

Evaluating the Effectiveness of Texas' Intellectual and
Developmental Disability Services: A Practical Ideal
Type Approach

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ABSTRACT

Purpose

This research identifies a set of standards for effectiveness and the best practices for delivering intellectual development and developmental disability (ID/DD) services in Texas. It also gauges the effectiveness of the Texas system against these best practice standards. Finally, based on the results, it makes recommendations for Texas to become a more effective state in providing needed services and supports for the ID/DD population.

Methodology

Two primary methodologies were employed for this research. Both document analysis and web-based surveys were used to gauge the effectiveness of the current ID/DD services in Texas. Data was collected through the survey method and state forms and documents were examined to identify the successes and challenges of the current ID/DD programs in Texas.

Findings

The findings of this research indicate that Texas's ID/DD services are adequately effective. United Cerebral Palsy's *Case for Inclusion* annual report has Texas listed at the bottom of the state rankings for such programs. The survey results show that individuals working within the program parameters generally feel more positive about the services than the broader national-level perspective. However, given that the satisfaction ratings are higher than anticipated, the findings still show that there are additional areas that need to be improved to further the effectiveness and worth of the state's current ID/DD service practices.

Evaluating the Effectiveness of Texas’s Intellectual Development and Developmental Disability Services: A Practical Ideal Type Approach

CHAPTER I

INTRODUCTION

In the United States, social insurance programs such as Medicaid make up a very large direct cost within the federal budget. It is under the Medicaid insurance umbrella that many intellectual development and developmental disability (ID/DD) services are delivered to the public. In fact, “programs for persons with disabilities have come full circle from institutional care to home and community-based services, largely funded as healthcare under Medicaid” (Agranoff, 2013, p. 127).

The number of federal dollars spent on disability services depends heavily on policies and legislation at the federal level, with the government collecting the tax dollars that pay for these programs. However, the need for these services varies across states and, like many services, the federal government has delegated the task of providing ID/DD services to the states individually. Unlike the larger federal government, states have a smaller, more specific population of people to serve and therefore have more control to implement the needed programs and services. Although there are benefits to the states implementing these disability services, there are also drawbacks. People served under the ID/DD umbrella are not able to move from one state to another state, transferring their services where they move. The services offered vary by state and although they can be the same programmatically, they can vary greatly in primary philosophy, focus population, and program objectives.

Years ago, people born with intellectual development and developmental disabilities were not well supported in the community, if at all, and were generally placed in institutions by families who were not able to care for them. Today, ID/DD programs “serve persons with mental retardation, epilepsy, cerebral palsy and autism in a small community and home setting, widely replacing public institutional care, mostly in large state-operated facilities” (Agranoff, 2013, p. 127). It is because of the efforts of public administrators and national and state legislation “that people born with ID/DD have the best opportunity for a long, healthy, full and meaningful life” (*United Cerebral Palsy*, 2016, p. 2).

Like all other U.S. states, Texas has its own ID/DD programs and services, and its ability to adequately provide these supports rests heavily on the funding and best practices and processes put in place by state lawmakers. Because most ID/DD services are delivered through social insurance programs, the Centers for Medicare and Medicaid Services (CMS) contracts with Texas to implement and ensure the delivery of various disability services and programs. ID/DD services in Texas assist all eligible individuals with an intellectual development or developmental disability.

As previously mentioned, the contracts developed between the CMS and each state vary. The funds are delivered to the states, which set up the programs and services that meet their populations’ needs. Because the states are contracted individually, within each contract lies potential variability in how the money is spent and how those services are delivered. The CMS, along with other organizations, conducts reviews to monitor implementation progress and evaluations to examine the impacts of the ID/DD services on the population.

Most of the programs implemented across Texas for individuals with ID/DD are called waivers. The state has chosen to use its federal money to “waive” the previous institutionalization standard and assist individuals in remaining within their own communities. There are waiver programs to assist people with varying levels of disabilities, such as serious mental illnesses and co-occurring disabilities or dual diagnoses. For ID/DD services today, a large majority of the services are delivered through a Medicaid waiver.

Although there are waivers for many different individual needs, this research focuses on the services provided for people who have intellectual disabilities, developmental disabilities, and related conditions, such as autism. The federal government has established initial guidelines for these disability services; however, there is the potential for each state to exercise flexibility after those minimum requirements are met. This flexibility gives states the management and majority oversight over their own programs. Every state has the opportunity to build upon the minimum requirements, or not, as they see fit. Texas has long been known as one of the least effective states in providing these needed disability services.

Beyond what is required by the CMS and their basic structure for program implementation, there are organizations such as United Cerebral Palsy (UCP) that work to evaluate these programs on a functional level, measuring their overall effectiveness. UCP releases an annual report, *Case for Inclusion*, that evaluates all 50 states and the District of Columbia, not just on their spending but on their outcomes for Americans with intellectual and developmental disabilities. Individuals with ID/DD, including older adults, want and deserve the same freedoms and quality of life as all Americans. The *Case for Inclusion* report is a functional tool that gives a comprehensive look at how well each state is performing individually and overall on a set of variables. The report further examines how each state matches up against the

other states regarding certain key data measures and the policies and practices of top performing states that may be considered as best practices. The *Case for Inclusion* looks at data from all states and measures the effectiveness of varying categories, such as how people with disabilities live and participate in their communities, if they are satisfied with their lives, and how easily the services and supports they need are accessed. By taking these factors into account, UCP develops a comprehensive analysis of each state's strengths, and challenges, in providing critical services to individuals living with disabilities. Texas is currently ranked 50th overall out of the 50 states and Washington, D.C. (*United Cerebral Palsy*, 2016, p. 12). Using UCP's disability services analysis tool, this research will explore the successes and challenges in Texas.

Research Purpose

Given the set of circumstances under which ID/DD services are implemented in Texas, the purpose for this research is threefold. First, it will identify a set of standards and best practices adopted for delivering quality ID/DD services. Then, it will gauge the effectiveness of the Texas system against these best-practice standards. Finally, based on the results, it will make recommendations for Texas to become a more effective state in providing needed services and supports for the ID/DD population.

CHAPTER II

POLICY HISTORY AND ID/DD RESOURCES

Chapter Purpose

The purpose of this chapter is to provide a historical background of the laws, policies, and service entities that are relevant to the discussion of ID/DD services in Texas. This background should be utilized to better understand the environment Texas's ID/DD services are currently operating in, as well as where they have come from. The policies brought forth through state legislation in Texas are behind the curve from the rest of the country.

Health and Human Services Commission

The Health and Human Services Commission (HHSC) is the regulatory agency in charge of managing and implementing the ID/DD services in Texas. According to HHSC guidelines, intellectual and developmental disabilities include many severe, chronic conditions that are due to mental and/or physical impairments. These types of disabilities can begin at any time in one's life, but to qualify for ID/DD services in Texas, they must occur prior to 18 years of age. The commission's explanation for the age cutoff is that these types of disabilities affect a person within the developmental stages of their life, preventing them from developing in the same way as non-disabled persons of the same age. ID/DD will certainly last throughout a person's lifetime and they will likely struggle with any combination of life activities, such as language, mobility, learning, self-care, and independent living. While the disability is always going to be present, it is up to the programs designed to support these individuals to ensure their quality of life is just as meaningful as anyone else's.

Diagnosis Information

To understand what qualifies as an ID/DD diagnosis, it is important to get information from the ICD (International Classification of Diseases). Though different editions of the ICD have been published, it is common practice to reference the most current version; today that is the ICD 10. The ICD 10 gives governments, service providers, insurance carriers, and other health professionals the ability to track and classify various diseases in a standard way. For intellectual disabilities, those diagnoses include mild ID through profound ID, as well as other and unspecified ID. Each category is paired with an IQ range. According to the ICD 10, intellectual disability is listed as a broad category of disorders characterized by impairment to the intelligence of an individual. Intellectual impairments result from trauma, birth or disease, and are not restricted to any age group.

A developmental disorder is characterized by less than average intelligence and significant limitations in adaptive behavior with an onset before the age of 18. As Thomas explained (Cowen and Reed, 2002, p. 273), developmental disability is a phrase used to describe the interruption, delay, or restriction of the sequence and rate of normal growth, development, and maturation due to congenital abnormality, trauma, deprivation, or disease. These disability types are ones that affect a person's physical development and, in turn, prevent them from achieving the same developmental milestones as quickly as other children. These types of disabilities are ones that affect how the brain, spinal cord, and/or nervous system function.

Some of these developmental disability diagnoses are referred to as “developmental or neurological disability NOS” (not otherwise specified). These disorders are extremely complex and can impair an individual's sensory systems, causing vision, hearing, and/or sight deficits.

Another tool that identifies various disorders and conditions is the Diagnostic and Statistical Manual of Mental Disorders (DSM). The DSM, which is currently in its fifth edition, has also been highly used by professionals in the psychology and psychiatry fields. Previously, the DSM was more commonly used because it crosses between the lines of behavioral health and ID/DD. However, this is not likely to continue as the ICD is a worldwide tool and accepted by the World Health Organization.

History of ID/DD and Relevant Policies

Intellectual and developmental disabilities have been documented for over 300 years. Because these disorders stem from neurological damage and other hereditary issues, they have likely existed as long as people have. The symptoms, treatments, and labels of these disabilities have gone through vast overhauls in that time span. ID/DD services have moved from an institutional model of treatment to a community-based model of inclusion. This shift has been made with many pieces of legislation throughout the last few decades.

Prior to Medicaid being established, several programs and policies were influential in their time. Still in effect today, “the Developmental Disabilities Act of 1970 established ID/DD councils, defined developmental disabilities, and promoted statewide planning and reforms” (Agranoff, 2013, p. 129). ID/DD councils are state-run organizations with various advocacy roles. The Texas Council for Developmental Disabilities (TCDD) represents people with ID/DD living in the state, and their guiding principles indicate that the “TCDD creates change so that all people with disabilities are fully included in their communities and exercise control over their own lives” (TCDD.Texas.Gov, 2017).

In addition to the Developmental Disabilities Act of 1970, another huge piece of legislation was the Education for All Handicapped Children Act of 1975 (EHA). The policies listed in this act worked to establish federal- and state-level financial assistance and grants for school-aged children with disabilities. The legislation mandated that education be provided to all children, regardless of disability, and maximized federal assistance for state school systems. The legislation continues to be extremely important for all children with disabilities, nurturing their abilities and ensuring they have access to a proper education. The EHA is now known as IDEA, the Individuals with Disabilities Education Act, after Congress amended the title and policy in 1990.

Socially productive legislation does not generally occur out of thin air. Over the last century, the United States has faced a multitude of lawsuits and experienced myriad policy changes to address our evolving understanding of what disabilities are and what the individuals with those disabilities are capable of and deserve. People with ID/DD, historically, were placed in institutions and not expected to be productive members of society. In the early 19th century, people with disabilities were referred to by a variety of labels. Today, some of the most offensive labels are ones such as “feeble minded,” “imbecile,” and, most recently, “handicapped” and “mentally retarded.” “In 2010, President Barack Obama signed Rosa’s Law, changing references in several federal acts to ‘intellectual disability’, thus changing legal references to mentally retarded persons to references to individuals with an intellectual and developmental disability” (Agranoff, 2013, p. 127). Rosa’s Law changed the term used within federal legislation, recognizing that it was outdated and extremely offensive to a lot of people.

As indicated in *Outdated Language* (Friedman, 2016), a large problem with “mentally retarded” is that the mainstream public uses it as a slang term to identify and label things that are

causing problems. It is obvious to see why people with ID/DD do not want to be referred to with this label. Rosa's Law and other legislation like it are newer examples of policy changes designed to add more acceptable verbiage to our law books; however, there are other policy changes that have arguably affected people with disabilities more positively on a larger scale.

The Americans with Disabilities Act of 1990 (ADA) says that when given the opportunity, individuals with disabilities can very much participate fully in all aspects of life. The ADA helps ensure that nobody is excluded from activities strictly because of a disability. Most widely known are the changes to public entrances and sidewalks, the additions of elevators to places only with stairs, and so on. These changes help to ensure that all people with varying ambulation have access to the same places as fully ambulatory individuals. The ADA also emphasizes equal opportunity and participation, independent living, and economic self-sufficiency.

The creation of the Medicaid program was a huge step forward for people with disabilities. Medicaid was created in 1965 as Title XIX of the Social Security Act. The insurance program was established to provide medical assistance for those who are most in need. Medicaid is funded through a combination of state and federal dollars. Because there is a combination of funding, states have been able to expand their services and tailor them for a more specific need, creating a high amount of service variability between the states.

Federal and State Partnerships

As previously described, the changes that have been made in the services provided to those with ID/DD have been extraordinary. "The most powerful force in making this transition has been the development of federal-state partnerships" (Agranoff, 2013, p. 127). The CMS

contracts with each state to deliver the ID/DD services needed for their specific populations. In Texas, the CMS contracts with the HHSC to ensure that the federal dollars are being utilized properly. “Meanwhile, the state-organized services themselves increasingly have been assumed by ... NGOs, a change largely attributable to increased public funding, particularly through the health financing vehicle [Medicaid]” (Agranoff, 2013, p. 127). The HHSC then further develops the programs and implementation guidelines for Texas residents, but contracts the actual program implementation out to local mental health authorities (LMHAs). In the state of Texas, the LMHAs are centers where ID/DD and other mental health services are delivered to the public and individuals in need. Specifically, there are 39 LMHA centers that cover the state’s 254 counties. See Table 2.1 for a list of the LMHAs and the counties they serve.

Table 2.1–LMHA Coverage Area

<p>Access: Anderson and Cherokee</p>	<p>Hill Country Mental Health & Developmental Disabilities Centers: Bandera, Blanco, Comal, Edwards, Gillespie, Hays, Kendall, Kerr, Kimble, Kinney, Llano, Mason, Medina, Menard, Real, Schleicher, Sutton, Uvalde and Val Verde</p>
<p>Andrews Center Behavioral Healthcare System: Henderson, Rains, Smith, Van Zandt and Wood</p>	<p>Lakes Regional MHMR Center: Camp, Delta, Franklin, Hopkins, Lamar, Morris and Titus</p>
<p>Austin Travis County Integral Care: Travis</p>	<p>StarCare Specialty Health System: Cochran, Crosby, Hockley, Lubbock and Lynn</p>
<p>Betty Hardwick: Callahan, Jones, Shackelford, Stephens and Taylor</p>	<p>MetroCare: Dallas</p>

Bluebonnet Trails Community Services: Bastrop, Burnet, Caldwell, Fayette, Gonzales, Guadalupe, Lee and Williamson	MHMR Authority of Brazos Valley: Brazos, Burleson, Grimes, Leon, Madison, Robertson and Washington
Border Region Behavioral Health Center: Jim Hogg, Starr, Webb and Zapata	MHMR Authority of Harris County: Harris
Burke Center: Angelina, Houston, Jasper, Nacogdoches, Newton, Polk, Sabine, San Augustine, San Jacinto, Shelby, Trinity and Tyler	MHMR Center of Nueces County: Nueces
Camino Real Community Services: Atascosa, Dimmit, Frio, La Salle, Karnes, Maverick, McMullen, Wilson and Zavala	MHMR of Tarrant County: Tarrant
Alamo Local Authority: Bexar	MHMR Services for the Concho Valley: Coke, Concho, Crockett, Irion, Reagan, Sterling and Tom Green
Center for Life Resources: Brown, Coleman, Comanche, Eastland, McCulloch, Mills and San Saba	NorthStar/North Texas Behavioral Health Authority: Collin, Ellis, Hunt, Kaufman, Navarro, Rockwall
Central Counties Services: Bell, Coryell, Hamilton Lampasas and Milam	Texoma Community Center: Cooke, Fannin and Grayson
Central Plains Center: Bailey, Briscoe, Castro, Floyd, Hale, Lamb, Motley, Parmer and Swisher	Pecan Valley Centers for Behavioral & Developmental HealthCare: Erath, Hood, Johnson, Palo Pinto, Parker and Somervell
Coastal Plains Community Center: Aransas, Bee, Brooks, Duval, Jim Wells, Kenedy, Kleberg, Live Oak and San Patricio	Permian Basin Community Centers for MHMR: Brewster, Culberson, Ector, Hudspeth, Jeff Davis, Midland, Pecos and Presidio

Community Healthcore: Bowie, Cass, Gregg, Harrison, Marion, Panola, Red River, Rusk and Upshur	Spindletop Center: Chambers, Hardin, Jefferson and Orange
Denton County MHMR Center: Denton	Texana Center: Austin, Colorado, Fort Bend, Matagorda, Waller and Wharton
Emergence Health Network: El Paso	Texas Panhandle Centers: Armstrong, Carson, Collingsworth, Dallam, Deaf Smith, Donley, Gray, Hall, Hansford, Hartley, Hemphill, Hutchinson, Lipscomb, Moore, Ochiltree, Oldham, Potter, Randall, Roberts, Sherman and Wheeler
Gulf Bend Center: Calhoun, DeWitt, Goliad, Jackson, Lavaca, Refugio and Victoria	Tri-County Services: Liberty, Montgomery and Walker
Gulf Coast Center: Brazoria and Galveston	Tropical Texas Behavioral Health: Cameron, Hidalgo and Willacy
Heart of Texas Region MHMR Center: Bosque, Falls, Freestone, Hill, Limestone and McLennan	West Texas Centers: Andrews, Borden, Crane, Dawson, Fisher, Gaines, Garza, Glasscock, Howard, Kent, Loving, Martin, Mitchell, Nolan, Reeves, Runnels, Scurry, Terrell, Terry Upton, Ward, Winkler and Yoakum
Helen Farabee Centers: Archer, Baylor, Childress, Clay, Cottle, Dickens, Foard, Hardeman, Haskell, Jack, King, Knox, Montague, Stonewall, Throckmorton, Wichita, Wilbarger, Wise and Young	

Medicaid Waiver Programs

Medicaid waiver programs are designed to support people with intellectual and developmental disabilities. Previously, the CMS gave states the option of offering services in people's homes; however, many states did not take full advantage of this option. Starting roughly around the 1980s, "HCBS [Home and Community-Based Services] Waivers led states to 'quickly recognize [Medicaid] to be a significant resource in the financing of community alternatives to institutional care for persons with ID/DD'" (Agranoff, 2013, p. 129). Waivers provide states the flexibility to assist people in different and non-traditional settings. These waiver services are often referred to as Long Term Services and Supports (LTSS). Texas partners with the CMS to provide services outside of the traditional scope. The rules and regulations are "waived" to allow individuals to be supported in a nontraditional setting. Although there are waiver programs for varying needs, the focus here is solely on the services for the ID/DD population.

CHAPTER III

LITERATURE REVIEW: IDEAL COMPONENTS OF ID/DD SERVICES

Chapter Purpose

The purpose of this chapter is to review the literature on intellectual development and developmental disability services. Specifically, this chapter will review the literature on the implementation of such services in Texas. The literature reviewed here supports the importance of these services in the lives of individuals with ID/DD. This chapter concludes with a conceptual framework developed from a thorough review of the literature on ID/DD services nationwide.

Ideal Service Components

As previously mentioned, the *Case for Inclusion* report identifies the ideal categories for effective ID/DD services. The United Cerebral Palsy group assembles the annual report, which details the measures in and rankings of all 50 states and the District of Columbia. The report shows how well state Medicaid programs serve Americans with ID/DD. *It* measures states in five major service areas. Those areas are: 1) promoting independence, 2) promoting health, safety, and quality of life, 3) keeping families together, 4) promoting productivity, and 5) reaching those in need. While these five categories have been explicitly drawn from *Case for Inclusion*, they have been mentioned and supported in other scholarly work on this topic.

Promoting Independence

All people, regardless of their backgrounds and potential differences, want to be independent, healthy, and well-functioning. Individuals with disabilities, however, are more

prone to stereotyping and the categorization of their skills, which constrict their ability to be more independent.

Another parallel concept to independence is self-determination. It is one of the guiding principles in working with individuals with ID/DD. Because their rights and independence are typically reduced due to their disabilities, it is the responsibility of service providers to assist these individuals in building some of that independence back into their daily lives. There are many ways that family members, social workers, and friends can assist in promoting independence for those with ID/DD. The CMS has four essential guiding principles to assist in that effort: person-centered planning, individual budgeting, financial management services, and supports brokerage (Cook, Terrell, and Jonikas, 2004, p. 11). Arguably the biggest component that contributes to promoting an individual's independence is their living environment. There are many different residential variations for those with ID/DD and each offers their own methods of independence.

Residential Services

The types of residential services for individuals with ID/DD are plentiful. In Texas, the residential services span all settings, ranging from large institutional care to services provided in an individual's home. As the philosophy in ID/DD services has shifted over the last few decades, residential services have also been changing. As a result, families, social workers, and lawmakers continue to assess the need for large state-operated residential centers, now called state-supported living centers (SSLCs). Texas currently operates 13 SSLCs that serve roughly 4,500 individuals with ID/DD, as well as individuals who are medically fragile or have behavioral issues (HHSC, 2016). Because these SSLCs have the largest bed capacity and around-the-clock care, residents don't have a need to venture outside the campus. If they are

confined to the campus, these individuals have the most restrictive living environment of all those living with ID/DD. Due to legislation and lawsuits that point to huge violations of residents' civil rights and liberties, these SSLCs are the placement of last resort.

A step down from the large-scale institutions is intermediate care facilities. These facilities are run by various private agencies but still fall under the HHSC and Medicaid guidelines for resident care. They hold any number of beds for more than five individuals. This type of setting is also considered restrictive since although the individual resides in the community, they must rely on group home staff to assist them with their needs. Staff members provide 24/7 care for individuals who may live in these settings for much of their lives.

There are also smaller group home settings, which are less restrictive in nature because the number of residents is smaller. In Texas, these group homes are operated through a Medicaid waiver program called HCS (home and community-based services) and host a range of 1–4 people in each home. Group home staff members are available 24/7 but typically focus more on each individual. The number of residents does correlate directly to the quality of services provided. One or two group home staff can only effectively work to promote independence and build skills for a small number of individuals at a time.

Another residential option offered through the HCS waiver program is host companion care (HCC), formally known as foster care. This option is provided to 1–3 residents at a time and is considered an even less restrictive option from a small group home because it does not generally require 24/7 staff. The HCC option offers individuals the ability to, essentially, rent a room from a person or family, and live integrated in that setting. The individual can come and go more freely and HCC does not have the same residential restrictions as group homes.

The least restrictive residential options offered to individuals in Texas are the ones that are provided in the person's home. Individuals who have strong natural supports in their lives may be able to maintain and live within those households or even live independently. Services offered to individuals in their homes promote independence and build upon the natural supports they have in place. All settings shy of the large-scale SSLCs are considered community-living and are provided to promote the independence of the individuals served.

Community-Based Waivers

It is because the independence of individuals is so important that Texas has the Medicaid waiver system. The waiver is the means of providing ID/DD services to individuals outside of the institutional setting. Before Medicaid established waiver service programs and guidelines, ID/DD services were primarily funded only at the institutional level. Other applicable settings were nursing facilities, state hospitals, and the like.

Keeping individuals in their communities not only assists in their independence, but also allows supports to be provided so many of them can work or attend day programming, volunteer in various ways, or otherwise be active members of society. Community-based waivers make continued integration a possibility for many people with ID/DD in the state of Texas. The importance of supporting individuals within their natural environments cannot be overstated. The non-community-based services are far costlier as they pay for staff, doctors, and nurses; building space; food; and so on. Community-based waivers are generally a win-win for all involved.

Additionally, Texas funds and operates six ID/DD LTSS waiver programs, along with other, more limited ID/DD services delivered directly at the LMHA-level and two service

umbrellas for state plan services. Table 3.1 will guide readers through the various LTSS waivers and supports that Texas currently offers.

Table 3.1–Texas’s LTSS Waivers

Waiver: State of Texas Access Reform (STAR)+Plus	Waiver: Medically Dependent Children Program (MDCP)	Waiver: Community Living Assistance and Support Services (CLASS)	Waiver: Deaf Blind with Multiple Disabilities (DBMD)	Waiver: Home and Community Based Services (HCS)	Waiver: Texas Home Living (TxHmL)
Established: 1998	Established: 1984	Established: 1991	Established: 1995	Established: 1985	Established: 2004
Ages Served: 21 and older	Ages Served: 0-20	Ages Served: All Ages	Ages Served: All Ages	Ages Served: All Ages	Ages Served: All Ages
Case Mgmt. Provided By: Managed Care Organization (MCO)	Case Mgmt. Provided By: HHSC	Case Mgmt. Provided By: Contracted Case Mgmt. Agency	Case Mgmt. Provided By: Provider Agency	Case Mgmt. Provided By: LIDDA	Case Mgmt. Provided By: LIDDA

Each waiver program offers different services to individuals with different needs. Depending on the program, the budget limit or financial service capacity is also different. The eligibility requirements vary as well (specific eligibility will be discussed later in the chapter). However, there are certain services that are offered across all programs. According to the HHSC’s LTSS waiver programs guide (2016), adaptive aids, employment assistance, minor

home modifications, respite, and supported employment are offered in all LTSS waivers. There are also additional services—such as dental, nursing, professional therapies, and unlimited prescriptions—available to all waiver programs except the Medically Dependent Children Program (MDCP). The reason that these services are not under the MDCP umbrella is that eligibility for the program requires a person to be under the age of 20, meaning those services are a direct Medicaid benefit. A direct Medicaid benefit is a service the individual already receives through that primary insurance package. These waiver services are very important and are all offered in an effort to keep individuals living in their natural homes and remaining integrated into their communities.

As noted previously, in addition to the six LTSS waiver programs provided for individuals with ID/DD, there are also state plan services. Similar to Table 3.1, Table 3.2 shows the services provided, the ages served, and those who provide the case management and advocacy for individuals in these programs.

Table 3.2–State Plan Services

Service: Community First Choice (CFC)	Service: Intermediate Care Facilities for Individuals with an Intellectual Disability of Related Conditions (ICF/IID)
Ages Served: All ages	Ages Served: All ages
Case Mgmt. Provided By: Service Coordinator from MCO or LIDDA (depending on the age of individual served)	Case Mgmt. Provided By: Qualified Intellectual Disability Professional (QIDP) (someone employed by the ICF agency)
Services Provided: Own Home/Family Home	Services Provided: Group Home

Promoting Self-Determination

Self-determination is similar to but a bit more specific than someone’s independence. Cook, Terrell, and Jonikas (2004) describe self-determination as referring to the rights of individuals to have full power over their own lives, encompassing concepts that are important to all members of a democratic society, including freedom of choice, civil rights, independence, and self-direction. Self-determination also focuses on the individual themselves and how they can direct their own services, furthering their independence over time. Person-centered planning is one of the first steps taken in building an individual’s services for a given service year. The person-centered model is one that is focused around the individual and their wants and needs. The individual’s preferences, strengths, and goals are the foundation for the

ID/DD services that are developed around them. Typically, social workers will want more people than just the individual to speak on their abilities to get a whole picture; however, anybody involved in those discussions should be chosen by the individual themselves. Although the person-centered model has been around since the 1980s, service plan team members need continual training and support for the model to remain effective for the individuals it is designed to benefit.

Active support is another important philosophy and engagement strategy for ID/DD services. The staff and support system around those with disabilities should know how to effectively engage the individuals in everyday choices to provide ongoing support and encouragement for increased decision-making skills. “Person-centered active support emphasizes the importance of supporting people to try new things, so that they can discover what they prefer or enjoy, which in turn can help them to make choices” (Beadle-Brown, Hutchinson, and Whelton, 2011, p. 304). As individuals increase their own decision-making skills, they are allowed more choice and further control in their lives.

According to *United Cerebral Palsy* (2016), the top performing states in the category of promoting independence for individuals receiving ID/DD services are: 1) Vermont, 2) New Hampshire, 3) Michigan, 4) Arizona, and 5) Hawaii; Texas ranks 46th of 51.

Promoting Health, Safety, and Quality of Life

It is not difficult to see why there is a need for good-quality services in any field. If people are delivered poor-quality services, businesses will not retain their support. The same is true for public-sector entities delivering social services. For years, individuals with ID/DD were assumed to not be able to participate in society like everyone else. They were vastly

institutionalized and their quality of life diminished. The overall health, safety, and quality of life of everyone, but especially of all vulnerable populations, such as individuals with ID/DD, need to be cared for. Unfortunately, the quality of the services and benefits provided to individuals with ID/DD is the easiest to abuse. There are certainly arguments on both sides; however, it is the inherent function of the government to ensure that its people are well cared for. If the services are not being delivered through a government route, the responsible agency still has an obligation to make sure that the disability services that people receive are valuable and meet the needs of all involved. Because individuals' civil rights are one of the highest priorities, there are multiple ways that their health, safety, and quality of life are being protected and measured.

Most of the individual rights protection is occurring at the state level in Texas. The HHSC has audit teams comprised of employees who work to evaluate the programs served under their purview. The audit teams are trained in the Texas Administrative Code for the program(s) they will be auditing. The HHSC conducts annual on-site audits of ID/DD programs to ensure that all individuals are being cared for and protected, and that the money allocated to those services is spent in an efficient and effective manner. Other service delivery agencies are also required to participate in the same type of audits from their overseeing entities. Many of the things being looked at during an audit are to ensure that the individual is the focus of the services and that they are receiving quality services that center around the needs that they have. Audits occur most often on an annual basis but, depending on the results, may occur more often as needed. Because the ID/DD services are typically delivered through a contract between an agency and the state, the state can choose to terminate a contract with an agency provider because of poor audit results.

There are many ways that client rights are protected outside of the annual audits. Examples of this can be general, such as protected-health-information laws like the Health Insurance Portability and Accountability Act, which restricts what can be shared about an individual to other parties. It covers the type of communication that can be shared, verbal and written, as well as to whom that information can be shared. More specific examples of protecting an individual's rights include the person-centered approach that was discussed previously. Social workers in general are now trained to use the individual as the center of the service planning. The wants and strengths of the person needing services should be at the forefront. The ID/DD services should be built around the individual's goals and outcomes and no longer around their needs and disabilities.

Although basic health and safety is a vastly important issue, quality of life is also important. Individuals with ID/DD diagnoses are prone to being isolated and dependent upon caregivers. As Petner-Arrey and Copeland note, "people with intellectual disability may need support specifically because they lack autonomy, yet the purpose of the support they receive is to help them realize their autonomy" (2014, p. 39). The issue that they point out is a very real one for many individuals with ID/DD. They need help remaining integrated in their society, but having people assist them already sets them apart. "For people with intellectual disability, even their most intimate settings (homes) are open to intrusions on their autonomy based on their mere participation in support services" (Petner-Arrey and Copeland, 2014, p. 43). A widely-used model by Schalock and Verdugo (2002) uses an eight-domain approach. "The eight core domains of this quality of life model are as follows: material well-being, physical well-being, emotional well-being, social inclusion, personal relationships, self-determination, personal development and rights" (Gómez, Arias, Verdugo, Tassé, and Brown, 2015, p. 926).

It is very telling that the first two domains relate strictly to physical needs and the other six are solely for emotional health. It is obvious that the measure of one's quality of life is much more than having their physical needs met.

Unpaid Relationships

Ongoing and constant community integration is one of the main goals for individuals with ID/DD. Integration is a major part of respecting their lives and ensuring they maintain a good quality of life. Depending on the level of a person's disability, maintaining relationships within their community is difficult. Many individuals are surrounded by staff during all waking hours. Program staff members are certainly important, but they are also paid caregivers. "Although caring within the support relationship may be necessary to promote autonomy, the support relationship is extremely problematic. This relationship involves paying one person to support another" (Petner-Arrey and Copeland, 2014, p. 46).

There is a definite difference between having paid and unpaid people around an individual when gauging the quality of that person's life. It is easy to see that if a person has nobody but paid workers around them, there are slim chances that their quality of life is as good as others without paid staff. Unpaid relationships are a key variable when assessing the quality of life that a person has. Individuals with ID/DD and their social networks range from having all unpaid relationships to none. Unpaid relationships are valuable for both the individual receiving services and the family involved; this will be discussed later in the section regarding family support. However, unpaid relationships for individuals with ID/DD are sometimes difficult to come by. Many times, the individuals do not have the ability to transfer themselves to and from social events and some lack the ability to maintain meaningful relationships because of their disability.

As explained in Asselt-Goverts, Embregts, and Hendriks (2014), attention to the social networks of people with intellectual disabilities has increased recently. This attention is influenced by and focuses on quality of life concepts, which encompass interpersonal relationships and personal development, self-determination, civil rights, participation, and emotional, physical, and material well-being. Social relationships have a huge impact on the way a person feels about their quality of life. In the study cited, Asselt-Goverts, Embregts, and Hendriks determined that many individuals with ID/DD are satisfied with their friendships and relationships. This is great news, although continued work needs to be done to improve the quality of life for many others.

Bukowski, Newcomb, and Hartup (as cited in Rossetti, Lehr, Huang, Ghai, and Harayama, 2016, p. 1) describe friendships as voluntary and reciprocal relationships. “Voluntary” meaning that the two people exhibit a mutual attachment to one another and there is obvious evidence of enjoyment and affection. The “reciprocal” piece can particularly be difficult for individuals with ID/DD due to impairments in expressive language. Friendships that do occur for those with ID/DD are typically with similarly disabled individuals. The number of non-disabled children and adults who are friends with a person with ID/DD is very low. Authors Rossetti et al. cite Wagner, Cadwallader, Garza, and Cameto (2004) reporting that nationally fewer than 25 percent of students receiving special education services spent any time away from school within friendship networks.

Community integration can be achieved both physically and emotionally. Support networks are very important for all people, but they are difficult for individuals with disabilities to achieve and maintain. There are not many ways that people can meet peers other than work, social events, and school, and some of those options are not open to individuals with a

disability. Boehm and Carter (2016, p. 183) describe “a friend” as the label for a generic social bond with unpaid people outside the family. It is within that definition that one can see that paid caregivers are not counted in friendship networks. Also noted in that definition is that anyone within the family cannot be counted as a friend either. If the individual does not have exposure to anyone besides family members and paid caregivers, they essentially do not have a friend network to draw support from.

Abuse, Neglect, and Exploitation

Another general method of protection in Texas was the establishment of client rights officers (CROs). The CROs are state employees who are employed solely to protect the rights of individuals being served in a state-funded program. Anybody involved in ID/DD services have access to the CROs, who they can call for information and direction, as well as to file a complaint against a person or agency that may have violated the individual rights of a person with ID/DD. The distinction should be made that this entity is not for criminal violations. Violations against individuals that are more serious in nature, those affecting a person’s health or well-being, should be directed to the Texas Department of Family and Protective Services (DFPS).

The DFPS is an agency responsible for investigating and mitigating threats to an individual’s health, both physical and mental; finances; and overall well-being. This agency will investigate reports of the abuse, neglect, and exploitation of both children and adults with ID/DD diagnoses. The DFPS has a statewide intake line that anyone can call to report abuse. The line operates 24 hours a day, every day of the year. The agency is designed to respond to calls within the same day they are placed in some situations. The DFPS also works very

closely with local law enforcement to make sure that if the abuse or neglect is criminal in nature, those legal issues will be handled by the correct law enforcement agency.

Palusci, Datner, and Wilkins (2015) determined time and time again that the ID/DD population is at a greater risk for all different types of abuse than their non-disabled peers. In their detailed conclusion, they state that too many people are abused too often and that people with intellectual disabilities have unique needs and struggles. People with ID/DD are at higher risk, as well as higher exposure, to abuse, neglect, and exploitation, and it is the duty of everyone in the community to try and report such situations whenever possible.

According to the *United Cerebral Palsy* (2016), the top performing states in the category of promoting the health, safety, and quality of life for individuals receiving ID/DD services are: 1) Tennessee, 2) the District of Columbia, 3) Alabama, 4) South Carolina, and 5) South Dakota; Texas ranks 23rd out of 51.

Keeping Families Together

One of the biggest struggles faced by families of individuals with ID/DD concerns is that they may not be able to continue to adequately provide for the needs of their loved ones. There are a variety of reasons why families may feel inadequate in meeting an individual's needs. The stress on parents and primary caregivers is tremendous when caring for individuals with ID/DD. "Many researchers have reported that respite care is an important intervention to prevent or at least lessen caregiver stress and burnout as well as to increase the social/peer interaction for the child with disabilities or chronic illness" (Cowen and Reed, 2002, p. 273). The level of stress and daily constraints on the caregiver can result in maltreatment, abuse, and neglect, as well as the need for residential placement.

Families are not only faced with burnout and stress, but also the financial strain of caring for adults who are not able to care for themselves. It is because of this struggle that Medicaid and states fund services that assist in keeping families together. Previously, there were little to no community-based services and families did not have much of a choice but to place their child in an institutional setting for around-the-clock care.

Community services are not only beneficial to the individual and family network, but also to the state. The financial burden on a state to support individuals with around-the-clock care is tremendous. It is far more beneficial, and cost-effective, to help the natural supports a person has than to have individuals living in residential settings. According to a study by the University of Colorado (2014), in fiscal year 2013, Texas spent roughly \$2.67 billion on ID/DD services. Of those \$2.67 billion, residential services consumed roughly \$190 million. In that same report it was detailed that 0.1 percent of that spending was for family support.

Family Support

When an individual with ID/DD is living in their family home, the entire family is affected by the weight of the needs of that person. The natural supports that a person has are vastly important and necessary to the individual's success. The family is employed on many levels and provides much-needed supports to and advocacy for their loved ones. As ID/DD services continue to become more person-centered, it may also become easier to overlook the importance of providing support to the family system as well.

It is not difficult to imagine that families who support individuals with ID/DD experience far greater stress than many other families (Boehm and Carter, 2016, p. 173). The services that an individual receives while living in a family home are largely related to their

personal care and skills. These services are needed to help the person gain new skills and work toward independence. When the individual is not receiving paid supports through whichever service channel they may be in, the natural supports and caregivers are expected to assume those tasks.

Respite care programs are essential in counterbalancing this stress. Cohen and Warren describe respite care programs as working to provide much needed rest and relief to the family members and/or primary caregivers of individuals with ID/DD (as cited in Cowen and Reed, 2002). In addition to respite care programs, there are other services that a family may access in an effort to reduce their burden. Service coordination is one that families benefit from in all waiver programs and most other ID/DD programs as well. The individual in need of services will have an assigned service coordinator who also assists with the needs of the family. Service coordinators are similar to social workers and should be using a holistic approach to providing care, taking the entire family into consideration.

Percent in a Family Home

In Texas, the family home is identified as a non-residential setting. The individual's home is essentially one that does not carry a unique code identifier in the state registry system. This code identifies that the person's home is not being compensated on a daily rate. The natural supports that the individual has are their primary caregivers. Looking at fiscal expenditures, the cost of supporting someone in their natural home is far less than the cost of supporting them in an institutional setting.

The U.S. Department of Health and Human Services says that Medicaid home care services play a critical role in keeping individuals with ID/DD in their own communities.

Without these at-home supports, they likely could not remain in the family home and the services they need, if institutionalized, would be costlier to the state. “Home-based personal care services are also consonant with recommendations for family-centered programs that facilitate the rituals and routines in family life and enrich the alliance between the family, the care recipient and formal health care service providers” (Patnaik et al., 2011, p. 383). The percentage of individuals receiving ID/DD services within their natural home ideally should be higher than the percentage in a residential setting. The percentage of individuals with ID/DD served in a family home is directly tied to the fiscal spending in community-based services and waivers, as well as to the individuals’ independence and quality of life.

According to the *United Cerebral Palsy* (2016), the top performing states in the category of keeping families together are: 1) Arizona, 2) Wisconsin, 3) South Carolina, 4) Louisiana, and 5) Ohio; Texas ranks 21st out of 51. Keeping individuals with ID/DD diagnoses together with their families is Texas’s best-ranked category.

Promoting Productivity

“Productivity” is a general term but in relation to individuals with ID/DD, just like the services they receive, it is very individualized. Productivity is different for everyone and can be accomplished in a variety of ways with a variety of supports. It is safe to assume that most adults enjoy being productive and take pride in their work. There are many services that both directly and indirectly support the employment goals and outcomes of individuals receiving ID/DD services. Some were established in 1987 by the Supported Employment Act. A major goal of this act was to integrate individuals with ID/DD into competitive employment settings by providing close mentoring and support from their coworkers (Chen and Barrera, 2014).

There is a very large transition that happens in a person's life when they graduate from high school and enter adulthood. This is true for non-disabled people, but it is even truer for individuals with ID/DD. Although students with ID/DD can remain in school until age 22 in Texas, once they graduate, they are done just like everyone else. For the individuals who can obtain competitive employment after high school or even college education, their transition is a bit easier and more like their peers'. Transitional services offered within the state's districts are very important to prepare individuals with ID/DD for the workforce.

Unfortunately, in Texas's current employment system, many individuals with ID/DD are not able to work in full-time employment after high school. Individuals who are not able to work or attend college typically will use a habilitative service during the day. This service does different things for different people. Some use it for socialization, some use it to continue building on their daily living skills, and some use it for vocational goals. This service serves as a transitional cushion for individuals with ID/DD.

Although a day habilitation service can be a good alternative to competitive employment and continued educational goals, these services are typically very segregated. Research shows that individuals with severe ID/DD achieve fewer community integration outcomes than those with milder disabilities. To clarify, this is not because the individuals do not desire those community integration outcomes, but rather they have them written into their service plans and are not able to achieve them. These issues are compounded by other concerns that individuals with more severe disabilities often attend day habilitation programs, are residents of group homes and other living arrangements, and have limited choice and self-determination (Crites and Howard, 2011).

The dynamics of the de-institutionalization movement in Texas and other states has led to a large increase in these types of services. Families often need assistance caring for their loved ones during the traditional workday, and individuals need ongoing social interaction after graduation. Although these services are incredibly needed for many people, barriers to a good day habilitation service are most often related to poor staffing. The poor staffing issues most concerning for individuals with ID/DD are frequent staff turnover, low staff morale, a lack of access to qualified trainers, little in-service training, and almost no feedback and reinforcement (Crites and Howard, 2011). The day habilitation service is certainly filling a needed gap in community services for individuals with ID/DD, although it needs more funding and support to truly fulfill its purpose in Texas.

Employment Support Services

Employment support services are needed across the entire population, regardless of ability. Non-disabled adults also need assistance finding their strengths, identifying their goals, and having a support network at home. Individuals with ID/DD traditionally are not as work-ready as their peers. School services provide post-graduation vocational training that is geared toward teaching those with ID/DD the skills needed to assist them in obtaining employment. These services should be individualized but often happen on a group level due to financial restrictions within the school system. Although the services are provided post-graduation, they still are contained within the school itself. In Texas, these services are commonly referred to as 18+ programs, transitional programs, or life skills programs. Most students get some form of life skills training in their district, individualized to their skill set and with their future goals in mind. Despite the transition requirements mandated through IDEA and a growing body of

research supporting effective transition planning, many adults with ID/DD are without employment or are significantly under-employed (Barnett and Crippen, 2014).

Some of the other direct types of employment support services are supported employment, employment assistance, and vocational rehabilitation. In Texas, the design for employment support services is short term. The expense to fund supported employment for an individual with ID/DD is heavy and typically costs far more than the daily rate for that same individual to attend a day habilitation facility. The cost to support people in their jobs requires hourly wages for a job coach, at a competitive rate. Policy constraints such as that limit competitive employment as an option for individuals with ID/DD.

Supported employment is the recommended practice for all working-age adults diagnosed with ID/DD because it allows workers to receive training while they are physically doing the job (Cullum, 2014). The supported employment service is most easily understood as receiving a job coach while working. Employment assistance, however, is a service designed to help individuals prior to having a competitive employment position. This service also provides paid support to individuals with ID/DD and can assist them in locating employment opportunities, turning in applications, and working on interviewing skills.

Vocational rehabilitation is a service in Texas provided under the HHSC umbrella. According to the HHSC's guidelines, a person may be eligible for such services if they have a disability that results in substantial barriers to employment, and if they require services to prepare for, obtain, retain, or advance in employment. Although the eligibility requirements are vague in description, that can work in the favor of the individuals seeking the service. Those with ID/DD should be able to prove they have a disability that prohibits them from obtaining employment.

Beginning in October 2016, these vocational rehabilitation services can be accessed through the local Texas Workforce Solutions center. Formerly known as DARS, the Department of Assistive and Rehabilitative Services, this agency services individuals with various disabilities, including those with ID/DD. According to DARS, these disabilities can range from behavioral and mental health needs to physical disabilities. (DARS, 2016). This range of eligibility allows for many individuals in Texas to access these needed employment services. They can provide employment counseling and guidance; rehabilitation devices such as hearing aids, wheelchairs, and braces; trade certifications; and so many others. There are also services specifically for hearing- and vision-related disabilities.

Percent in Competitive Employment

The number of individuals with ID/DD who are working in competitive employment is difficult to gauge. There are individuals who have ID/DD but are not utilizing the benefits that are available to them. According to Barnett and Crippen (2014), only about 26 percent of older youth with ID/DD are working for compensation. Within this relatively small group, 43 percent are working in settings comprised almost exclusively of individuals with ID/DD, such as sheltered workshops with sub-minimum wages. Despite all the supports in place for individuals with ID/DD, they still are not able to reach close to the national employment percentage of 95.5%. (Bureau of Labor and Statistics, 2017). It is also important to note that individuals with ID/DD fluctuate in and out of employment regularly, causing limitations within reported data.

Medicaid Buy-In Program

It is because many of the ID/DD services are delivered solely through Medicaid that the need for a buy-in program was identified. Prior to 1997, Medicaid eligibility was largely based on income limits. Depending on the state in which an individual resided, it was, and still may be, to the disservice of many to seek competitive employment because they would lose their disability benefits. Although there has been various legislation to combat this issue, many individuals and families still believe that they are not able to work.

Disability benefits come in the form of health services and other needed services and supports. These benefits are not solely comprised of a monthly income given to assist in the replacement of employment. Yet there are many public misconceptions surrounding disability benefits for individuals.

As Dalto clearly points out in his 2011 research on Medicaid benefits, nobody gets rich from these cash payments. The average Social Security Disability Insurance benefit is only \$1,066 per month, and the Supplemental Security Income benefit is much less. However, these benefits still provide a measure of security and most people who receive the checks solely depend on them to pay their basic living expenses. The greater benefits and services that come along with the income, such as Medicaid and the doctors and therapies that an individual likely would not have access to otherwise, generally far outweigh the financial support.

Because the income limits for Medicaid eligibility are generally very low, there are programs in place to assist individuals in keeping these benefits while also having competitive employment. With federal programs such as Ticket to Work and the Balanced Budget Act of 1997, an individual can exceed the Medicaid income limits due to their work earnings, but also

buy into Medicaid as their insurer of choice. As of 2011, 44 states have joined the effort to assist workers with disabilities in keeping their benefits with the Medicaid buy-in option. These programs do encourage people with significant disabilities to work, helping to recognize that many people with ID/DD need the services that Medicaid provides in order to seek and maintain employment (Dalto, 2011).

According to the *United Cerebral Palsy* (2016), the top performing states in the category of promoting productivity for individuals receiving ID/DD services are: 1) Washington, 2) Vermont, 3) West Virginia, 4) Maryland, and 5) Oregon; Texas ranks 43rd out of 51.

Reaching Those in Need

To effectively and efficiently deliver needed ID/DD services to individuals, it is essential to spread the information about these services through various community service channels. Many community agencies use networking and referrals as a primary function of their agency. There are many programs and services around the United States for individuals with an ID/DD diagnosis and it goes without saying that such services cannot be provided to people who are not aware of them. It is the responsibility of the state and any partnering agencies to serve the individuals in their community. Community outreach and education are key ways to get the information about ID/DD services out to the people who will need and benefit from them the most.

In Texas, the HHSC oversees the 211 informational phone line. According to the HHSC, the 211 program is committed to helping Texas residents connect with the services they need. Citizens can connect by phone or on the Internet. The program's goal is to provide

accurate, well organized, and easy-to-find information from state and local health and human services programs. A main benefit with this service is that wherever a person may be in the state, they can dial 2-1-1 (or 877-541-7905) from any phone and find information about the services where they live. Because of many different factors in Texas, even though there may be a variety of services for individuals in need, they often first must wait.

Waitlists

Of the ID/DD waiver programs that are currently offered in Texas, most of them have a waitlist for services. For the programs that have them, the waitlists are managed at different agencies for different services. The waitlists can range from an almost immediate enrollment opportunity to many years long. Texas, however, prefers to use the term “interest list” instead of waitlist. This is because it does not take confirmed eligibility to be on the interest list; rather one’s eligibility for a program is determined by the responsible agency once they have gotten to the top of the list. As more and more service information gets out to the public, the amount of people seeking ID/DD services each year will continue to rise. The movement of people on these waitlists depends heavily on the amount of monetary resources given to the programs by each legislative session. Texas’s latest available data is as of June 2016. Current waitlist counts vary by waiver program and are listed in Table 3.3.

Table 3.3–Interest List Totals

Waiver: CLASS	Waiver: DBMD	Waiver: HCS	Waiver: MDCP	Waiver: TxHmL
Interest List Total: 56,718	Interest List Total: 114	Interest List Total: 79,560	Interest List Total: 18,773	Interest List Total: 57,824

To accurately gauge how effective a program or set of programs are, one must examine the amount of people receiving the services compared to the amount of people waiting for the services. The prevalence of those waiting to those served is a large ratio. ID/DD services in Texas are drastically underfunded when looking at the amount of people who continue to wait for assistance. There has been interesting research around the maintenance of waitlists for services. Brown, Parker, and Godding note that “the level of demand for specific mental health services is a result of a complex set of factors, including population density, cultural norms, fluctuations in the prevalence of mental health problems, differences in the efficiency with which disorders are identified, and the degree of stigmatization associated with seeking help” (2002, p. 218). Although the authors reference “mental health services” as a broad term, ID/DD services are certainly susceptible to these same issues. To show the vast need across the United States, the CFI report states that, “almost 350,000 people are on a waiting list for Home and Community-Based Services” (2016, p. 10).

In Texas, the interest lists for ID/DD services are generally maintained at the state level, but some are managed at the direct-service-provider level. The LMHAs operate the interest list for the HCS waiver program, which is the most funded community waiver in Texas. Research suggests that a cost-benefit analysis can be conducted to ensure the use of waitlists is fiscally

responsible. However, while a cost-benefit analysis is a great tool for evaluating a program's finances, there are also costs for the individuals on those waitlists, both financial costs and costs to their health.

The many costs to an individual with ID/DD when treatment is postponed include terrible side effects such as longer or increased emotional distress, the loss of typical occupational or social functions, harm to themselves or other community members, victimization, and possibly even incarceration (Brown, Parker and Godding, 2002). IDD/DD services need to begin as soon as there is an indication of a disability or need. Unfortunately in Texas, that is not always possible.

Many issues surround the availability of services for individuals with ID/DD, but service funding is certainly a main factor. In 2015, John Savage reported for the Texas Observer that roughly 73,000 Texans with ID/DD are on a waitlist to receive home and community services such as employment assistance, behavioral counseling, dental care, and the ability to live in small group homes with around-the-clock care. This is a huge number of citizens waiting for assistance.

Texas has taken measures to help these individuals by implementing other programs while they wait for the HCS waiver services. Those services are not as costly to the state and do offer assistance while the residents wait. The need is so high, however, that programs to help alleviate the waitlist strain continue to be needed. Funding an expansion to the HCS waiver program would do roughly the same good that implementing the new programs is doing, and with an already established set of policies and procedures.

As Savage points out in stark contrast, at least 17 other states have waitlists with fewer than 1,000 people on them. Texas could most certainly take advantage of doing a cost-benefit analysis to determine if the ongoing waitlist usage is effective and whether the cost of implementing new programs is lower than giving more funding to existing ones. Savage cites Dennis Borel, the executive director of the Coalition of Texans with Disabilities, who says that underfunding social services and housing support really means that taxpayers spend more when those people end up in jail or the hospital. This is a very large problem for the state when looking at fiscal and social responsibilities.

Eligibility Determinations

Eligibility is the largest factor deciding whether a person will receive services in any program. Unfortunately, a person could have many different disabilities and still not be able to receive ID/DD services. There are different guidelines and requirements that must be met for each waiver program in Texas. Greater variability in eligibility may also occur between the states. Program rules and implementation are left mostly to the states and because of this, there is the chance for differences.

In Texas, the various state-level services, both waiver and non-waiver, have general eligibility differences. What may qualify a person for one service package may not qualify them for another. Another thing for individuals and families to consider is that when a person is enrolled in one package of waiver services, they cannot be enrolled in any other. A person must select which program is needed at that time, and weigh it against the service options in other waiver packages. This can be particularly problematic for individuals with ID/DD and limited decision-making abilities. Even with a natural support network, Elliott et al. (2014)

indicate that families often encounter very confusing and inconsistent eligibility requirements for services.

To qualify for ID/DD services in Texas, individuals need to have a diagnosis of intellectual disability, developmental disability, or otherwise related condition. Autism is possibly the most commonly known type of related condition. Table 3.4 provides eligibility guidelines for each of the eight ID/DD service packages discussed previously. The first chart listed is strictly for the state-level services of Community First Choice (CFC) and Intermediate Care Facilities (ICF) group homes. The second chart illustrates eligibility guidelines for the six waiver programs.

Table 3.4–ID/DD Services Eligibility Guidelines

Service: CFC	Service: ICF/IID
<p>Functional Eligibility: All ages; Need help with activities of daily living, such as dressing, bathing and eating; and meet an institutional level of care including: a hospital, NF, ICF/IID, institution providing psychiatric services for individuals under age 21, or institution for mental diseases for individuals age 65 or over.</p>	<p>Functional Eligibility: All ages; ICF/IID Level of Care (LOC) I3 or VIII4 and be in need of and able to benefit from active treatment.</p>

Service: STAR+Plus	Service: MDCP	Service: CLASS	Service: DBMD	Service: HCS	Service: TxHmL
<p>Functional Eligibility:</p> <p>21 and over; Medical necessity and level of care criteria for NF admission</p>	<p>Functional Eligibility:</p> <p>0 to 20; Medical necessity and level of care criteria for NF admission</p>	<p>Functional Eligibility:</p> <p>All ages; ICF/IID Level of Care (LOC) VIII: (1) primary diagnosis by a licensed physician of a related condition; 1 and (2) moderate to extreme deficits in adaptive behavior.</p>	<p>Functional Eligibility:</p> <p>All ages; (1) Be an individual with deaf blindness or function as a person with deaf blindness; (2) Have an additional disability that impairs independent functioning; and (3) Qualify for an ICF/IID LOC VIII.</p>	<p>Functional Eligibility:</p> <p>All ages; ICF/IID LOC I: (1)full scale IQ of 69 or below; or full scale IQ of 75 or below and a primary diagnosis by a licensed physician of a related condition; and (2)mild to extreme deficits in adaptive behavior - ORICF/IID LOC VIII: 2 (1) primary diagnosis by a licensed physician of a related condition; and (2) moderate to extreme deficits in adaptive behavior.</p>	<p>Functional Eligibility:</p> <p>All ages; ICF/IID LOC I: (1)full scale IQ of 69 or below; or full scale IQ of 75 or below and a primary diagnosis by a licensed physician of a related condition; and (2)mild to extreme deficits in adaptive behavior - ORICF/IID LOC VIII: 2 (1) primary diagnosis by a licensed physician of a related condition; and (2) moderate to extreme deficits in adaptive behavior.</p>

The previous charts list the eligibility criteria for the different programs; however, it would not be likely that individuals with ID/DD or their families could decipher between the acronyms without assistance. According to the *United Cerebral Palsy* (2016), the top performing states in the category of reaching those in need are: 1) New York, 2) California, 3) South Dakota, 4) North Dakota, and 5) Arizona; Texas ranks 51st out of 51. Reaching individuals in need is Texas’s worst performing category.

Listed below is the conceptual framework table that details literature sources for each of the ideal type categories.

Table 3.5–Conceptual Framework

<p><u>TITLE</u>: Evaluating the Effectiveness of Texas’ Intellectual and Developmental Disability Services: A Practical Ideal Type Approach.</p> <p><u>PURPOSE</u>: The purpose for this research is threefold. First, it will identify a set of standards and best practices adopted for delivering quality ID/DD services. It will then gauge the effectiveness of the Texas system against these best practice standards. Finally, based on the results it will make recommendations for Texas to become a more effective state in providing needed services and supports for the ID/DD population.</p>	
Practical Ideal Type Category	Literature Sources
<p>I. Promoting Independence</p> <p>1.1 Residential Services</p> <p>1.2 Community Based Waivers</p> <p>1.3 Promoting Self-Determination</p>	<p>Friedman, Lulinski, & Rizzolo (2015). Cook, Terrell & Jonikas (2004). Colvin, & Larke (2013). Aldridge (2010). Beadle-Brown, Hutchinson & Whelton (2012).</p>
<p>II. Tracking Health, Safety, Quality of Life</p> <p>2.1 Unpaid Relationships</p>	<p>Rossetti, Lehr, Huang, Ghai, & Harayama (2016). Gómez, Arias, Verdugo, Tassé, & Brown (2015). Palusci, Datner, & Wilkins (2015).</p>

2.2 Abuse/Neglect/Exploitation	Asselt-Goverts, Embregts, Hendriks & Frielink (2013). Petner-Arrey, & Copeland (2014).
III. Keeping Families Together 3.1 Family Support 3.2 Percent in a Family Home	Cowen & Reed (2002). Boehm & Carter (2016). Robert, Leblanc, & Boyer (2014). Elliott, Patnaik, Naiser, Fournier, Mcmaughan, Dyer & Phillips (2014). Patnaik, Elliott, Moudouni, Fournier, Naiser, Miller, Phillips (2011). Heller, Miller & Hsieh (1999).
IV. Promoting Productivity 4.1 Employment Support Services 4.2 Competitive Employment Percent 4.3 Medicaid Buy-In Program	Diallo & Barrera (2014). Barnett & Crippen (2014). Gimm, Davis, Andrews, Ireys & Liu (2008). Dalto (2011). Crites & Howard (2011). Cullum (2014). Chen & Barrera (2014).
V. Reaching Those in Need 5.1 Waiting Lists 5.2 Eligibility Determinations	Savage (2015). Lakin (1998). Brown, Parker & Godding (2002).

CHAPTER IV

METHODS

Chapter Purpose

This chapter explains the research methods that were used to gauge the ID/DD services in Texas. The Texas services were measured against the best practices in other U.S. states in five key domain areas. To obtain the most comprehensive information on Texas's services, a multi-method approach was undertaken to collect data for this study. The methods used here included surveys of many ID/DD service professionals and current Texas policy documents detailing the existing practices. This chapter provides details about the research design, the methods and procedures, and concludes with an operationalization table.

Research Setting and Research Participants

To conduct this research in the most effective manner, the researcher focused on document analysis of current practices and survey response data. The survey participants included people affiliated and familiar with the ID/DD services offered in Texas. They are identified by one of the following categories: ID/DD service professionals, community partners, individuals receiving ID/DD services, or family and friends of individuals receiving ID/DD services. The survey participants were made aware that their identities would be kept completely anonymous. The results of this study will be used to identify shortcomings and successes within the Texas ID/DD services system and offer suggestions on changes that could be made to further those successes.

According to information on the HHSC webpage, there are 39 LMHAs identified as ID/DD service providers. LMHAs and the staff were the primary correspondents for surveys. A variety of community partner organizations were also identified that would provide adequate

information about such services. Also surveyed were ID/DD agencies that provide direct services to individuals in Texas. Although individuals receiving ID/DD services were not surveyed, their family members and guardians were. This option was chosen to avoid surveying a vulnerable population. Table 4.1 provides a list of the different organizations that were used for the survey distribution, as well as their locations. Because no identifying survey questions were asked, an exact representation of a respondent’s location was not possible.

Table 4.1–Survey Participant Representation and Locations

Organization Name	Administrative Location	Area Represented
Alamo Local Authority (LMHA)	San Antonio	Bexar County
Andrews Center (LMHA)	Tyler	Henderson, Rains, Smith, Van Zandt and Wood Counties
Attorneys and Advocates	Statewide	Statewide
Austin Travis County Integral Care (LMHA)	Austin	Travis County
Bluebonnet Trails Community Services (LMHA)	Round Rock	Bastrop, Burnet, Caldwell, Fayette, Gonzales, Guadalupe, Lee and Williamson Counties
Central Counties (LMHA)	Temple	Bell, Coryell, Hamilton Lampasas and Milam Counties
Dallas Metro Care Services(LMHA)	Dallas	Dallas County
Family Members	Burnet and Williamson County	Burnet and Williamson County

Georgetown Independent School District	Georgetown	Georgetown
Gulf Bend (LMHA)	Victoria	Calhoun, DeWitt, Goliad, Jackson, Lavaca, Refugio and Victoria Counties
Harris County (LMHA)	Houston	Harris County
Health and Human Services Commission (Guardianship Department)	Austin	Statewide
Health and Human Services Commission (Utilization Review Department)	Austin	Statewide
Helen Farabee Centers (LMHA)	Wichita Falls	Archer, Baylor, Childress, Clay, Cottle, Dickens, Foard, Hardeman, Haskell, Jack, King, Knox, Montague, Stonewall, Throckmorton, Wichita, Wilbarger, Wise and Young Counties
ID/DD Direct Service Providers	Statewide	Burnet and Williamson County
Managed Care Organization	Austin	Statewide
Residential Treatment Centers	Statewide	Statewide
Round Rock Independent School District	Round Rock	Round Rock
Star Care (LMHA)	Lubbock	Cochran, Crosby, Hockley, Lubbock and Lynn Counties
United Way	Austin	Statewide

Survey Instrument

A survey was the primary research method used to gather data for this project. Surveys are a very useful tool to collect data from multiple people and organizations, and offer a reliable way to analyze the collected data. The survey technique was the most effective method of data collection for this research for a variety of reasons. In particular, it allowed for respondents to have time to think critically about the questions being asked and allowed for them to respond honestly and without fear of retribution. The survey used 23 questions using Likert-scaled responses ranging from “Strongly Disagree” through “Strongly Agree”; there were seven total response options. The number of questions addressing each of the ideal type domains was equal through the survey. The research also used eight demographic questions to assist in the data compilation and statistics. A complete copy of the survey is provided in Appendix A.

Strengths and Weaknesses of Survey Technique

Potential faults identified with surveys do include their response rates, which tend to be lower than those with scheduled face-to-face interviews, and the possibility that the respondent did not fully understand the question (Babbie, 2010, p. 274). The researcher was able to obtain 86 full responses out of the total 150 surveys that were distributed out. The survey was initially sent out on a Friday afternoon and closed exactly two weeks after first distribution. After the survey was closed for responses, the overall response rate was then calculated at 59 percent. With these strengths and weaknesses well identified, the survey was well written and therefore avoided the pitfalls others may have encountered.

Research Procedure and Survey Distribution

Internet surveys were utilized over mail-in surveys and face-to-face interviews to maximize time and financial resources. As Table 4.1 shows, there were a variety of community agencies and ID/DD service providers that responded to the survey by email. Email communication about the purpose of the study and confidentiality was initially mailed out along with the survey itself. A copy of the email is listed in Appendix B. All potential respondents were chosen because of their affiliation with ID/DD services. There was a qualifying question at the beginning of the survey identifying the respondent's relationship with ID/DD services. There was a special note to not complete the survey if they were not knowledgeable of persons with disabilities or those related services. The survey was distributed to 150 people in Texas with knowledge of and experience in the ID/DD services field.

Information Collection

Document analysis was a secondary method used to collect information for the variety of ID/DD services and practices offered across the state of Texas. Documents were available through the state government, the HHSC, and, more specifically, agencies falling under the HHSC's purview, such as DARS and LMHAs. Yin (2003) gives information on both the advantages and disadvantages of document analysis. Documents in general are discrete and precise; however, they also have some bias and are not always accessible. Although many documents are found online, it would be difficult for someone to find them who may not already know where to begin searching. Regarding the information in this research, Yin's assessment would be correct. Document analysis was used to determine the standards and policies set forth by the state of Texas that were not up for interpretation, but used to show factual rules and current practices.

IRB Approval Exemption

The research plan was reviewed by Texas State University’s Institutional Review Board (IRB). The IRB determined that this research is exempt from the board’s review. The project was approved by the board and can be found with application number 2017516. A copy of the IRB exemption is provided in Appendix C.

Human Subject Protection

Participants in this study were provided with information about their rights, about how to contact the researcher, and stating that their participation was voluntary. This research did not present any physical or psychological harm to any participant. Participants responded to the survey using an anonymous link sent by email.

Table 4.2–Operationalization Table

Practical Ideal Category	Research Methods	Evidence	Sources
I. Promoting Independence			
1.1- Residential Services 1.2- Community Based Waivers 1.3- Promoting Self-Determination	*Document Analysis *Survey data	*Current Texas policy *Individuals' independence and autonomy are highly promoted by the service providers. (Q3)	*LTSS Waiver Programs *Person Centered Practices *CFI report *ID/DD professionals and families of service recipients

		<p>*There are an adequate amount of residential service options for individuals. (Q4)</p> <p>*Medicaid funded residential options are located in areas with easy access to public transportation. (Q5)</p> <p>*There is more than one waiver service package to meet the individual's needs. (Q6)</p> <p>*Individuals are able to receive services in the waiver package of their choosing. (Q7)</p> <p>*Individuals direct many of their own services. (Q8)</p> <p>*More often than not, individuals are able to choose the way their time is spent. (Q9)</p>	
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<p>II. Tracking Health, Safety & Quality of Life</p>			
<p>2.1- Unpaid Relationships</p> <p>2.2- Abuse/Neglect/Exploitation</p>	<p>*Document Analysis</p> <p>*Survey data</p>	<p>*Current Texas policy</p> <p>*The individual's health and safety is a priority of the service providers working with them. (Q10)</p> <p>*Individuals in service are generally protected from abuse, neglect and exploitation. (Q11)</p> <p>*Individuals have the information, and access, to make complaints against service providers as needed. (Q12)</p> <p>*The overall quality of life for an individual in services is comparable to the average Texas resident. (Q13)</p>	<p>*CFI report</p> <p>*ID/DD professionals and families of service recipients</p>

		<p>*Individuals spend an average amount of time with their friends and/or family. (Q14)</p> <p>*Most individuals have at least one hobby or outside interest they are able to participate in. (Q15)</p>	
III. Keeping Families Together			
<p>3.1- Family Support</p> <p>3.2- Percent receiving services in a Family Home</p>	<p>*Document Analysis</p> <p>*Survey data</p>	<p>*Current Texas policy</p> <p>*ID/DD services promote individual's success within the natural family environment. (Q16)</p> <p>*Services provided help support the wellness of the family and/or unpaid caregivers. (Q17)</p> <p>*Individuals are able to live in their own home or family home with services that support that decision. (Q18)</p>	<p>*CFI report</p> <p>*ID/DD professionals and families of service recipients</p>

IV. Promoting Productivity			
<p>4.1- Employment Support Services</p> <p>4.2- Competitive Employment Percent</p> <p>4.3- Medicaid Buy-In Program</p>	<p>*Document Analysis</p> <p>*Survey data</p>	<p>*Current Texas policy</p> <p>*ID/DD services support an active and productive lifestyle. (Q19)</p> <p>*Employment services are supportive of all individual ability levels. (Q20)</p> <p>*If individuals do choose to work, they are able to earn at least minimum wage. (Q21)</p> <p>*Individuals easily maintain their insurance benefits while working at least part time. (Q22)</p>	<p>*Texas Work Force Vocation Rehabilitation brochure</p> <p>*Medicaid Buy In Application H1200</p> <p>*CFI report</p> <p>*ID/DD professionals and families of service recipients</p>

V. Reaching Those in Need			
<p>5.1- Waiting Lists</p> <p>5.2- Eligibility Determinations</p>	<p>*Document Analysis</p> <p>*Survey data</p>	<p>*Current Texas policy</p> <p>*General information on ID/DD services is easily found and accessed by all. (Q23)</p> <p>*After first sought, ID/DD services were offered within a reasonable time frame, causing little to no disruption for the individual. (Q24)</p> <p>*Eligibility requirements for ID/DD services are clear and concise. (Q25)</p>	<p>*Long Term Services and Supports Form 2121</p> <p>*Explanation of ID/DD Services and Supports</p> <p>*Texas Medicaid State Plan Services and Supports</p> <p>*CFI report</p> <p>*ID/DD professionals and families of service recipients</p>

CHAPTER V

RESULTS

Chapter Purpose

This primary objective of this chapter is to present the results of this research. Data was collected for this study both via document analysis and a web-based survey sent to individuals with knowledge and experience in the ID/DD services field. The results are broken down by the five categories that were presented in the conceptual framework (see Table 3.5) in chapter III. Results from the document analysis phase of the research are presented first, followed by results from the survey phase of research.

Document Analysis

Documents were analyzed that assisted the researcher in verifying the different practices that Texas employs for its various ID/DD programs. The information examined focused on the different waiver programs, their eligibility criterion, and other state-offered services, such as employment support services. The various documents and state forms that were examined are listed in Appendix D. Specific information from each of the documents examined will be explained further throughout this chapter.

Survey Response Rate

The primary data collection method was a web-based survey. The survey was distributed to 150 individuals, all with working knowledge of and experience in the ID/DD services field and currently living in Texas and familiar with its services. Of the 150 surveys offered, 86 responses were received. Of those 86 surveys, four were partially completed and

those responses were deleted from the sample. Eighty-two respondents completed the survey all the way through, yielding an overall response rate of 54.66 percent. The results presented in this chapter are based on individual survey question responses, causing totals to range anywhere from 1 to 82, depending on the number of participants who responded to each question.

Demographic Information

The survey collected basic participant information such as gender, race, education level, and information on their relationship with ID/DD services. No other identifying information was collected. Demographic information was collected at both the beginning and the end of the survey; a total of eight demographic questions were used.

The first demographic question addressed the respondent’s role in providing or receiving ID/DD services. The response options are listed in Table 5.1. The researcher used this question to determine if relationships existed between the role of the respondent and their overall agreement or disagreement with the questions asked.

Table 5.1–Respondent’s Role in ID/DD Services

Role in ID/DD services	Frequency	Percentage
ID/DD service professional	73	90.12%
Family member of service recipient	2	2.47%
Other ID/DD role	6	7.41%
No experience with ID/DD services	0	0.00%
Total	81	100%

As is evident from Table 5.1, far more responses were received from those identifying themselves as ID/DD service professionals than from any other category. A follow-up to the first demographic question inquired about the respondent’s length of time in that role. Table 5.2 lists the answer distribution for this question.

Table 5.2–Length of Time in ID/DD Services

Time in ID/DD Services	Frequency	Percentage
0-4 years	28	34.15%
5-9 years	23	28.05%
10-14 years	8	9.76%
15+ years	23	28.05%
Total	82	100%

A longer length of time in the role would likely lend itself to more knowledge and experience to draw from. According the responses, there was equal representation in the 5–9 years selection and the 15+ years selection. The highest represented length of time in the role was 0–4 years. This distribution indicates that roughly one-quarter of the respondents in this study had the least amount of ID/DD experience to draw from. However, when looking at the frequency of their representation, they comprised only 28 of 82 respondents.

Another potentially interesting demographic was gender distribution. The gender frequency weighed heavily toward female respondents. Because of this, the researcher did not examine any relationship between gender and service opinions. The gender distribution is listed in Table 5.3.

Table 5.3- Gender Distribution

Gender	Frequency	Percentage
Male	13	17.11%
Female	63	82.89%
Total	76	100%

Although the relationships were not closely examined, the researcher expected that the gender distribution of the respondents would not be similar to the overall population's gender frequency. In general, social workers are more frequently female and therefore were unevenly favored in the survey distribution.

Table 5.4 shows the respondents' race distribution. As with gender, the researcher did not closely examine any relationship between a respondent's race and their opinions on ID/DD services. The race categories used were taken from the most recent U.S. census.

Table 5.4–Race Distribution

Participant Race	Frequency	Percentage
American Indian or Alaska Native	1	1.41%
Asian	0	0.00%
Black or African American	3	4.23%
Native Hawaiian or Other Pacific Islander	1	1.41%
White or Hispanic	66	92.96%
Total	71	100%

Respondents were also asked about their education level, but it was not expected to be reflective of the general public’s education level. The surveys were distributed primarily to ID/DD service professionals working in different capacities across the state. Because of the nature of the employment requirements for these positions, many participants had a bachelor’s or advanced degree. Table 5.5 shows the distribution of participants’ education levels.

Table 5.5–Education Level Distribution

Education Level	Frequency	Percentage
High School graduate	6	8.11%
Bachelor's Degree	45	60.81%
Graduate Degree or higher	23	31.08%
Total	74	100%

Opinion-Based Responses

As previously mentioned, the purpose of this research was threefold. The third goal was to make recommendations based on the survey responses and current state documents about where Texas could improve its ID/DD services. The data that was most closely examined were the responses in which most participants felt that Texas was not meeting the standards set forth by the literature. That data is consolidated and grouped by three headings: agreement, disagreement, and neither agree nor disagree. Because the survey questions were all stated in the positive, the researcher only examined the questions that received more disagreement than agreement.

The following tables group the survey questions related to the practical ideal type categories that were originally discussed in the literature review and conceptual framework

chapters. The columns listed represent the total percentage of agreement, disagreement, neither agree nor disagree responses. These totals give an indication of how the people involved with Texas's ID/DD services feel about those individual standards. To assist in reading the tables, the areas with the most disagreements are printed in bold text and notated with an asterisk (*), showing the significance.

Promoting Independence

Table 5.6 summarizes the responses for the following questions related to the domain of promoting independence.

Table 5.6–Promoting Independence

Promoting Independence	Agreement Percentage	Neither Agree nor Disagree Percentage	Disagreement Percentage
3. Individuals' independence and autonomy are highly promoted by the service providers.	78.05%	6.10%	15.86%
4. There are an adequate amount of residential service options for individuals.	32.93%	1.22%	65.85%*
5. Medicaid funded residential options are located in areas with easy access to public transportation.	29.27%	8.54%	62.19%*
6. There is more than one waiver service package to meet the individual's needs.	79.01%	9.88%	11.10%
7. Individuals are able to receive services in the waiver package of their choosing.	51.86%	8.64%	39.51%
8. Individuals direct many of their own services.	72.50%	7.50%	20.00%
9. More often than not, individuals are able to choose the way their time is spent.	56.79%	4.94%	38.27%

Of note in this category is that more people feel the residential options are not likely meeting the needs of individuals with ID/DD and therefore are not promoting autonomy.

Question 4 in particular asked about the overall availability of residential options in Texas.

Medicaid funds group homes through different programs, but living in such a home generally

means individuals are more limited in their independence. Group homes are considered the most restrictive environment besides an institution. Even though group homes are restrictive, they do provide 24/7 care that a lot of individuals with ID/DD need. Texas has few options for placement and there appear to be a lot of individuals in need of group homes who do not have access to them.

In addition to group homes, there is the living option of host companion care. This service is offered to individuals with ID/DD by the HCS waiver program. No other waiver program offers this residential service. In Texas, there is just one waiver program that offers residential options. If an individual is not residentially supported by their natural family and are not enrolled in the HCS waiver program, they would have to select a more restrictive living option such as ICFs.

Question 5 addresses the transportation options for individuals living in residential homes. Many of the individuals needing ID/DD services do not have driver's licenses and depend on their provider staff to transport them. If public transportation was a more readily available option, individuals would be able to access activities without staff accompanying them. The dearth of transportation options for individuals with ID/DD is extremely limiting to their independence and autonomy. Transportation is costly, so without it being provided, individuals are heavily impacted financially if they need to access something independently. This issue furthers their dependence on their caregivers and provider agencies, and can often be a barrier to employment and other personal goals.

According to LTSS Form 2121, individuals in Texas with an ID/DD diagnosis have access to three programs with a residential option. The type of residential service offered varies

with how the individual's independence is shaped. The ICF homes are covered by Medicaid, and range in size, with six beds being the smallest option. The larger the home, the less the individual independence a person will have. Group homes, however, do promote independence by teaching and reinforcing daily living skills to the individuals in their care.

The larger group living options in Texas are state-supported living centers, which are generally very restrictive. Individuals residing here do not have the same ability to decide their daily activities as they do in smaller, less restrictive living environments. The resident population and the few staff on shift at any time create a large staff-to-client ratio. This prevents individuals from getting individualized care and independence.

As mentioned earlier, other types of residential placements are embedded in the HCS waiver program. The host companion care option, for example, is a home with 1–3 individuals. There is also the smaller group home option, which ranges in size from 1 to 4 beds. These options are delivered within the community and are therefore considered to be less restrictive. As a result, these options further the independence of individuals with ID/DD and allow for more self-determination opportunities.

As part of the document analysis, the researcher examined person-centered thinking. Located in Appendix D is a training brochure for the Person-Centered Thinking Program. “Person-centered” is a term and philosophy employed by Texas to promote the independence of the individuals it serves. This philosophy is embedded in a training course that many service professionals go through. The course is two full days and teaches attendees how to promote

the wants and needs of the individuals they serve. The training teaches them ways to assist individuals with ID/DD in directing their own services to achieve their goals and outcomes.

Person-centered thinking is an approach offered by many of the programs that fall under the HHSC service umbrella. The individual decides who is on their service planning team, what available services they receive for the year, and what their individual goals and outcomes are for those services. The individual's goals and outcomes drive their plan of care and are measured for progress.

Promoting Health, Safety, and Quality of Life

Table 5.7 summarizes the responses for the following questions related to the domain of promoting health, safety, and quality of life.

Table 5.7–Promoting Health, Safety, and Quality of Life

Tracking Health, Safety & Quality of Life	Agreement Percentage	Neither Agree nor Disagree Percentage	Disagreement Percentage
10. The individual's health and safety is a priority of the service providers working with them.	90.13%	3.70%	6.17%
11. Individuals in service are generally protected from abuse, neglect and exploitation.	90.00%	1.25%	8.75%
12. Individuals have the information, and access, to make complaints against service providers as needed.	88.75%	2.50%	8.75%
13. The overall quality of life for an individual in services is comparable to the average Texas resident.	47.50%	8.75%	43.75%*
14. Individuals spend an average amount of time with their friends and/or family.	58.75%	16.25%	25.00%
15. Most individuals have at least one hobby or outside interest they are able to participate in.	57.50%	12.50%	30.00%

Of note in this category is that the disagreement responses are very low regarding the abuse, neglect, and exploitation of individuals in ID/DD services. This shows that Texas is doing a good job of promoting education around the issues of abuse. The quality of life for individuals in such services was more difficult to gauge because of similar percentages in the agreement and disagreement categories. Questions 13, 14, and 15 addressed the overall quality of life, asking about individuals' hobbies and time spent with family and friends. Unfortunately, individuals in ID/DD services do not have the same general ability to participate in hobbies or social groups. The transportation need is a huge part of this service deficit.

Of the five categories rated in the *Case for Inclusion* report, Texas ranked 23rd in health, safety, and quality of life, but this was the second-highest rating for Texas in any category. The respondents agreed with the more specific questions about health and safety; however, when asked for their overall opinion of the individuals' quality of life, they did not agree that it was where it should be.

Keeping Families Together

Table 5.8 summarizes the responses for the following questions related to the domain of keeping families together. Keeping families together means physically and emotionally connected. ID/DD services should support families and allow them to remain together through relief options and support services that prevent caretaker burnout. If a caretaker is no longer able to care for their loved one, the state then has to assume that responsibility. The residential options for individuals in ID/DD services are costlier to the state and are more emotionally costly to the family and individual.

Table 5.8–Keeping Families Together

Keeping Families Together	Agreement Percentage	Neither Agree nor Disagree Percentage	Disagreement Percentage
16. ID/DD services promote individual’s success within the natural family environment.	86.08%	5.06%	8.87%
17. Services provided help support the wellness of the family and/or unpaid caregivers.	63.29%	11.39%	25.31%
18. Individuals are able to live in their own home or family home with services that support that decision.	88.61%	3.80%	7.60%

There were no major disagreements to report in this category. According to most respondents on all four questions related to family supports and services, Texas is doing well in these areas. This was also Texas’s highest ranking category in the *Case for Inclusion* report. Texas ranked 21st out of 51 in 2016 for keeping families together. Texas does offer a lot of in-home waiver services to individuals with ID/DD. These services offer support to the family by providing respite to the primary caregivers, training opportunities for both caretakers and individuals, and behavior support services, personal attendant services, and day habilitation services for the individual. These services are all extremely beneficial toward the goal of supporting the family unit and the success of the individual.

Texas’s LTSS Waiver Programs Form explains the various services available under each of the state plan services and programs. Consistently offered in each state plan service is the respite option. The definition of respite in this form is a service provided on a short-term basis to address a need caused by the absence or needed relief of the person(s) normally providing care for the individual. This service definition is validating the need for primary caregiver relief. This service is vital to prevent the exhaustion of family members and the burnout of caretakers. This service is a preventative option working toward keeping natural families together.

Promoting Productivity

Table 5.9 summarizes the responses for questions related to promoting productivity.

Table 5.9–Promoting Productivity

Promoting Productivity	Agreement Percentage	Neither Agree nor Disagree Percentage	Disagreement Percentage
19. ID/DD services support an active and productive lifestyle.	75.95%	8.86%	15.19%
20. Employment services are supportive of all individual ability levels.	41.77%	12.66%	45.57%*
21. If individuals do choose to work, they are able to earn at least minimum wage.	62.02%	20.25%	17.72%
22. Individuals easily maintain their insurance benefits while working at least part time.	46.83%	20.25%	32.91%*

The responses in this category are important for a variety of reasons. The first issue the respondents seemed to agree on is that the employment services for those with ID/DD are not supportive of all individual ability levels. These employment services are offered by the state directly, such as through the Texas Workforce Commission, formally the Department of Rehabilitative Services. Because these employment services mostly support individuals with a high ability to function independently, more people would benefit from the employment services if they supported various functional abilities.

Another issue regarding individuals' ability to be productive community members is that the waiver programs require Medicaid, which is most often given to people who make very little income. Individuals with ID/DD need to maintain their Medicaid eligibility to keep their residential options or other services. This causes issues for them and their employment. If an individual makes too much money, their benefits will be discontinued. There is a set equation to determine the amount of money a person can earn before their benefits decrease. This is a stressful and confusing process as the equation changes every year. This prevents the individual from easily keeping their benefits while also working, and is confusing for individuals and their families. Families will continue to shy away from individuals' employment goals as long as they fear the discontinuation of their loved one's benefits.

The Medicaid buy-in program is an option for some people who make more than the set income limit for traditional Medicaid. Individuals who earn more than the income limit must "buy in" to the insurance program to keep their services and benefits. This is a great option for some earners, but is not offered in all states. This option is very valuable for individuals who are able to work and maintain their employment, but also need access to medical services due to

their disability needs. Although there are a lot of benefits to the buy-in option, it can also be very burdensome because the cost of insurance is expensive.

The Vocational Rehabilitation Guide for Applicants details the services offered to individuals diagnosed with a disability and who are looking for employment services. The employment services offered in Texas are used to help individuals find jobs that allow them the flexibility and assistance they need to complete their tasks. As part of these services, there are designated job coaches who are trained to assist with job placement and job retention as needed. The individuals may also need adaptive equipment, such as hearing aids or other communicative devices, and this program can assist with those matters as well. The services offered further include benefits counseling so that individuals with ID/DD can learn what their employment compensation means in terms of their medical or financial benefits through Medicaid or Medicare. This information is very important for employees when looking for and keeping their employment.

Reaching Those in Need

Table 5.10 summarizes the responses for the following questions related to the domain of reaching those in need. In particular, it highlights the results for information dissemination and public education on the ID/DD services that are available to support individuals with disabilities, their family members, and their friends.

Table 5.10–Reaching Those in Need

Reaching Those in Need	Agreement Percentage	Neither Agree nor Disagree Percentage	Disagreement Percentage
23. General information on ID/DD services is easily found and accessed by all.	44.30%	8.86%	46.84%*
24. After first sought, ID/DD services were offered within a reasonable time frame, causing little to no disruption for the individual.	37.98%	17.72%	44.31%*
25. Eligibility requirements for ID/DD services are clear and concise.	59.50%	13.92%	26.58%

According to the collected data, respondents agree that the information on ID/DD services in Texas is not easily located. Roughly half of the respondents disagreed that it was easily found and accessed by all, as asked in Question 23. To provide these services, the relevant information must first be disseminated to the public and particularly to the right places where the people who would benefit most would find it; unfortunately, this is not the case in Texas. In the 2016 *Case for Inclusion* report, Texas ranked 51st out of 51 in this category and appears to have a lot of work to do in getting the word about ID/DD service options out to the people who need it. The younger a person is when they first access these services correlates with improved personal successes. Texas could do a better job of reaching out to those in need and informing people on what is available for them.

The Explanation of IDD Service and Supports and the LTSS Waiver Programs forms detail the eligibility requirements for each of the ID/DD programs offered. There are pieces of these requirements that are easily understood for most people, such as IQ score, but there are also pieces that are more difficult to understand, such as level-of-care needs. The functional eligibility is listed for each ID/DD service, however it is difficult for most people to interpret this information without assistance.

The outreach services are also a barrier to this information getting to the public. The local mental health authorities are primarily responsible for these services, although this is dependent on their availability to provide them. The research was not able to establish a baseline for outreach expectations imposed by Texas or its smaller programs and services. Outreach services are vital to getting information about ID/DD supports to the public and need to be continually evaluated.

Outside State Experience

To gauge the overall quality of ID/DD services in Texas, the survey asked respondents if they had experience in another state and if so, which state(s) specifically. Table 5.11 lists the states that were received back from Question 31.

Table 5.11–Respondents’ Experience in Other States

Arizona	Louisiana	Oregon
California	Massachusetts	Pennsylvania
Connecticut	Missouri	Vermont
Florida	Nebraska	Washington
Hawaii	New Mexico	Wisconsin
Illinois	New York	

Further, if the research participant had ID/DD experience in any other state(s), they were asked whether they rated Texas higher or lower in the ID/DD services it provides than the other state experiences they have had. Table 5.12 shows the distribution of those responses from Question 30.

Table 5.12–Participants’ Rating of Texas’s Services

Texas’ Rating	Frequency	Percentage
Lower than other state(s)	13	81.25%
Higher than other state(s)	3	18.75%
Total	16	100%

Of the maximum number of survey respondents (82), the percentage of participants that had out-of-state knowledge was 19.51 percent. Sixteen total respondents had outside state experience and of those 16, 13 felt that Texas should be rated lower than the other states’ ID/DD services. Of the people who have worked or lived in other states, 81.25 percent believe those other states are operating better ID/DD services than Texas.

Chapter Summary

The research data does consistently show that Texas has many improvements to make in their ID/DD services. The funding that human services get in the state is not supportive of the quantity of people that need help. Because one of the goals of this research was to further expose the areas that need improvements, it did not fully discuss the areas that were rated most favorably by the survey respondents.

CHAPTER VI
CONCLUSION

The results of this study lead to the conclusion that most ID/DD services provided in Texas have an adequate approval rating. There was no one particular area of service that stood out significantly from the others. There was not a significant amount of agreement or disagreement in any of the categories. The fact that most of the survey respondents were ID/DD service professionals may have made them respond favorably to the services they offer. It is understandable that many professionals do not want to undervalue the importance of their careers and their roles in their clients' lives. Listed below are the evidence levels and recommendations for each of the ideal categories.

Table 6.1–Evidence and Recommendations

Category I- Promoting Independence		
Ideal Type Category	Evidence	Recommendations
1.1- Residential Services	Limited	Improve quantity of residential service providers and options. Train providers who are better able to serve a more difficult client population.
1.2- Community Based Waivers	Adequate-Strong	Continuing funding the community based program options. Fully fund waiver programs to allow more community based living options for individuals.
1.3- Promoting Self-Determination	Adequate	Continue with person centered planning and expand the training to all services and providers. Ongoing training.

Category II- Tracking Health, Safety & Quality of Life		
Ideal Type Category	Evidence	Recommendations
2.1- Unpaid Relationships	Adequate	Fund and sponsor more recreational activities and social networking groups within local communities.
2.2- Abuse, Neglect, Exploitation	Strong	Continued education for all service providers. Ongoing training.
Category III- Keeping Families Together		
Ideal Type Category	Evidence	Recommendations
3.1- Family Support	Adequate	Continue and expand respite options. Increase educational groups and parent networking.
3.2- Percent in Family Home	Strong	Continue funding home based programs that help individuals remain in their own residence safely.
Category IV- Promoting Productivity		
Ideal Type Category	Evidence	Recommendations
4.1- Employment Support Services	Limited	Increase awareness on employment services. Focus efforts on school district transitional programs.
4.2- Competitive Employment Percent	Adequate	Increase funding for supported employment services.
4.3- Medicaid Buy-In	Limited	Add benefits counseling to all individual service plans. Continue funding the program and increase awareness of its benefits.

Category V- Reaching Those in Need		
Ideal Type Category	Evidence	Recommendations
5.1- Wait List	Limited	Move from the wait list option. Consider service planning around need based assessments.
5.2- Eligibility Determinations	Limited	Clearly define program eligibility. Outreach more with school districts.

Recommendations

When United Cerebral Palsy completed their annual *Case for Inclusion* report in 2016, Texas had a lot of work to do. This research further breaks down the areas that best serve people with ID/DD and organizes the ground-level data on how service providers and families truly feel about those areas' effectiveness. The amount of support services that are offered within communities, directly to the individuals with ID/DD, will further their independence and autonomy and allow them to be productive members of society. The funding that the ID/DD programs have in Texas should focus primarily on helping individuals achieve greater independence. The more independent people are, the less they need from the government. Working toward the independence of all citizens allows Texas to produce positive outcomes for the individuals and the state alike.

Community-based services are where the need is and where state dollars should be going. The services are available in Texas, but they are difficult to staff. Working with individuals with varying levels of disabilities is difficult work. Texas needs to better fund the services so they can reimburse the work at a higher rate. Higher pay both values the employees and the

individuals' needs. If Texas does not commit to fully funding community-based services, institutional care services will never dissolve and the state's funding allocation will continue to be spread very thin. A cost-benefit analysis would be beneficial to see what the non-institutional design might do to benefit the individuals with ID/DD, as well as the state budget.

Recommendations to improve the health, safety, and quality of life for individuals with ID/DD in Texas would focus more on the individuals' quality of life. The survey responses showed that individuals are protected from abuse, neglect, and exploitation, and are generally informed about their rights. The actual quality of their lives, however, is at a deficit. Individuals with ID/DD generally have restricted pedestrian skills and they need assistance to access the community on their own. They need the assistance of their caregivers to get around and are therefore limited in the activities they can participate in. Social networking and peer groups would be a great way for individuals with ID/DD to find and keep friendships, discuss issues they are dealing with, and have overall socializations that they otherwise may be missing. The day habilitation service is filling this gap for some individuals but not all have access to it. There are also individuals who are employed, meaning that the day habilitation service is not utilized for them, but they are still lacking the social piece of their lives. Social skill groups, peer support services, and other similar programs could use more funding and participation.

Families of individuals with ID/DD continue to benefit heavily from respite services and Texas is doing a fairly good job with its in-home offerings. In-home services are very similar to the community-based options. These services work to keep individuals in their natural family homes, and out of restrictive institutions. Again, a cost-benefit analysis should be done to examine these costs and weigh these options. Recommendations are to continue funding the

respite services heavily and look for more ways to better support the entire family unit when possible.

Employment support services also still need a lot of work in Texas. As previously mentioned, day habilitation is a service designed to keep individuals busy during the day and allow them to socialize with their peers. Again, this service serves a great purpose for some but not all individuals can access it. Many individuals receiving ID/DD services would be able to work competitively if they had more support. Recommendations include better funding for employment programs and supports and extending the amount of time an individual can receive those services.

The cost of supporting day habilitation facilities is lower than the cost of employment services, but the result of empowering individuals to be employed benefits more than just them. Increased tax dollars and revenue and a decrease in social security support should be heavily considered in this funding change. Additionally, all Texas school districts should have transitional programs for older youth with ID/DD. These services are vital to getting kids on the vocational track early on. They can discover the kids' existing skills and abilities and teach them new ones to help support job readiness. The other barrier to a higher employment percentage for those with ID/DD is the fear around losing one's benefits. Individuals who receive ID/DD benefits need to be counseled on what they have to do to keep the services they need. This might be costlier on the front-end but the overarching goal is, again, employing more people with disabilities and enabling them to be productive members of their communities.

Readily available information on ID/DD services for eligible individuals is vital to providing support. More education and outreach opportunities need to be considered, especially

those involving government agencies and school districts, to ensure the information is getting out to those who need it. Eligibility requirements are difficult to interpret, so encouraging families to contact their local mental health authorities to better understand what is available is necessary. Many families do not find out about available ID/DD services until their loved ones are headed toward high school graduation. This doesn't serve the individual for a variety of reasons. In particular, the younger an individual is when they first access ID/DD services, the better their chance at being successful toward their goals.

Limitations

The results of this research pose bias because of the limited scope of knowledge for some of the survey participants. A functional example is that someone in the Texas ID/DD services field with no other experience will rate Texas's services based only on that knowledge and experience. However, someone with experience elsewhere will have a variety of experiences and knowledge to pull from when answering the questions.

The type of survey sample used would also be considered a limitation to this research. The research used a convenience sample to obtain the survey data. As Johnson states in *Research Methods for Public Administrators*, "a convenience sample is similar to an accidental sample in that not everyone has an equal chance of being selected" (p. 156). The sample polled was made up of professionals working in the ID/DD services field, primarily at the LMHA level.

Another limitation of this study's results is that location information for each participant was not collected. Surveys were distributed to many work locations around the Texas; however, responses were not recorded by location. Participants were not asked where they worked, either by agency name or city. This prohibits the research from being able to apply the results fully to

the entire state. The response rate was high and therefore it can be logically assumed that there was a vast area represented, but there is no way to justify that information with data.

Further Research Opportunities

Further research could and should be conducted to evaluate additional views of ID/DD services in Texas. A limit to this research was the low response rate by family members. It is also important to examine the state practices of those that are successful in the five domain areas. Research should go further into what they are doing well and what their best practices are. It would benefit Texas to learn other ways of meeting the service criteria set by the CMS. There are also cost-benefit analyses that can be done to see how Texas can better spend its current ID/DD services budget to serve the individual population.

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APPENDIX A
SURVEY INSTRUMENT

Dear Respondent,

I am a Master in Public Administration student interested in evaluating Intellectual Disability/Developmental Disability Services (hereafter, ID/DD) in Texas. Your knowledge and experience in this field is why you were chosen to participate. The survey should not take longer than 10 minutes of your time and the data gathered will be used to better inform the practices of ID/DD services in our state. This survey will also use the term *individuals* to specifically identify individuals receiving ID/DD services in Texas. There will be no identifying information asked for or tracked by this survey. If you have any questions or concerns, please email me at vmh26@txstate.edu. Thank you kindly for your participation.

1. Which best describes your role within Texas ID/DD services?

- ID/DD service professional (1)
- Family member of service recipient (2)
- Other ID/DD role (3)
- No experience with ID/DD services (4)

2. How long have you been in the above selected role?

- 0-4 years (1)
- 5-9 years (2)
- 10-14 years (3)
- 15+ years (4)

3. Individuals' independence and autonomy are highly promoted by the service providers.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

4. There are an adequate amount of residential service options for individuals.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

5. Medicaid funded residential options are located in areas with easy access to public transportation.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

6. There is more than one waiver service package to meet the individual's needs.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

7. Individuals are able to receive services in the waiver package of their choosing.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

8. Individuals direct many of their own services.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

9. More often than not, individuals are able to choose the way their time is spent.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

10. The individual's health and safety is a priority of the service providers working with them.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

11. Individuals in service are generally protected from abuse, neglect and exploitation.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

12. Individuals have the information, and access, to make complaints against service providers as needed.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

13. The overall quality of life for an individual in services is comparable to the average Texas resident.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

14. Individuals spend an average amount of time with their friends and/or family.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

15. Most individuals have at least one hobby or outside interest they are able to participate in.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

16. ID/DD services promote individual's success within the natural family environment.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

17. Services provided help support the wellness of the family and/or unpaid caregivers.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

18. Individuals are able to live in their own home or family home with services that support that decision.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

19. ID/DD services support an active and productive lifestyle.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

20. Employment services are supportive of all individual ability levels.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

21. If individuals do choose to work, they are able to earn at least minimum wage.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

22. Individuals easily maintain their insurance benefits while working at least part time.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

23. General information on ID/DD services is easily found and accessed by all.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

24. After first sought, ID/DD services were offered within a reasonable time frame, causing little to no disruption for the individual.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

25. Eligibility requirements for ID/DD services are clear and concise.

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

26. Please select your gender.

- Male (1)
- Female (2)
- I prefer not to identify (3)

27. Which best describes your race?

- American Indian or Alaska Native (1)
- Asian (2)
- Black or African American (3)
- Native Hawaiian or Other Pacific Islander (4)
- White or Hispanic (5)
- I prefer not to identify (6)

28. Please select your highest level of education.

- High School graduate (1)
- Bachelor's Degree (2)
- Graduate Degree or higher (3)
- I prefer not to identify (4)

29. Do you have any experience with ID/DD services outside of Texas?

- Yes (1)
- No (2)

30. If yes above, do you feel Texas' services rate higher or lower for overall client service options and quality?

- I would rate Texas' services LOWER than other state's ID/DD services. (1)
- I would rate Texas' services HIGHER than other state's ID/DD services. (2)
- No other experience (3)

31. If applicable, please list which states you specifically have ID/DD service knowledge of.

APPENDIX B
SURVEY EMAIL

To:

From: Vanessa Hawley

BCC:

Subject: Research Participation Invitation: Evaluating the Effectiveness of Texas' Intellectual and Developmental Disability Services

You have been chosen to participate in this research because of the unique information you have regarding ID/DD services in Texas. This survey is voluntary and should only take about 10 minutes of your time.

The goal of this research is to evaluate the ID/DD services in our state and their effectiveness within given service areas. Your feedback is greatly appreciated and will assist me in concluding where Texas is doing well and where improvements in our ID/DD services can potentially be made.

There will be no personal identifying information collected and no participant demographics will be listed in the research.

To participate in this research or ask questions about this research please contact me at vmh26@txstate.edu.

Thank you so much for your time and participation!

This email message is an approved request for participation in research that has been approved or declared exempt by the Texas State Institutional Review Board (IRB). This project 2017516 was approved by the Texas State IRB on February 27, 2017. Pertinent questions or concerns about the research, research participants' rights, and/or research-related injuries to participants should be directed to the IRB chair, Dr. Jon Lasser 512-245-3413 – (lasser@txstate.edu) or to Monica Gonzales, IRB administrator 512-245-2314 - (meg201@txstate.edu).

APPENDIX C
IRB REVIEW AND EXEMPTION

Confirmation of Approval: IRB Application 2017516. DO NOT REPLY to this message.

AVPR IRB <avpr-irb@txstate.edu>

This email message is generated by the IRB online application program. Do not reply.

The reviewers have determined that your IRB Application Number 2017516 is exempt from IRB review. The project is approved.

=====

Institutional Review Board

Office of Research Compliance

Texas State University-San Marcos

(ph) 512/245-2334 / (fax) 512/245-3847 / avpr-irb@txstate.edu / JCK 489

601 University Drive, San Marcos, TX 78666

Texas State University is a member of the Texas State University System

APPENDIX D

DOCUMENTS AND FORMS ANALYZED

*Services by County

*Person Centered Practices

*LTSS Waiver Programs

*Long Term Services and Supports Form 2121

*Explanation of ID/DD Services and Supports

*Texas Medicaid State Plan Services and Supports

*Texas Work Force Vocation Rehabilitation brochure

*Medicaid Buy-In Application H1200