals with the disabilities. When supervisors enter the room, they should be client-centered. It's someone's home so ask to come in. Ask if things are okay before talking to the DSP. Ask if you can touch something or open the fridge or enter a room.

This comment was coming from a DSP who was complaining that supervisors really don't get it. Knowing the agency has invested in DSPs understanding its vision and attending advanced trainings, it needs to continue to work to align all employees across all levels to this vision. Some DSPs have got it, and they wish their employers and supervisors did too.

4.3.5 ABC Center

The last of the case agencies was also the most traditional. In the course of the field visit, the researcher had the opportunity to walk through a small part of the agency, to see a handful of people waiting in the hallways, sitting alone. There was nothing to do, and a DSP mentioned they were probably just waiting to be changed, since there are not enough bathrooms. Looking through the doorway, people were gathered around a screen, idly watching some show. Later, the buses come to take huge groups of people away from the day program at the end of the day.

In many of the interviews, DSPs mentioned how their job was to help people accomplish their goals. However, when pressed further as to what these goals were, it was shown that they were not truly person-centered or valuing things that are actually important to people's quality of life. A DSP mentioned how

goals are updated every year. Sometimes people keep the same goal in between years. For example, goals could be like taking lunch out and using the microwave independently or engage in group activities with others. Or for example, one participant's mom wanted his goal to be learning the names of others.

These goals were a great illustration of the agency's values. Goals were supposed to be updated annually, but sometimes that was not even achieved. The goals seemed really odd or arbitrary—no one's life is really that exceptional or noteworthy knowing they can use a microwave individually or that they learn everyone's name. Additionally, the goals often focus on the parent's values or that of the "higher ups" making the plans.

Seven people at the agency were scheduled to be interviewed. Frustrated by the way people were being supported and the despair of the staff interviewed, the researcher decided not to finish the final interview, only completing six. This note is necessary to understand how the cases were constructed, since it is impossible to remove the researcher from this analysis and since personal frustrations can impact the interpretation of this case.

4.3.5.1 Role Descriptions and Context Approaches

When initially coding the data for the interviews, the role perception of the DSPs from ABC Center could be described as partially traditional but also including more "community" codes than one might expect. Every DSP interviewed had some "community" or "activity" based codes with some traditional custodial care codes. DSPs mentioned "community" throughout. They discussed their job as to "get them out into the community," "take them fishing," "have parties for them," "go to the

YMCA every week,” “take them to parks,” and “provide activities”. With an initial review, the findings of this, as discussed prior, may indicate more innovative understandings of their role.

However, it is important to consider how each of these keywords were used in relation to power and control. The way these DSPs talked about community compared to the other agencies focused on who got to make the decisions and what was the purpose of the tasks. The activities were described as “something to keep them occupied.” Often the descriptions focused more on the interests of staff, for instance one DSP mentioning “I really like parks, so I take them to parks” and another discussing their love of horses and how they own a farm, so they brought the horses to the facility, to share with the participants. The calendar of events was decided by staff and served people in groups.

The coding structure, without context, cannot actually differentiate between these different uses of the word community. Just because a DSP says they need to go out into the community as much as possible, it does not consider how the DSP made the schedule of activities. Or that the outings actually only occur “three times a week” and are often to the same places, parks and the YMCA. It is always large groups of people being served at a single time in enclaves. These descriptions thus are the most traditional found. Power and control are not in the hands of the people being supported. One DSP illustrated their role perception vividly, describing his job as “I wipe butts and do activities”.

4.3.5.2 DSPs Need More Support from the “People Upstairs”

Direct Support Professionals at ABC Center were also being treated unfairly at their agency. DSPs mentioned that “the higherups need to understand what we do

every day, the challenges we have, and what stresses us out. There are too many things to do and limited time... we don't feel cared about". DSPs throughout the agency felt unappreciated and misunderstood by the "higher ups". One mentioned "we don't ever see the people upstairs." Administration and management were seen within a very strict hierarchy, demonstrated by the way the building itself is even constructed, with the ground floors being the direct support staff and people being supported, and all but one upper admin, being physically on the second level, never interacting or encountering a person being supported by their agency. DSPs are feeling underappreciated recognizing that

the higherups get recognized but not us... some of them don't even listen to what you're saying, they think, 'you're just a DSP'... DSPs are never invited to the actual meetings, meetings with DSPs are just Dos and Don'ts... if it wasn't for us DSPs some of these companies couldn't run... They wouldn't think of this or know what was important to us, unless they asked.

These sentiments were within practically everyone interviewed at this agency and mirror the national findings. DSPs want their voices heard and actually used to help make decisions. Even at the most traditional agencies, these practices are needed.

Chapter 5

DISCUSSION

This study uses qualitative research methods, centering direct support professional voice, to investigate two primary research questions:

- 1) How do the role perceptions of direct support professionals differ between agencies across the spectrum of service providing?
- 2) What is needed in the field to better support direct support professionals?

The study identified differences in role perception across the spectrum of service providing and identified six distinct support needs of DSPs through the use of a structured national survey and semi-structured interviews at five case agencies.

5.1 Role Perception

In regard to role perception, it was found that as anticipated, more innovative service settings tended to have more innovative role perceptions and more traditional service settings tended to have more traditional role perceptions. Traditional custodial role functions, such as an exhaustive emphasis on health & safety, performing or supporting activities of daily living, and administering medication, were all found at the highest relative rates in more traditional agency settings. This view was amplified in the case studies, where the most traditional settings often simply discussed checking if someone was wet, monitoring their medications, and documenting such efforts. In a field that has dense histories of institutionalizing disabled people, these same role functions found in the initial institutions, are still present as primary job functions today.

However, that is not to say that those role functions disappear in more innovative settings. Still direct support professionals will need to support people's

health, administer medications, and assist people in their ADLs. However, those are not the only identified roles, and they are not the primary goal of service provision. In contrast, functions like independence, employment, choices, self-determination, and non-locational community, are found in highest relative rates for more progressive agencies. DSPs in those agencies still discuss ADLs, health & safety, and medication, but the focus of their goals are shifting. Other studies have documented that the necessary roles are evolving, but none have begun tracking or evaluating how the frontline staff are actually perceiving these changes, and if they are adopting different lenses to view their service delivery.

What was curious about the results for the keyword analysis were some of the highest relative uses for intermediate agencies. Providing activities, developing skills, meeting goals, transportation, trying new things, and locational uses of community, were found at the highest relative percentages in intermediate agencies. Each of these role descriptors are fascinating when examined through a lens of change.

For instance, something like providing activities may not even be occurring in the most traditional of settings, where only custodial care is the goal, however in more innovative settings, providers are recognizing that you are taking away power and control when “providing activities”. Keeping people busy is not necessarily promoting a meaningful life. Additionally, the same logic applies to skill development, goals, and trying new things. These expectations of the person receiving services may not be present or at least as important in traditional settings, however these functions also do not fit in more innovative settings. The obsession with setting and achieving goals, with developing skills, or with trying new activities, are found in agencies that are trying to transition from congregate care towards person-centered supports. However,

these ultimate obsessions will hold service providers back from actually achieving quality outcomes.

In regard to transportation, agencies that are changing or in transition, historically did not have to consider transportation. For instance, the ABC Center used full buses to transport the people they support, because segregated, congregate settings do not require complex transportation. However, a transitioning agency suddenly has a crisis of how to actually transport folk in a person-centered and individualized way. These transitioning agencies do not have the infrastructure nor person-centered design to facilitate truly person-centered services, but in attempting to do so, transportation becomes a major concern at the forefront of DSPs experience.

Another crucial part of the role descriptions was in regard to the term or concept of community. Agencies are beginning to recognize that their services should be “community-based.” However, agencies and their direct support staff can begin to adopt buzzwords in replace for meaningful development in their services. In a search for becoming “person-centered” and “community-based”, the depth of knowledge or appreciation for those concepts can be lost. DSPs would discuss bringing people on outings to the community, recognizing this as a task or activity to accomplish and less as an honest value and orientation of their service-delivery. They would discuss calendars of events they put together or could give a number of the times they go out to the community, in a way that would never happen in the life of a person that did not receive services at their agency. The field of direct support has become so intent on capturing outputs and outcomes, that in doing so, it has erased the intent of the concept of community-based services themselves. When taking locational or task-based uses of the word community out, the highest level of community in the role perceptions

were of more innovative settings. However, intermediate providers are talking about “community” more often. Service providers need to recognize this in the development of their services to really consider what community means, how it is imbedded in their development and implementation of their services and evaluations, and how it is translated to their frontline staff.

It is undisputed that the roles are evolving in direct support, and it is crucial that agencies consider how direct support staff understand or perceive their role. Direct support staff are the key to quality services, since they are the point of interaction with the people agencies support. In recognizing the integral role these professionals have on the lives and outcomes of disabled people, it is vital that they understand their role as promoting the outcomes these services ultimately desire.

5.2 Support Needs

It is valuable for organizations to center the voices of their frontline staff as well as the people they support in making organizational and management decisions. In recognizing the current workforce crisis, it is the voices of these professionals and the people they support that need to be highlighted in order to address the workforce development itself. This study identifies six predominant support needs identified by direct support professionals, that mirror the common practices of talent management and strategic human resources management (Berger & Berger, 2018; Pynes, 2013). Ultimately, in order to retain high quality, talented employees, organizations need to consider how they are strategically investing in their employee’s development and creating organizations that foster talent.

DSPs are eager for improved access to training and development. This finding mirrors other research in the field that has shown this desire among DSPs. Agencies

need to do more to improve trainings and increase access to additional topics for direct support staff. Organizations increasingly need to provide training and development that is tied to competency-based frameworks (Bogenschutz et al., 2015; Pynes, 2013). Direct support staff have identified they want more training, and their service providers and the state need to do more to actualize quality, engaging, non-repetitive, competency-based trainings. Trainings should consider the changing role of direct support to ensure that professionals have the competencies to be working in this evolving field. Trainings focused on unpacking what “community-based” services really look like and how to embed self-determination in their work, as opposed to repetitive fire drill and blood borne pathogens training.

As research has indicated, the field of direct support has high turnover, low retention and high vacancy rates (National Core Indicators, 2018). DSPs were able to document that the concerns around the quality and reliability of their staffing significantly impacts their success in their agencies. Quality DSPs are being bogged down in additional unfair responsibilities due to an agencies inability to retain quality staff to fill their needs. In an earnest desire to grow, agencies are more concerned with their bottom line, opening more services, and fail to adequately address the current issues with lack of staffing. Many DSPs acknowledge the difficulties that their agencies have in recruiting and retaining, staff but were able to document how that impacts their day to day responsibilities.

Many DSPs discussed the need for reasonable expectations. The first research question about role perception captures that the roles of DSPs have been changing, but the actual requirements of the position are not just evolving but are actually expanding. Instead of simply being required to keep someone healthy and safe and

meeting their most basic needs, DSPs are required more of today. However, often their role descriptions do not capture everything that management is asking of them. DSPs mention having overwhelming casework, overwhelming documentation requirements, and not enough support or compensation for what they are required to do. In order to recruit and retain professionals, expectations need to be outlined transparently in the recruitment process.

One promising practice identified from human resource management literature and already incorporated into the field of direct support is realistic job previews (President's Committee for People with Intellectual Disabilities, 2017; Pynes, 2013). DSPs want to know what is required of them and want to be held accountable for what they were told upon recruitment, not tricked into doing more. If managers are going to start adding job responsibilities beyond what was initially agreed upon, they need to adequately and fairly compensate for those additional tasks.

One of the more robust findings of the support needs is the need for fair and just compensation and recognition. This issue is well-documented in the field of direct support (Carman et al., 2009; President's Committee for People with Intellectual Disabilities, 2017) and an issue that many DSPs are advocating for. Direct support staff are paid a median hourly wage of \$11.41 an hour (Carman et al., 2009) and about half receive public benefits such as food, medical, and housing assistance (President's Committee for People with Intellectual Disabilities, 2017). This issue is pressing in the field and vitally important. Direct support work is more rigorous than other forms of work with comparable pay, and DSPs ethically deserve just pay. Agencies and governments need to value the outcomes of disabled people, recognize the integral

component DSPs have to promoting those outcomes, and invest in the field of direct support.

The study however also found many ways that agencies can support DSPs and help them feel appreciated for the work they do, that does not include wages. Direct support professionals want to be treated fairly and transparently and want to be appreciated more than at “DSP week”. A simple thank you note can go a long way. Direct support staff at the case agency Excellence in Direct Support, demonstrate the best possible outcomes when it comes to the identified support need of fair and just compensation and appreciation. It means something for DSPs to feel supported and known by the highest positions in their agency, to be given flexibility and trust in their work, to be given fair second chances, and to be appreciated personally and throughout the year.

The most extensive finding was about quality and participatory management practices. DSPs were identifying the many different elements that contribute to fair, transparent, quality, and participatory management. Direct support professionals should be a part of decisions that impact their lives, and as valuable stakeholders in service providing, should be included in the design and development of services. This study aims to center their voices as experts on their own profession. However, it was incredibly interesting to see the number of responses from people who are not direct support staff. A CEO filled out the national DSP survey, indicating they surround themselves with DSPs and thus can speak on their behalf. While I am sure that the CEO who responded was incredibly well-intentioned, they demonstrate one of the major issues in the field, that DSPs are being ignored in their agencies. Instead of managers thinking they are intrinsically right, quality managers consult information

and feedback from all levels of their agency, including those in frontline positions. DSPs are experts in their own experience, and managers need to recognize this and make use of that expertise, allowing DSPs to contribute in the design of services and to improve their quality.

DSP expertise can also identify discrepancies between policy and practice. A couple examples were revealed in the course of this study where “higher-ups” decided on a policy without include direct support staff in the decision-making. However, when putting that policy into action, direct support staff understand what works, what is possible, and what is potentially conflicting. DSPs have identified specific instances where policy does not create quality practice (e.g. cell-phone policy, contacting supervisor policy, issues implementing person-centered plans). Managers would be well advised to authentically include DSPs in the design and implementation of policies due to the unique perspective and information they can provide.

DSPs are asking for improved professional development opportunities, an established career trajectory, opportunities for performance evaluation, transparency in decision-making, and strong, timely communication. These elements are well documented in strategic human resources management literature and need to be applied to the field of direct support. Agencies should invest in their direct support staff’s development in addition to their training. There should be opportunities for DSPs to develop skills and competencies they can apply in the workforce, and room to rise within an organization in order to retain those employees. DSPs, like all employees, desire effective performance evaluation and feedback, and agencies need to put more resources into providing opportunities for feedback pathways for those

employees. DSPs desire what all employees desire, fairness and transparency, and agencies can do a better job at ensuring both.

One major finding from both the case studies and the national DSP survey is that the field of developmental disability services is unnecessarily complicated and maintains complicated and unnecessary bureaucracy. State and federal requirements are making the field of developmental disability services incredibly complex, and rather than improving quality of services, it is detracting resources from the people being supported. The field spends so much time documenting outputs and trying to capture the outcomes, that it is embedding historical ideas of disability services into evolving agencies. Agencies should consider how it can simplify the unnecessary complexity of planning, implementation, and evaluation, so that direct support staff can actually deliver quality services.

While the field of developmental disabilities is constantly evolving, much of service delivery and the DSP workforce crisis has remained stagnant. The field is in need of innovation and changemaking in order for disabled people's lives to be truly self-determinant and community-based. Many agencies that are changing face major backlash from staff and from supervisors, throughout the agency. In order to create true change, you need some people at all levels to believe in it. It is not enough for supervisors to believe in the change and to develop "better person-centered plans", if the direct support staff do not understand their evolving role. Likewise, many supervisors do not truly understand what it means for the agency to actually support people individually, so a reevaluation of what quality means, is an important step across all levels of service-providing. Role perception impacts the quality of services, so agencies should spend time understanding the changing role that will be needed to

provide truly quality services, and examine how the planning, implementation, and evaluation of their services truly cultivate and capture quality. Having a strong direct support workforce is required to create quality services, however alone it is not sufficient. All agencies should invest in their workforce, and consider the six identified support needs, however supporting DSPs is only a part of the process of changemaking in the field and supporting quality services.

5.3 Limitations of the Study and Opportunities for Further Research

There is difficulty in capturing the voices of direct support professionals due to the difficulty in unbiased recruitment. NADSP is one of the best recruitment tools available to the research field to capture direct support professionals as the one national organization for DSPs, however it is possible that the DSPs recruited through NADSP are not representative of direct support professionals nationally, due to some of their accepted values. The sample size of 440 is reasonable to draw conclusions from, however breakdowns into particular sub-agency types (traditional, intermediate, and innovative) are less reliable. In interpreting the results of this study, readers should be aware of the smaller responses when broken down into sub-agency types.

Another limitation of the study is the influence of the researcher. The values and beliefs the researcher brings into the research are inextricably connected to the analysis and the research design. There is a potential that a researcher with different perspectives on the field of developmental disabilities and placement within the work, may have approached the analysis and display of the case studies differently.

One of the major limitations of the role perception portion of the study was the need to calculate or quantify role perception and differences in relative keyword usage. It is difficult and potentially impossible to adequately quantify role perception,

so keyword usage was a proxy measure. However, future studies should consider applying a NOVA analysis to the relative keyword breakdowns to determine the significance of any differences across the continuum of services. Without this analysis, it is difficult to say if the differences between types of agencies and relative keyword usage is significant. Future studies could examine the significance of these differences and consider other avenues to capture role perception beyond a keyword analysis.

Chapter 6

CONCLUSION

As one might expect, the role perceptions of direct support professionals are different across the spectrum of service-providing from more traditional to more innovative services. In agencies seeking to change, emphasis should be placed on the role perception of direct support staff who are the key to quality services. The recognition of one's role as promoting the self-determination and community connection of the people being supported is crucial to actually evolving services. Unfortunately, most DSPs do not recognize their job in this way, which is just one reflection on the current state of service-provision in the U.S. Visioning forward, role perception is a useful tool for understanding the quality of service provision, and agencies should consider this in the training and development of their workforce.

In addition to the prerequisite of evolving role perceptions, agencies need to invest in their direct support professionals. DSPs need and want more training, reliable staffing, reasonable job expectations, fair compensation and recognition, quality and participatory management, and funding for basic needs. These six identified support needs are sourced from direct support professionals themselves, who are the experts in their own experience. The field needs to work towards addressing the thirty-year DSP workforce crisis to recruit, train, and retain quality DSPs, and major solutions lie within DSPs themselves, and mirror findings in other fields. While alone, investing in the direct support workforce crisis is not sufficient to creating quality outcomes, it is a necessary component.

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Appendix A

SEMI-STRUCTURED INTERVIEW GUIDE

1. Qualitative Interview Introduction

Length: 20-30 minutes

Primary Goal: To see your perspective on your role as a direct support professional; more like a conversation with a focus on your experience; your opinions and perspective about the topics

2. Consent documentation

All questions below will be semi structured and dependent on participants original responses to survey questions. We may ask all or a portion of the questions below. We may also structure questions to build off of previous answers, for instance, instead of asking "Can you describe what types of services your agency provides," we may ask "you indicated that you provide several types of services, can you expand on that." Semi structured interviews allow the interviewers to gather more in-depth information to supplement, clarify and enhance survey findings.

3. Agency information

- a. Can you briefly describe what type of services your agency provides?
Where those services are provided?

4. Role definition

- a. What types of services do you provide?
Where do you support people?
How many people do you support at a time?
- b. How would you briefly explain your job?
 - i. What are your responsibilities?
 - ii. What does a typical day look like?

5. Evaluation

- a. On what factors are you evaluated?
- b. What would help you do your job better?
 - i. How could your organization better support you?
- c. What is your perspective on [topic revealed from preliminary survey data] in your role?
- d. Is there anything else you'd like to share related to your role as a DSP that we haven't had the opportunity to discuss?

6. Closing Remarks

Appendix B

DSP SURVEY QUESTIONS

Throughout the survey, we will be asking you about your experiences as a Direct Support Professional; we will refer to your position as “DSP”. We know that your agency might have another name for this position, such as direct care provider or personal assistant; often you may also be referred to as “Staff.” To qualify to participate in this survey, we ask that you meet the following criteria. DSPs are someone who:

- *Provides primarily non-medical hands-on supports, training and supervision, and personal assistance to adults with intellectual and developmental disabilities*
- *Is at least 18 years of age; and*
- *Work as either full-time or part-time Direct Support Professionals.*

This excludes DSPs that have additional duties related to administration or shift supervision (often referred to as “coordinators,” “lead staff,” and “house managers”).

1. Are you a DSP, as defined above? (If no- take to the end of the survey)
2. Are you using a screen reader to complete this survey or would otherwise request an accessible format? (If yes- take to more accessible version of the survey)
3. Name of agency:
4. Drop down: State
5. Drop down: total number people my agency supports
 - 0-10
 - 11-50
 - 51-150
 - 151-300
 - 301-700
 - 701-1000
 - 1001-2000
 - 2001-3000
 - More than 3,000
 - Unsure/Do not know
6. Services my agency provides (please check all that apply)
 - Residential group homes
 - Intermediate Care Facility/ICF residential facilities
 - Shared Living/ Host Homes/ Adult Foster Care
 - Services in family homes (home of the family member(s) of the person I support)
 - Services in individual’s homes (home of the person to whom I am directly providing supports, not a group home or residential facility)
 - Center-based day program
 - Community-based day supports
 - Pre-vocational support
 - Sheltered workshops

- Supported employment
 - Other:
7. Where I support people (places where I work when I am providing direct services) (please check all that apply).
- Residential group homes
 - ICF residential facilities
 - Shared Living/ Host Homes/ Adult Foster Care
 - Services in family homes (home of the family member(s) of the person I support)
 - Services in Individual's home (home of the person to whom I am directly providing supports, not a group home or residential facility)
 - Center-based day program
 - Community-based day supports
 - Pre-vocational support
 - Sheltered workshops
 - Supported employment
 - Other:
8. Please explain your job and the purpose of your role in three sentences or fewer.
9. What are the three most important things you do in your job? (Items 1, 2, & 3)
10. Do you receive a regular performance evaluation formally or informally?
- Yes
 - No
 - Unsure
11. If yes: what are the factors on which you are evaluated? (*Please select all that apply*)
- Following agency rules
 - Not using cell phone
 - Arriving on time
 - Medication Administration/Errors
 - Following the Person Centered Plans of the people you support
 - NADSP DSP competencies (<https://www.nadsp.org/15-competency-areas/>), or similar competencies
 - Outcomes of the people you support
 - Being a team player
 - Skills Evaluation
 - Getting along with co-workers
 - Following the Behavior Plans of people you support
 - Availability to fill in when there are open shifts
 - Other: _____
12. What would help you do your job better? (i.e. How could your supervisor or organization better support you to do your job well?)
13. From the options provided, what are your top three reasons you stay in the role of a direct support professional?
- Opportunities for career advancement

- Quality supervision
 - Haven from home life
 - Flexible hours
 - You are an advocate for the people you support
 - Culture of your agency
 - Personal relationships with people you support
 - Religion and/or spiritual calling
 - Opportunities for professional development
14. Please rank those three reasons from most important (1) to least important (3).
- Opportunities for career advancement
 - Quality supervision
 - Haven from home life
 - Flexible hours
 - You are an advocate for the people you support
 - Culture of your agency
 - Personal relationships with people you support
 - Religion and/or spirituality
 - Opportunities for professional development
15. Participants who complete this survey can enter in a drawing to win one of ten \$50 Amazon gift cards. If you wish to be entered in the drawing, please submit your email here. Your email will only be used for the purposes of the prize drawing and will not be linked to your responses or be used for any marketing purposes. Your email will be erased from our records after the drawing.
16. Please enter me in the drawing for ...
- Free \$50 Amazon Gift Card
 - I would not like to be entered into the drawing
17. Please write your email address to be included in the prize drawing

Appendix C

AGENCY GROUPINGS SCHEMA

Innovative Services (Green):

- Supported employment
- Services in Individual's home (home of the person to whom I am directly providing supports, not a group home or residential facility)

Intermediate Services (Yellow):

- Services in family homes (home of the family member(s) of the person I support)
- Shared Living/ Host Homes/ Adult Foster Care
- Community-based day supports

Traditional Services (Red):

- Residential group homes
- Center-based day program
- Pre-vocational support
- Sheltered workshops
- ICF residential facilities

Overall Innovative (Green):

- Green Only
- Yellow and Green

Overall Intermediate (Yellow):

- Yellow Only
- Red, Yellow, and Green
- Red and Green

Overall Traditional (Red):

- Red and Yellow
- Red Only

Appendix D

TABLES OF KEYWORD ANALYSIS BY AGENCY TYPE

| Agency Group | Red Role Description (Traditional) | Yellow Role Description (Transitioning) | Green Role Description (Innovative) |
|-----------------------------------|---------------------------------------|--|--|
| Green (Innovative) n=70 | 21 30% | 23 32.9% | 23 32.9% |
| Yellow (Intermediate) n=128 | 62 48.4% | 37 28.9% | 24 18.8% |
| Red (Traditional) n=242 | 168 69.4% | 50 20.7% | 16 6.6% |
| Total n=440 | 251 57% | 110 25% | 63 14.3% |

| Agency Group | Health & Safety | ADLs | Medication | Activities | Independence | Full potential | Skill Development |
|-----------------------------------|---------------------|---------------------|---------------------|--------------------|---------------------|-------------------|--------------------|
| Green (Innovative) n=70 | 23 32.9% | 25 35.7% | 5 7.1% | 12 17.1% | 21 30% | 0 0% | 16 22.9% |
| Yellow (Intermediate) n=128 | 48 37.5% | 52 40.6% | 25 19.5% | 26 20.3% | 26 20.3% | 2 1.6% | 34 26.6% |
| Red (Traditional) n=242 | 100 41.3% | 153 63.2% | 77 31.8% | 44 18.2% | 59 24.4% | 8 3.3% | 39 16.1% |
| Total n=440 | 171 38.9% | 230 52.3% | 107 24.3% | 82 18.6% | 106 24.1% | 10 2.3% | 89 20.2% |

| Agency Group | Advocate | Relation- ships | Goals | Cheer- leader | Employ- ment | Meaning- ful Day | Meaning- ful Life |
|-----------------------------------|--------------------|--------------------|--------------------|-------------------|--------------------|---------------------|----------------------|
| Green (Innovative) n=70 | 8 11.4% | 5 7.1% | 12 17.1% | 3 4.3% | 17 24.3% | 2 2.9% | 6 8.6% |
| Yellow (Intermediate) n=128 | 16 12.5% | 12 9.4% | 28 21.9% | 4 3.1% | 15 11.7% | 0 0% | 10 7.8% |
| Red (Traditional) n=242 | 27 11.2% | 11 4.5% | 25 10.3% | 12 5% | 4 1.7% | 6 2.5% | 24 9.9% |
| Total n=440 | 51 11.6% | 28 6.4% | 65 14.8% | 19 4.3% | 36 8.2% | 8 1.8% | 40 9.1% |

| Agency Group | Transportation | Choice | Emotional support | Sheltered work | New things | Person- centered |
|-----------------------------------|--------------------|-------------------|----------------------|-------------------|-------------------|---------------------|
| Green (Innovative) n=70 | 9 12.9% | 6 8.6% | 2 2.9% | 0 0% | 2 2.9% | 3 4.3% |
| Yellow (Intermediate) n=128 | 22 17.2% | 1 0.8% | 8 6.3% | 2 1.6% | 7 5.5% | 5 3.9% |
| Red (Traditional) n=242 | 12 5% | 4 1.7% | 10 4.1% | 4 1.7% | 3 1.2% | 7 2.9% |
| Total n=440 | 43 9.8% | 11 2.5% | 20 4.5% | 6 1.4% | 12 2.7% | 15 3.4% |

| Agency Group | | | | |
|-----------------------------------|--------------------|--------------------|-----------------------|--------------------|
| Green (Innovative) n=70 | Self-determination | 12 17.1% | | |
| | | | Wants/Needs* | 4 33.3% |
| | | | Goals/Dreams* | 6 50% |
| | | | Decision-making* | 5 41.7% |
| | | | Self-Determined Life* | 1 8.3% |
| Yellow (Intermediate) n=128 | Self-determination | 13 10.2% | | |
| | | | Wants/Needs* | 4 30.8% |
| | | | Goals/Dreams* | 2 15.4% |
| | | | Decision-making* | 6 46.2% |
| | | | Self-Determined Life* | 4 30.8% |
| Red (Traditional) n=242 | Self-determination | 23 9.5% | | |
| | | | Wants/Needs* | 5 21.7% |
| | | | Goals/Dreams* | 10 43.5% |
| | | | Decision-making* | 5 21.7% |
| | | | Self-Determined Life* | 7 30.4% |
| Total n=440 | Self-determination | 48 10.9% | | |
| | | | Wants/Needs* | 22 45.8% |
| | | | Goals/Dreams* | 30 62.5% |
| | | | Decision-making* | 27 56.3% |
| | | | Self-Determined Life* | 23 47.9% |

*Data presented here is a breakout of the self-determination keyword and should be interpreted as a percentage of people who used self-determination keywords.

| Agency Group | | | | |
|-----------------------------------|-----------|---------------------|-------------------|--------------------|
| Green (Innovative) n=70 | Community | 26 37.1% | | |
| | | | Locational* | 10 38.5% |
| | | | Connection-Based* | 2 7.7% |
| Yellow (Intermediate) n=128 | Community | 52 40.6% | | |
| | | | Locational* | 29 55.8% |
| | | | Connection-Based* | 1 1.9% |
| Red (Traditional) n=242 | Community | 77 31.8% | | |
| | | | Locational* | 41 53.2% |
| | | | Connection-Based* | 3 3.9% |
| Total n=440 | Community | 155 35.2% | | |
| | | | Locational* | 80 51.6% |
| | | | Connection-Based* | 6 3.9% |

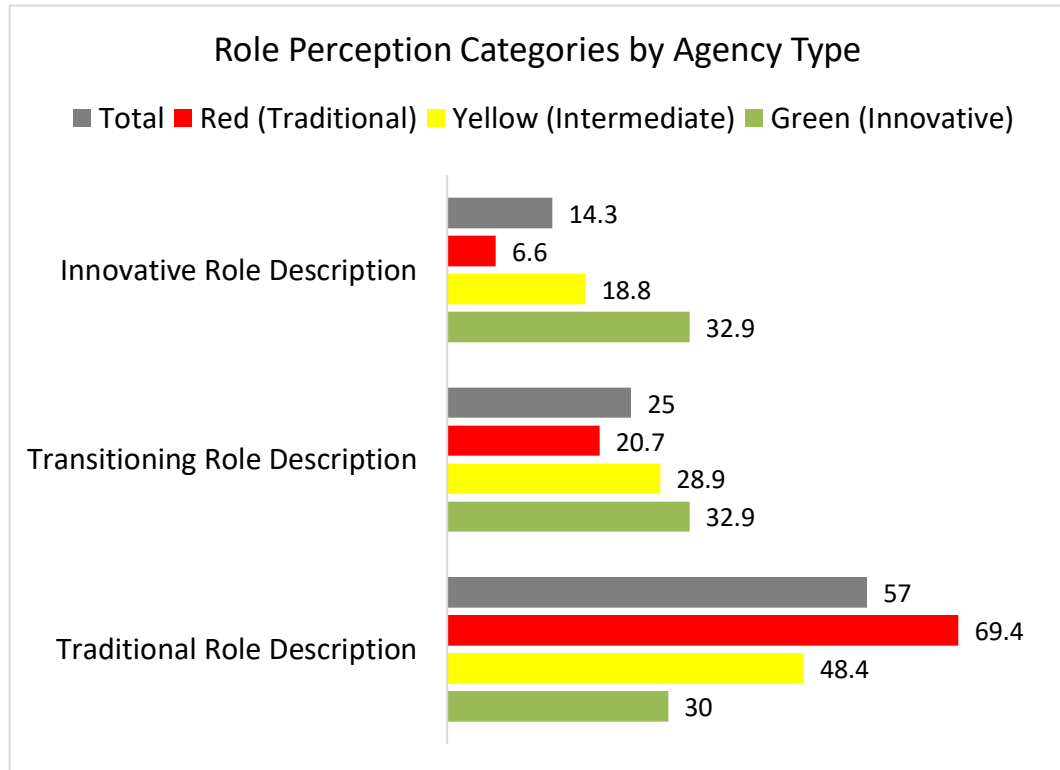
| Agency Group | | |
|--------------------------------|-------------------------------|--------------------|
| Green (Innovative) n=70 | Community w/o Locational** | 16 22.9% |
| Yellow (Intermediate) n=128 | Community w/o Locational** | 34 18% |
| Red (Traditional) n=242 | Community w/o Locational** | 36 14.9% |
| Total n=440 | Community w/o Locational** | 75 17% |

*Data presented here is a breakout of the community keyword and should be interpreted as a percentage of people who used community keywords.

**Community w/o locational eliminates all locational uses of the term community from the analysis.

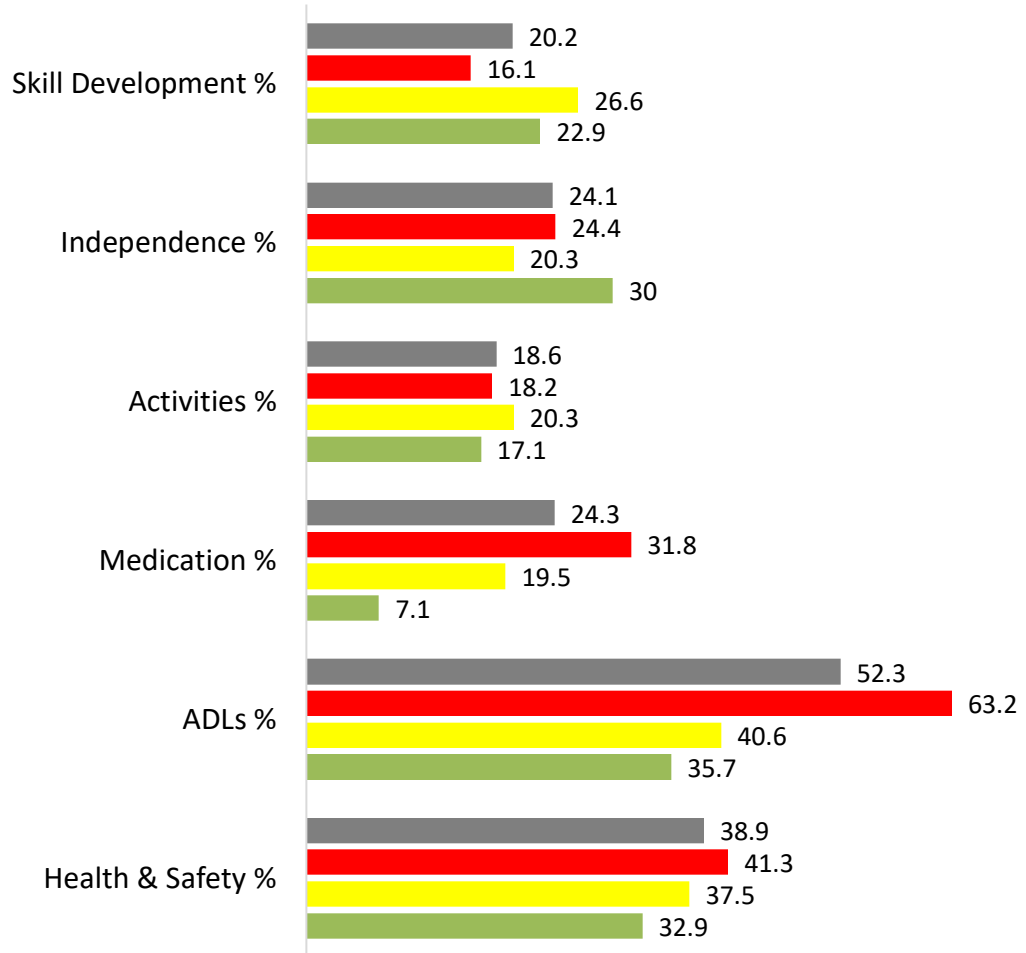
Appendix E

CHARTS OF KEYWORD ANALYSIS BY AGENCY TYPE



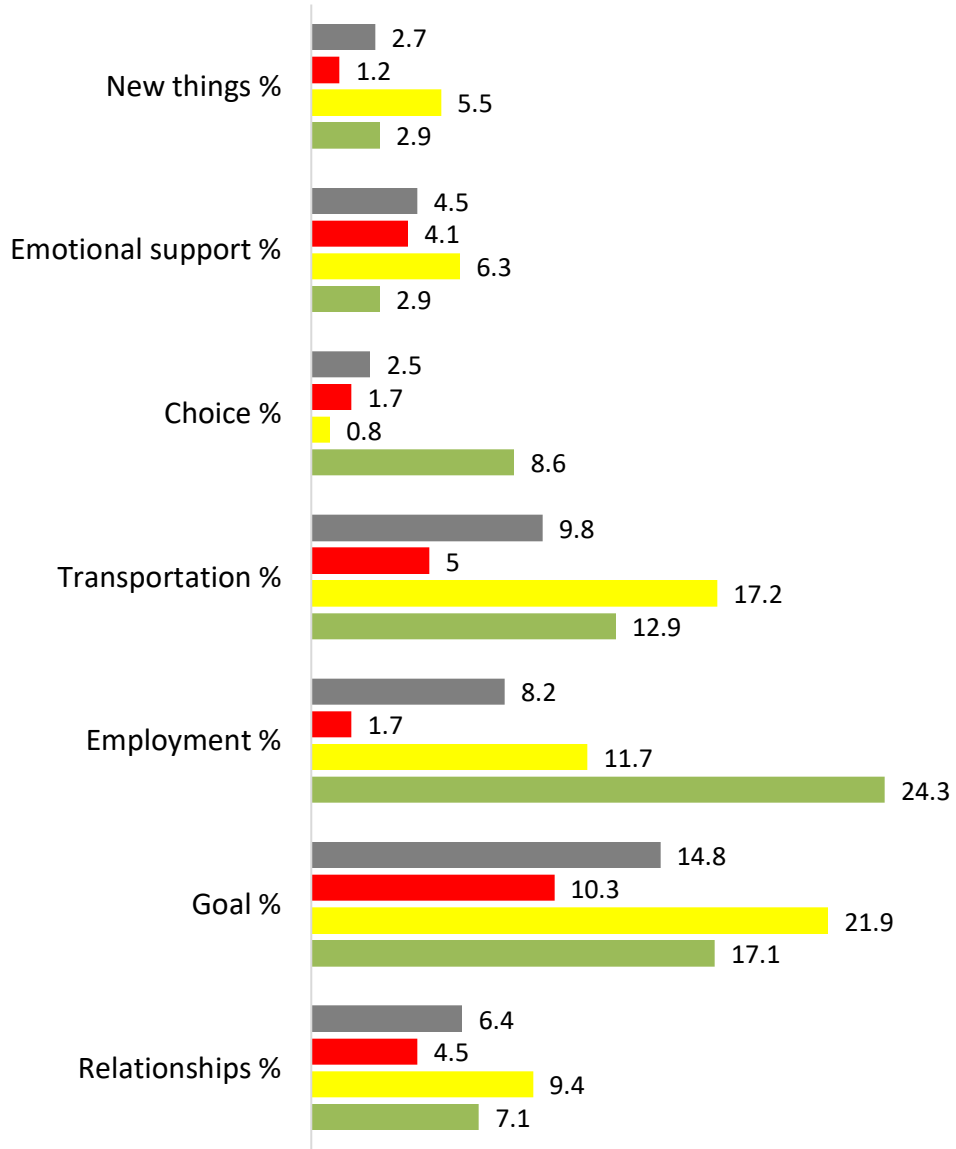
Keywords by Agency Type

■ Total ■ Red (Traditional) ■ Yellow (Intermediate) ■ Green (Innovative)



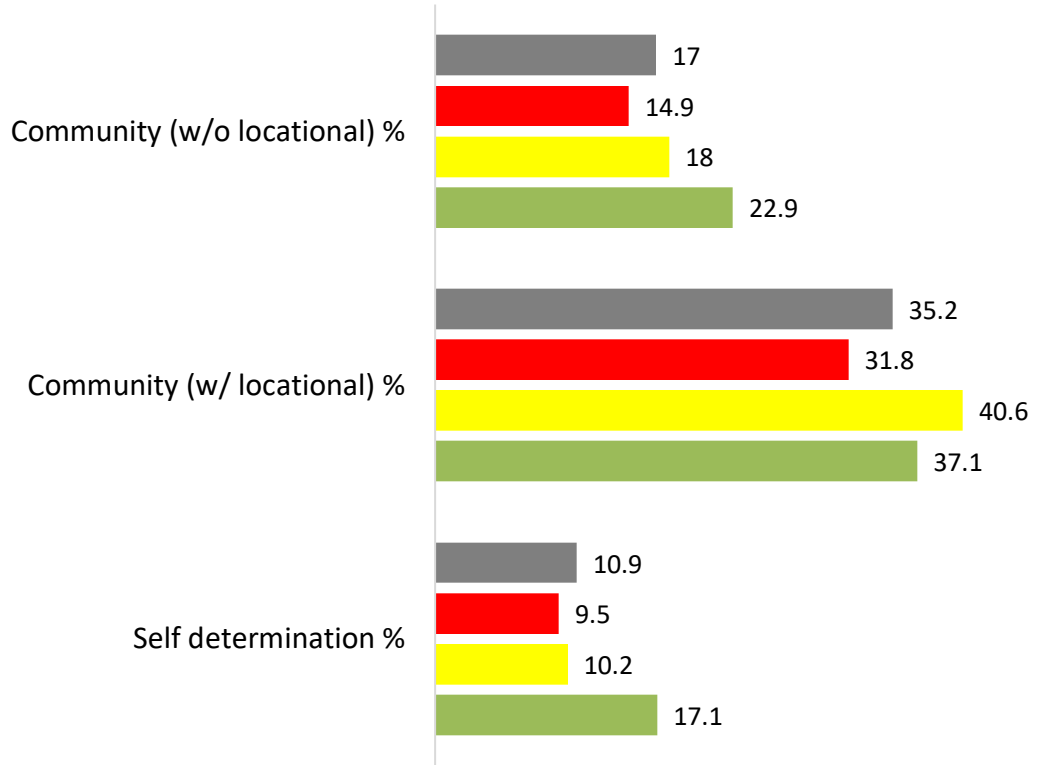
Keywords by Agency Type

■ Total ■ Red (Traditional) ■ Yellow (Intermediate) ■ Green (Innovative)



Community & Self Determination by Agency Type

■ Total ■ Red (Traditional) ■ Yellow (Intermediate) ■ Green (Innovative)



Appendix F

EXEMPT FROM REVIEW



RESEARCH OFFICE

210 HULLIHEN HALL
UNIVERSITY OF DELAWARE
NEWARK, DELAWARE 19716-1551
Ph: 302/831-2136
Fax: 302/831-2828

DATE: July 26, 2018

TO: Caitlin Bailey, PhD ABD
FROM: University of Delaware IRB

STUDY TITLE: [1222566-1] Exploring Perspectives of Direct Support Professionals

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: July 26, 2018

REVIEW CATEGORY: Exemption category # (2)

Thank you for your submission of New Project materials for this research study. The University of Delaware IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will put a copy of this correspondence on file in our office. Please remember to notify us if you make any substantial changes to the project.

If you have any questions, please contact Nicole Farnese-McFarlane at (302) 831-1119 or nicolefm@udel.edu. Please include your study title and reference number in all correspondence with this office.

cc: