

Background:

- **Federal Policy Issues** — TCDD Public Policy Staff will provide an overview of the status and implementation of federal legislative initiatives that could impact people with disabilities. Discussion topics include:
 1. Workforce Investment Opportunity Act
- **State Supported Living Centers Update** — The Committee will receive an update regarding SSLC Ombudsman Reports.
- **State Policy Issues** — TCDD Staff will provide an update regarding recent public policy activities. Discussion topics include:
 1. How to Keep Parents Involved in Your ARD Meetings
 2. Autism Services Update
 3. Health and Human Services Transition
 - A. Consolidation Plan
 - B. Rulemaking Recommendations

Public Policy Committee — Agenda Item 7

Expected Action:

The Committee will receive updates on these items and may make recommendations for consideration by the Council.

Council — Agenda Item 11. A.

Expected Action:

The Council will receive a report on the Public Policy Committee discussion.

TRANSITION AND WIOA

Employment First

In 2013, Texas was first in the nation to pass legislation making Employment First a state law. The achievement was largely the result of the leadership of the Texas Council for Developmental Disabilities, as the recommendation was originated in the Public Policy Committee. Senate Bill 1226 (2013) established that it is the policy of Texas that earning a living wage through competitive employment in the general workforce is the priority and preferred outcome for working-age individuals with disabilities who receive public benefits. Texas is joined by at least 42 other states with Employment First efforts.

SB 1226 required the Health and Human Services Commission (HHSC), the Texas Education Agency (TEA), and the Texas Workforce Commission (TWC) to jointly adopt and implement an Employment First policy. Through the Employment First Task Force established by the new law, the first step was to develop recommendations that addressed a broad range of matters regarding policy, procedures, and rule changes necessary to allow the Employment First policy to be jointly adopted and implemented by HHSC, TEA, and TWC.

The Workforce Innovation and Opportunity Act (WIOA)

In the past two years, the Task Force's work across state agencies has been integral to understanding policy barriers to increasing innovation and getting people to work. It has provided an excellent proving ground from which to go forward with implementing the provisions of WIOA, many of which require the collaboration of HHSC, TEA, and TWC in providing pre-employment services and supports to students and youth transitioning to postsecondary education or employment. A central provision in ensuring collaboration is the requirement that the agencies submit a unified/combined strategic plan.

WIOA, which was signed into law in July 2014, is a landmark federal act that comprehensively reauthorizes, updates, and adds to existing federal statutes (principally the Workforce Investment Act and the Rehabilitation Act of 1973). Its provisions affect state and local area workforce development systems as well as a number of national programs for youth and special populations, including persons with disabilities.

The new law defines and uses the term "competitive integrated" to describe desired employment outcomes for individuals with disabilities, including individuals with the most significant disabilities. It defines competitive integrated employment as employment meeting three criteria:

1. **Income** — The higher of the minimum wage rate established by federal or state law. In jurisdictions with minimum wage rates higher than those provided under federal or state law, the earnings must be at least equal to the legally established local minimum wage.
2. **Integration** — A setting found in the community, where a person interacts with employees and others who are not persons with disabilities to the same extent that employees without disabilities interact in the work unit and work site:

- a. Community rehabilitation programs specifically established for the purpose of employing individuals with disabilities (e.g., sheltered workshops) do not constitute integrated settings because these settings are not typically found in the competitive labor market.
 - b. The requirement for interaction is applicable regardless of whether the individual with a disability is an employee of the work site or a community rehabilitation program hires the individual with a disability under a service contract for that work site.
3. Advancement — The employee with a disability must be provided the same opportunities for advancement as employees without disabilities in similar positions.

Most important, WIOA significantly expands states' commitment to ensuring that students and youth seeking to transition to higher education or employment are provided the services and supports that have proven critical to postsecondary success. It does this in part by requiring that at least 15 percent of each state's vocational rehabilitation allocation be used in support of students and youth under the age of 24. At the April 2015 meeting of Rehabilitation Council, it was estimated that the amount to be spent on transition services by DARS would be at least \$29.4 million for DRS and \$7.25 million for DBS.

WIOA authorizes the provision of five specific pre-employment services that are to be delivered in preparing students and certain youth for transition:

1. Job exploration counseling;
2. Work based learning experiences;
3. Counseling on opportunities for higher education;
4. Workplace readiness training; and
5. Self-advocacy, self-determination, and peer mentoring.

Through proposed regulations at 34 CFR Part 397, WIOA establishes that the VR program can provide pre-employment transition services to any student with a disability who needs these services, **regardless of whether the student has applied for or been determined eligible for VR services**. In the same way, the VR agency can provide transition services to groups of youth with disabilities, **regardless of whether they have applied for or been determined eligible for services**.

If either a student or youth with a disability requires more intensive services, he or she would apply for VR services. Once determined eligible, an individualized plan for employment would be developed, which would outline the specific services that he or she may need in order to achieve the desired employment outcome.

In this way, the VR program can provide a range of services, from most basic to the most individualized and intensive service, to better meet the evolving needs of a student or a youth with a disability who is transitioning from school to post-school life.

For students and youth who need more intensive services, the following are required to be made available:

- Assessment for determining eligibility and priority for services by qualified personnel, including, if appropriate, an assessment by personnel skilled in rehabilitation technology.
- Vocational rehabilitation assessment by qualified personnel, including, if appropriate, an assessment by personnel skilled in rehabilitation technology.
- Vocational rehabilitation counseling and guidance, including information and support services to assist an individual in exercising informed choice.
- Referral and other services necessary to assist applicants and eligible individuals to secure services from other agencies and advise those individuals about client assistance programs.
- Physical and mental restoration services, to the extent that financial support is not readily available from a source other than TWC (such as health insurance or a comparable service or benefit).
- Vocational and other training services, including personal and vocational adjustment training, advanced training in a field of science, technology, engineering, or mathematics (including computer science), medicine, law, or business; books, tools, and other training materials. The only exception is that no training in an institution of higher education (universities, colleges, community or junior colleges, vocational schools, technical institutes, or hospital schools of nursing or any other postsecondary education institution) may be paid for unless maximum efforts have been made by TWC and the individual to secure grant assistance from other sources to pay for that training.

A key facet of the law places new obligations on vocational rehabilitation agencies to ensure that students and youth are not placed in sheltered workshops or other segregated, subminimum wage settings. Individuals age 24 or younger may not begin work that pays subminimum wages unless the individual has completed, and documentation indicates completion of, pre-employment transition services or transition services under IDEA, and an application for VR services.

A student or youth who has not been found ineligible for services, or has been determined eligible for VR services but has not been successful, must have been provided career counseling and information and referral to other appropriate resources for services designed to assist the individual in attaining competitive integrated employment.

Furthermore, entities holding 14(c) certificates may not continue to employ an individual at subminimum wage, **regardless of age**, unless the individual is:

- Provided career counseling, information, and referrals by the VR agency; and
- Informed by the employer of self-advocacy, self-determination, and peer mentoring training opportunities provided by an entity that does not have a financial interest in the individual's employment outcome (independent school districts can no longer contract with sheltered workshops or other 14(c) certificate holders to accept students).

A significant provision of WIOA is required establishment of a multiagency group at the federal level to develop recommendations and report to the Secretary of Labor regarding issues related to the 14(c) certificate program. The Advisory Committee for Increasing Competitive Integrated Employment for Individuals with Disabilities delivered an interim report to Secretary Thomas Perez on September 1, 2015, with the final report due in September 2016. Many of the committee's recommendations relate to eliminating 14(c) programs and have resulted in federal and nonprofit advocacy, as well as 14(c) certificate holders, providing public testimony at each meeting.

WIOA is a complex piece of legislation that presents new opportunities for agencies to work together to make community life and work the rule, not the exception, for people with disabilities.

The Value of Integrated Competitive Employment

The passage of WIOA is greatly encouraging. Work is a fundamental part of adult life for people with and without disabilities. It provides a sense of purpose, shaping who we are and how we fit into our community. Meaningful work is associated with positive physical and mental health benefits and is a part of building a healthy lifestyle as a contributing member of society. Because it is essential to economic self-sufficiency, as well as self-esteem and well-being, people with disabilities who want to work should be provided the opportunity and support to work competitively within the general workforce. Individually tailored and preference based job development, training, and support should recognize each person's employability and potential contributions to the labor market.

Individuals with disabilities are much less likely to have a job than individuals without disabilities. According to the Census Bureau American Community Survey, in 2014 about 75% of working-age Americans without disabilities were employed, in contrast to only 34% of people with disabilities. Less than 24% of individuals with cognitive disabilities were employed. Data for Texans is similar. Yet, the majority of non-employed people with disabilities would like to be working, and their job preferences are well within the mainstream — 80% said they would like a paid job now or in the future, which is comparable to the 78% of nondisabled, working-age people who are not employed. And like all workers, individuals with disabilities value job security, income, flexibility and chances for advancement and career.

These numbers challenge the idea that the low employment rate of people with disabilities is due to low motivation or job preferences — this data suggests the supply is there. With the coming labor shortages as baby boomers retire; people with disabilities represent a valuable and underutilized resource. Technology advances foster greater ease in integrating workers with disabilities in the workplace.

When individuals with disabilities are provided the appropriate supports to earn competitive wages alongside their non-disabled peers, they are given the opportunity to build wealth and assets, which lead to a higher quality of life and a greater degree of independence. The poverty rates of people with disabilities are much higher than that of the general population. Approximately 34% of people with disabilities live on a household income of less than \$15,000 per year, compared to 12% of people without disabilities. High levels of poverty lead to people with

disabilities being dependent on government funded programs. An Employment First policy that holds individuals with disabilities to the same employment standards and responsibilities of any working-age adult can help individuals with disabilities be independent in the community, build assets, reduce dependence on public funds and services, and avoid the costs associated with current programs.

Data from the National Core Indicators Project suggest that only 14.7% of working age adults supported by state I/DD agencies participated in integrated employment. Community rehabilitation providers (CRPs) reported that only 27% of individuals with I/DD supported by their organization worked in integrated jobs, including both individual jobs and group supported employment. Those who are employed typically work limited hours with low wages. At the same time, participation in facility-based and non-work services has grown, suggesting that employment services remain an add-on rather than a systemic change.

Purchasing from Persons with Disabilities Advisory Committee (PPDAC)

At the state level, the abolition of the Texas Council for Purchasing from Persons with Disabilities, and the transfer of responsibilities to the Texas Workforce Commission, signals public recognition of the need for closer scrutiny and evaluation of the “State Use Program.” Under state law, governmental entities at state and local levels and well as certain others, can elect to forego bidding out contracts for goods and services by purchasing them directly from State Use Program providers. The providers employ thousands of people with disabilities, and with the exception of providers whose employees are blind, generally pay workers pennies on the dollar using 14(c) certificates. The group that manages this process charges a 6 percent fee on all sales, amounting to an annual income of well over one million dollars.

Part of TWC’s responsibilities has involved the appointment of members to the newly formed Purchasing from People with Disabilities Advisory Committee (PPDAC). The committee is charged with the development of performance standards for community rehabilitation programs, a large number of which currently hold special certificates and employ people with disabilities for subminimum wages.

Currently there are 116 certificate programs in Texas, employing more than 9,950 people at subminimum wages. Of these, at least 350 are working on federal contracts. TCDD is one of two VR advocates represented on the PPDAC and recently invited the director of the Department of Labor’s San Antonio Regional Office of Federal Contract Compliance Programs (OFCCP) to address the committee. OFCCP is responsible with enforcing Section 504 of the Rehabilitation Act, which prohibits discrimination against people with disabilities by federal contractors.

During the 2015 Texas Legislative Session a bill was introduced that would have set out timelines for the elimination of 14(c) programs from participation in the State Use Program. TCDD staff continue to respond to related legislative inquiries as part of its advocacy for Employment First and competitive integrated employment for all people with disabilities. Legislation likely will be reintroduced during the 2015 Texas Legislative Session.

Texas Workforce Investment Council (TWIC)

TCDD reviewed and commented on the TWIC state plan, leading to clarification in several portions of text that “employment” is “competitive integrated employment.” TWIC is the designated state agency for implementing WIOA in Texas (February TCDD Binder).

Day Habilitation Services

Earning a living wage through competitive employment in the general workforce is the priority and preferred outcome for working-age individuals with disabilities who receive public benefits. Texas is a long way from reaching this goal for people with disabilities and some Texans may choose not to work.

Day habilitation facilities provide services in a group setting during weekday work hours and are offered to DADS clients through community-based I/DD waiver and intermediate care facility programs. Day habilitation services are designed to help individuals make connections within their communities. Texas and other states developed day habilitation programs, work activities centers and sheltered workshops recognizing the need to have viable day program options for individuals with I/DD. While these programs were developed to meet real needs, these services are not inclusive and as currently designed, isolate individuals from meaningful involvement in community activities.

In fiscal year 2013, Texas spent more than \$96 million on day habilitation services. DADS requires program providers to ensure their subcontractors, including day habilitation facilities, provide safe and adequate services. However, these requirements vary across programs, and contracts between facility owners and providers are not required to include basic quality and safety measures.

Despite rising use of these facilities, DADS only recently has started to collect basic information on how many of its clients attend day habilitation, where the facilities are located, or problems at these facilities. Directing providers to include basic requirements in day habilitation contracts may improve services and add a layer of protection for clients who attend the facilities; however, it is important to note that some long-term services and supports providers also operate day habilitation facilities. Thus, the improvement would be minimal if a provider is put in a position to hold itself accountable to contract requirements. Tracking day habilitation information would allow the agency to identify trends and problems at these facilities and help its clients and providers choose a day habilitation facility.

Employment Assistance and Supported Employment Verses Day Habilitation

Employment Assistance (EA) is a service that helps people “obtain” competitive, integrated employment.

Supported Employment (SE) is a service that helps people “maintain” competitive, integrated employment.

Day habilitation (DH) is defined as a facility-based service provided in a group setting during weekday work hours.

In 2013, SB 45 defined these services in law and required them to be offered in all Medicaid community-based waivers. These programs include case management/service coordination, services specifically designed to assist people to be employed, and to get other services to help them meet their goals. The tables below demonstrate that although people want to work, competitive employment is not a goal reflected on service plans.

Table 1 — Supported Employment Utilization by Waiver FY 2015

Waiver	Total People in Waiver	Number of People Approved for SE	Percent of People Approved for SE	Number of People Received SE	Percent of People Received SE
CLASS	5,169	10	0.2%	7	0.14%
DBMD	249	1	0.4%	0	0.0%
HCS	24,778	596	2.4%	420	1.7%
MDCP	6,423	0	0.0%	0	0.0%
TxHmL	8,157	211	2.6%	128	1.6%
Grand Totals	44,776	818	1.83%	555	1.24%

Table 2 — Employment Assistance Utilization by Waiver FY 2015

Waiver	Total People in Waiver	Number of People Approved for EA	Percent of People Approved for EA	Number of People Received EA	Percent of People Received EA
CLASS	5,169	3	0.06%	2	0.04%
DBMD	249	0	0.0%	0	0.0%
HCS	24,778	221	0.9%	109	0.4%
MDCP	6,423	0	0.0%	0	0.0%
TxHmL	8,157	198	2.4%	83	1.0%
Grand Totals	44,776	422	0.94%	194	0.43%

Although individuals are not required to include DH on their service plans, Medicaid community-based waiver participants' service plans typically include day habilitation (57%). Services offered in DH vary, but may include recreational activity, specialized therapy, and life skills training. It is widely accepted that DH programs require remediation for compliance with the HCBS Settings Rule.

Many DH programs are segregated, involve repetitive tasks rather than skill building activities or employment goals, and some are co-located with sheltered workshops where some workers are paid below minimum wage.

Table 3 — Day Habilitation Utilization by Waiver FY 2015

Waiver	Total People in Waiver	Number of People Approved for DH	Percent of People Approved for DH	Number of People Received DH	Percent of People Received DH
CLASS	5,169	322	6.2%	282	5.6%
DBMD	249	29	11.6%	27	10.8%
HCS	24,778	19,848	80.1%	18,182	73.4%
TxHmL	8,157	4,327	53.0%	3,509	43.0%
GRAND TOTALS	38,353	24,526	63.9%	22,000	57.4%

Texas Employment First Task Force has begun discussions about system improvements, but without sustained agency commitment and effort, some are concerned that their work will stall. Best practices to consider include Oregon state agencies who strengthened collaboration by entering into a Memorandum of Understanding to support transitioning students with disabilities to enter the workforce. They were able to leverage new funding as well as sequence existing funding strategies to support their efforts. The MOU addressed reporting by streamlining agency data collection and making it available to stakeholders. Other states, like Vermont and New Hampshire, have also reduced duplication of effort by implementing effective strategies and partnerships to efficiently coordinate resources.

Recommended Actions for System Improvement

- Expect that employment is the first and preferred option provided to working age adults who receive public benefits.
- Designate employment supports as the primary method of funding state-financed day services.
- Initiate day activity plans before high school graduation by offering comprehensive transition programs that give students credit for working in the community within multiple work settings to explore interests and skills.
- Modify reimbursement methodologies because the current allocation supports segregated day options.
- Prohibit the co-location of sheltered workshops and day habilitation facilities.
- Ensure waiver participants know they may choose or decline to include day habilitation on their individual plans of care.
- Assist employed persons who receive SSI to implement work incentives to exclude money, resources, and certain expenses from total earned income.

Transition: Keeping Parents Involved in ARD Meetings

Transition: How to Keep Your Parents Involved in Your ARD Meetings

When students who receive special education services turn 18 years old, their parents are no longer automatically included in the students' Admission, Review, and Dismissal (ARD) committee meetings. However, students may still want their parents to be involved in the ARD committee meetings and decisions about their education. Multiple alternatives can enable parents to stay involved in their child's educational decisions **without placing the student under guardianship**.

ARDs Before & After Turning 18

During transition, a student with a disability participates in activities designed to help them achieve their postsecondary goals, like going to college or getting a job. State and federal law require formal transition to begin when a student turns 14 years old. While in transition, a student learns self-advocacy and self-determination skills, and in some cases, may even lead the ARD committee meeting.

Until the student turns 18, the student's parents must be included in every ARD committee meeting and are considered members of the ARD committee. In that role, parents participate with teachers, administrators, and other school personnel in making decisions about the student's education. While parents are not the sole decision makers about their child's education, they are active and equal participants in the ARD committee's decisions.

However, when a student turns 18, he or she is legally an adult. As an adult, the student automatically becomes the educational decision maker in ARD committee meetings, regardless of disability or level of need. Under the law, all adults have the capacity for decision-making, including students who receive special education services.

Also, when the student turns 18, parents are no longer considered members of the ARD committee and the rights of the parents in the ARD process transfer to the student. At this point, the student and the parent will each receive notices about ARD committee meetings from the school (as required by Texas Administrative Code §89.1049(a) and IDEA, Part B). It is important to understand that ARD committee meeting notices are not an invitation for the parent to attend or participate in the meeting, or to make decisions about the student's education.

Inviting Parents to ARDs

The adult student or the school can invite parents to attend an ARD committee meeting.

If the student invites the parent, a formal invitation is not required. The parents should tell the school if they plan on attending. However, being invited to attend does not automatically make the parents decision makers. Parents may continue to be involved in educational decisions only with the student's permission.

Some students may not want to invite parents to the ARD committee meeting, but the parents may ask the school for an invitation. Many schools see the benefit of continued parental participation in the meetings and may invite the parents to attend the meeting even if the student is opposed.

Official Involvement without Guardianship

Some adult students may choose to make parental involvement in educational decisions official. There are a number of ways to do this that do not require placing the student under guardianship. Two of the simplest ways are by using a supported decision-making agreement or an educational power of attorney:

1. **Supported Decision-Making Agreement** — The student can invite the parent (or another person the student chooses) to enter into a supported decision-making agreement. The agreement allows the parent/person to be included in educational planning meetings and help the student understand the information necessary for the student to make his or her own decisions. The parent or other person does not make decisions for the student. A supported decision-making agreement is a legally valid document and it does not require an attorney or a trip to a courthouse. At the time it is signed, it also must be signed by two other people as witnesses or it can be signed in the presence of a notary public (notarized).
2. **Educational Power of Attorney** — An educational power of attorney is a legal document signed by the student that allows the student's parent or guardian to be included in all educational planning activities and communications without violating privacy laws. This is a good fit for students who can express their desire to have their parents continue to make educational decisions for them. Some schools can provide an educational power of attorney form and/or a parent can consult an attorney to access legal services. Like other types of powers of attorney, the educational power of attorney must be witnessed or notarized when signed.

These are just two of the options available for a parent to continue to be involved in educational decisions that can affect an adult student who receives special education services. Even though some guardianships are initiated when a student turns 18, a guardianship is not required to keep a parent involved in ARD committee meetings. Under the law, the alternatives described above – and others – must be considered before guardianship. The Texas Estates Code requires evidence that all less-restrictive alternatives, as well as supports and services, have been evaluated before guardianship is considered.

UPDATE: AUTISM SERVICES IN TEXAS

Autism Basics

The autism services system is expected to be addressed by the 85th Texas Legislature that convenes on January 17, 2016. A more comprehensive state strategy is evolving to meet the needs of increasing numbers of Texans diagnosed with autism. The most commonly cited estimate is that 1 in 68 children has an autism spectrum disorder (ASD), up from 1 in 88 in 2008. Some recent estimates place the incidence as high as 1 in 45. Males are diagnosed with autism four times more frequently than females. A genetic link has been established in some cases.

Many explanations are given about why there seems to be more ASD now than ever: Some of the increase is attributed to improved methods of assessment, to changes in diagnostic guidelines, and to greater public and professional awareness.

“Autism spectrum disorder” comprises a wide range of symptoms and levels of severity. People with autism are not all the same and their needs are not the same. Individuals diagnosed on the autism spectrum range from being gifted to having severe disabilities or being nonverbal.

Autism is a developmental disability in which the core diagnostic markers are behavioral: (1) impaired social interaction and communication, and (2) repetitive behavior and restricted interests. Because of this diagnostic emphasis, symptoms related to physical comorbidities, mental disorders, and the effects of trauma can sometimes be misunderstood as behavioral in nature.

Focusing exclusively on behavior does not take into account considerations such as level of language and intellectual disability and the presence of medical conditions which themselves affect the way a person behaves. Frequently co-occurring conditions include epilepsy or other seizures; immune conditions; sleep disorders; psychiatric disorders, such as anxiety and/or depression; gastrointestinal problems; food intolerance and other nutritional issues; and allergies.

People with ASD must have access to services and supports for the whole person, not just behaviors. Symptoms of physical illness, disorder, or pain may not receive appropriate or timely medical intervention when understood as behavioral problems. Significant variations in a person’s behavior require a medical (or dental) evaluation (e.g., earache? toothache? other acute pain? evidence of physical or emotional trauma?) before concluding behavior is the result of ASD, especially when expressive communication deficits are present. There is no “one size fits all” in providing treatment and support services.

The same is true of psychiatric disorders: When an individual’s behavior changes dramatically, and physical disorder and pain are ruled out, an assessment of whether there is an underlying mental disorder is required. Estimates are that as many as 60-70 percent of people with autism have one or more co-occurring psychiatric disorders. For example, 65% of people with Asperger’s syndrome also have anxiety and depression, compared with 18% of the general population.

Most important, when a person has ASD, normal responses to physical or psychological trauma may result in behaviors that are misunderstood and that lead to behavioral interventions that make the underlying trauma worse.

Current Autism Services in Texas

Statewide planning for autism services in Texas is challenging. The existing patchwork of services does not meet the known demand.

For Medicaid-eligible children, the Early Periodic Screening, Diagnosis, and Treatment Program (EPSDT) provides a broad array of services, including physician services, private duty nursing services, personal care services, home health services, rehabilitative services, and medical equipment and supplies. Access to these services terminates when a child turns 21.

Some services are available to adults and children in Medicaid residential treatment programs and some waiver programs. For people who are not Medicaid eligible, most private insurance covers a portion of the cost of care. (Self-insured programs, such as insurance for state employees, are not required to cover autism.)

The only state-funded autism program is operated by the Department of Assistive and Rehabilitative Services (DARS). It charges a prorated copay and provides one type of therapy only, applied behavior analysis. This popular form of evidence-based therapy is favored by parents and teachers because it focuses exclusively on modifying children's behaviors that interfere with learning and community inclusion. However, unlike other state programs, it operates in the absence of federal oversight. Currently it does not prohibit the use of aversives or techniques causing pain or discomfort, nor does it currently fully inform adults and parents of children with autism of their rights under federal and state disability laws. Other issues involve provision of services by staff who may not be adequately trained or supervised.

During the 84th Texas Legislature, appropriations for the DARS autism program and related efforts were increased more than fourfold, to total more than \$24 million. DARS was appropriated \$14.4 million to expand applied behavior analysis services to serve 1,970 children (up from 295 children in 2014). The Texas Higher Education Coordinating Board (THECB) was given \$8.1 million to reach children with autism indirectly through grants for training their parents, teachers, and paraprofessionals in ABA techniques. An additional \$1.4 million was appropriated for research, development, and evaluation of innovative treatment models, with \$300,000 for administration.

Initiatives to Change the Shape of Autism Services in Texas

Licensure of Board Certified Behavior Analysts (BCBAs)

During the 84th Texas Legislature, Senate Bill 1871 was introduced to create a state license for BCBAs. The bill would have allowed BCBAs to more easily bill Medicaid and also to bill for work done by people that BCBAs supervise. It was hoped that state licensure would increase the numbers of BCBAs in Texas and discourage those who are unqualified from practicing unapproved methods.

The proposed qualifications for licensure, which were wholly based on the certification standards of the national Behavior Analyst Certification Board, did not require the same levels of training, experience, and supervision as similar licensed professions in Texas, such as social work and professional counselling.

The bill did not pass but is likely to be reintroduced in the 85th Texas Legislative Session that convenes January 10, 2017. The Children's Policy Council is considering a recommendation that BCBA licensure qualifications more closely align with similar licensed professions in Texas.

State Plan Amendment (SPA)

The federal government has been active in shaping state autism policy for children with respect to scope of services. It has repeatedly directed states to broaden the array of Medicaid services and supports available to meet each individual's need.

In July 2014, the Centers for Medicaid and Medicare Services (CMS) issued guidance that ABA services could be made available but that they are not the only evidence-based services that should be made available. It instructed states to make all covered services under the Social Security Act available to meet each Medicaid-eligible child's individual needs, including ESPDT services (previously noted); vision, hearing, and dental services; and speech, occupational, and physical therapy services.

ASD treatment is not specifically referenced as a covered service under the Social Security Act, but many treatment modalities are within the scope of the Medicaid program under service categories such as other licensed practitioners, preventive services, and therapies. Services to address ASD can be provided in each of these categories.

Although stopping short of requiring states to put in place a state plan amendment (SPA), CMS stated that a SPA **“is strongly encouraged to articulate the state's menu of services for ASD treatment.”** A menu of available services would be helpful not only to the person seeking services, but also to physicians and other health professionals who need to understand available options for care and treatment.

The issue of the role of applied behavior analysis as a treatment strategy was raised again in July 2015 by the US Department of Education (DOE). DOE issued a letter noting that the Office of Special Education Programs (OSEP) had received reports that a growing number of children with ASD were not receiving needed speech and language services. Further, it noted that when identifying special education services for children with ASD, programs were including applied behavior analysis (ABA) therapists exclusively without including, or considering input from, speech language pathologists and other professionals who provide different types of specific therapies that may be appropriate.

In 2015, Texas Medicaid officials began working on a state plan amendment to make services like those available to children enrolled in EPSDT available on a statewide basis to Medicaid-eligible adults. The plan would be inclusive and broad enough to respond to the needs of children

transitioning to adulthood and requiring different services at that time and later. A state plan amendment will greatly increase the numbers of Texans with ASD who receive services.

During the transformation and reorganization of health and human services agencies that was required by the 84th Texas Legislature, work on the state plan amendment slowed. The Children’s Policy Council is considering a recommendation to the Health and Human Services Commission to take up this important initiative again. Legislative direction may be required.

The Takeaway

- ➔ Autism services should be made available to everyone who needs them.
- ➔ Early assessment and intervention are critical but needs change over time. It is important that services available to children continue in the transition to adulthood and later.
- ➔ The scope of available services should be sufficient to ensure that individual needs are met on an ongoing basis.
- ➔ Treatment and support needs range across clinical (medical), educational, and behavioral spheres. People with ASD must have access to services and supports that treat the whole person, not just behaviors.
- ➔ When receiving services and supports, people with autism are protected by the same laws and have the same rights as other people with developmental disabilities. These protections need to be reflected in all federal and state-funded services for people with autism.

Resources

- ➔ “Autism: Caring for Children with Autism Spectrum Disorders—A Resource Toolkit for Clinicians,” American Academy of Pediatrics (first 3 chapters free to download) www.aap.org/autism
- ➔ Centers for Disease Control, www.cdc.gov/ncbddd/autism/index.html
- ➔ National Institute of Mental Health, www.nimh.nih.gov/
- ➔ Eunice Kennedy Shriver National Institute of Child Health and Human Development, www.nichd.nih.gov/Pages/index.aspx
- ➔ Texas Autism Research and Resource Center (TARRC), www.dars.state.tx.us/tarrc/index.html
- ➔ HHS Autism Information (federal), <http://www.hhs.gov/programs/topic-sites/autism/index.html#>
- ➔ “Texas Register,” Title 40. Social Services and Assistance, Part 2. Department of Assistive and Rehabilitative Services, Chapter 105, Autism Program, 40 TexReg 9307-9315, December 18, 2015 www.sos.state.tx.us/texreg/pdf/backview/1218/1218adop.pdf



promoting progressive public policy for Texans with disabilities

Email: HHS_Transformation@hhsc.state.tx.us

April 15, 2016

Re: HHS Rules Process

To Whom It May Concern:

Thank you for addressing the accessibility of HHSC's rulemaking process to the public and other stakeholders. This is especially important given the consolidation and reorganization of health and human services functions, including the centralization of policy- and decision-making, and the changing role of public advisory committees in guiding those processes.

Texas Disability Policy Consortium (DPC) is an independent group of disability advocacy organizations committed to promoting the rights, inclusion, integration and independence of Texans with disabilities. DPC is made up of 21 members of statewide and local disability organizations. The Consortium provides an ongoing forum for analysis and discussion on important disability issues in Texas. Consortium members may take independent positions, as appropriate, on specific policies as they develop. DPC has a longstanding interest and priority supporting meaningful input by individuals with disabilities regarding how services are designed: "Nothing about us without us."

Rulemaking is often regarded by staff as a pro forma exercise. The reality is that rulemaking can be a powerful public relations tool through which an agency can engage its most interested stakeholders in working together toward a common cause. These stakeholders include employees. The approach an agency takes to rulemaking can strengthen an agency's public profile and can also lend stability to its internal landscape. This is especially true in times of transformation.

The extent to which the rulemaking processes of HHSC are transparent and accessible will facilitate its productive and timely transition. Clearly articulated policies and procedures governing rulemaking will benefit not only the public at large, but also HHSC employees who are charged with implementing and monitoring rules. **To help achieve that goal, DPC strongly recommends that HHSC convene a broad-based stakeholder group to provide advice concerning the design of its agency-wide rulemaking system.**

In response to HHSC's request for stakeholder input, the following balanced analysis and technical recommendations on behalf of the Disability Policy Consortium are based on provisions of the Government Code as well as our combined experiences as human services professionals and advocates:

1. **HHSC Proposal** — Establish an informal period during which draft rules are made available to stakeholders for review and comment prior to Executive Council meetings and posting of proposed rules in the “Texas Register.” This informal review period should allow sufficient time for staff to respond to stakeholders. The informal review period can consist of face to face or electronic communications between agency staff and stakeholders. Programs may also choose to solicit feedback from stakeholders prior to drafting rules:
 - a. Programs should be **encouraged**, and **required in most circumstances**, to solicit feedback from stakeholders prior to drafting rules. After a rule is drafted, the conceptual framework is set and very difficult to change except in relatively perfunctory ways. Understanding issues that prompt consideration of rule changes should be discussed with stakeholders prior to initial drafting in order to glean full knowledge of creative options that may already exist or could be developed. Information and opinions on rules that directly affect the quality of life of people receiving services merit discussion with stakeholders prior to rule drafting except in very limited emergency situations;
 - b. Given the range in education and experience of individuals leading rulemaking activities, some formalization of the consideration of pre-draft stakeholder input needs to occur in the form of an agency-wide policy. Formal training may also be needed;
 - c. In reviewing and responding to stakeholder input on draft rules, the same level of professionalism and attention needs to be paid to formulating a response to commenters as is taken in responding to comments on rule proposals;
 - d. Ideally, the formulation of rules should involve stakeholders representing a balanced range of legitimate interests **at the table** as rules are being developed;
 - e. Rules generally apply statewide and greater effort is needed to involve people who are not located in or near Austin in rulemaking processes. Consider using webinars for rules development and remote livestream to accept public comments. This will enable greater statewide participation, including rural areas.
2. **HHSC Proposal** — Modify the existing rules web page on the HHSC website to allow stakeholders to view draft rules and submit comments electronically. The web page may also contain a continuously updated list of rules that are in the drafting stage, so that stakeholders will be aware of draft rules to be posted for review at a later date:
 - a. Maintain public listing of stakeholders for each subchapter that is continuously (and automatically) updated so that they can be personally notified of impending changes to rules in which they have expressed interest. Any person or organization who requests placement on the list will be placed on the list with no further qualification required. The request can be made online, by mail, or by phone call;

- b. Continue to maintain a continuously updated online public index of all subchapters as required by the APTRA. The list should be formatted so that it can be printed out. Subchapter titles should link to subchapter content in the Texas Administrative Code;
 - c. Continue and expand broad use of govdelivery.com to provide notices of rule or policy development at each stage;
 - d. The public index of subchapters should include:
 - i. The effective date of the current subchapter, if applicable (new subchapters would not have effective dates);
 - ii. Whether the subchapter is currently being initiated, amended, or repealed;
 - iii. The stage of modification:
 - 1. Preliminary drafting;
 - 2. Proposal, indicating the date and page reference in the “Texas Register,” and a link to the content;
 - 3. If a public hearing is being held, the date, time, and place of the hearing;
 - 4. If recently adopted, the date and page reference in the “Texas Register,” with a link to the content.
 - iv. If a pending action is in response to federal or state legislation, a notation of the statutory reference(s) and link to the pertinent law(s);
 - v. If a pending action supports access to services in the most integrated setting;
 - vi. The name, office, and phone number of a contact for programmatic questions;
 - vii. The name, office, and phone number of a contact for legal questions.
 - e. Internal policies, procedural guidelines, handbooks, and manuals should also be listed, available online, and up-to-date. Rules should be cross-linked to these documents so that HHSC staff as well as external stakeholders can determine when a requirement is an administrative law (a rule) versus an internal procedure;
 - f. Consider developing a way for individuals and employees to easily identify the rules governing programs in which they have an interest, which minimally would provide a keyword search across chapter, subchapter, and rule titles. Given the complexity of how rules are created and titled, it may also be of benefit to provide groupings of rules by service setting, service recipient, or other descriptor that enables individuals to easily identify all pertinent provisions.
3. **HHSC Proposal** — Use agency advisory committees for feedback on rules, during public meetings or through electronic communications. This is not a proposed requirement to take all rules to an advisory committee (unless there is a statutory requirement to do so), but

relevant advisory committees could be identified at the initiation of new rules projects as a valuable sounding board for rules development:

- a. The larger issue is determining whether all relevant stakeholders have been identified and given a reasonable opportunity to provide comments on draft and proposed rules. Even if not statutorily required, advisory committees with responsibilities in an area under consideration for rulemaking should be invited to comment or invited to send a representative to participate in rulemaking activities. Given the change in the role of most advisory committees away from decision making, advisory committee recommendations that are made generally are not required to be followed but should be invited and considered in the course of normal business.
4. **HHSC Proposal** — Allow public testimony on rules at meetings of the new HHS Executive Council, as established under Government Code Section 531.0051:
- a. A pragmatic way to meet this requirement is needed. The volume of rulemaking by HHSC exceeds the capacity of the Executive Council to entertain comment on all rules being proposed and/or adopted;
 - b. One way to provide a public forum for stakeholders to deliver public comments is through public hearings. These hearings can be transcribed by court reporters for accuracy and the comments can be summarized by staff. Hearings regarding rules that directly affect the quality of life of people receiving services need to be routinely held **without requiring a request to do so**. Certainly issues in controversy should allow for the broadest public participation and a public hearing provides this opportunity;
 - c. Public comments should be taken on each agenda action item prior to the vote on the action and informational items that are considered emergency should be kept to a minimum so that assigned advisory committees and the public have a meaningful role in rulemaking.
5. **Other considerations:**
- a. The hallmarks of quality rulemaking are not limited to the legal requirements contained in APTRA. The responsibilities of HHSC are sufficiently broad, and the numbers of programmatic and legal staff sufficiently varied, that some common ground agency-wide needs to be found for how rulemaking is to meet minimum standards as being both rational and responsive to stakeholder interests and concerns. For example, in responding to public comment, both informally and especially in the “Texas Register,” HHSC should require all programs to specify the reason(s) why a suggested change is or is not being accepted;
 - b. Agency-wide procedures are needed to make rules **and related documents** easily retrievable. For example, rule requirements found in policies (such as State Supported Living Center facility policies), procedures, standards, etc., as well as

letters of interpretation, should be indexed, updated, and made available in the same way that rules are made available. HHSC should develop criteria that staff can use to determine when policies and procedures are internal versus public, i.e., affecting private rights and procedures and requiring rulemaking. These suggestions are for the benefit of both the public and staff. We urge formal rulemaking for facilities such as SSLCs rather than “facility policies;”

- c. To the extent that the decisions that HHSC makes about its rulemaking processes affect private rights and interests, those decisions should be reflected in rules about how HHSC makes rules.

These recommendations are not comprehensive but provide a measure of the importance that rulemaking holds for public entities and are intended to help HHSC develop and maintain its profile as a publicly accountable and responsive agency. Attention to details of process and content like these will save employees, stakeholders, and the general public time and confusion. Now is the time to provide a groundwork for transparent, productive interaction around issues that directly affect the lives of Texans who both deliver and receive health and human services.

We look forward to continuing as external stakeholders in partnership with the health and human services system throughout the decision making process to create informed and effective policies.

For additional information, please contact:

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Texas Council for Developmental Disabilities

The mission of the Texas Council for Developmental Disabilities is to create change so that all people with disabilities are fully included in their communities and exercise control over their own lives.

2015 Public Policy Priorities

Long Term Services and Supports:

Improve the system of long-term services and supports to ensure the availability, timeliness and quality of community-based services and supports for individuals with developmental disabilities throughout the lifespan with an emphasis on providing services in integrated, community settings thereby reducing reliance on the need for institutional services.

Employment:

Improve the system of employment services and income supports for individuals with developmental disabilities, including programs that help individuals develop assets and resources and help students with disabilities transition from school to work, by maximizing federal opportunities.

Education:

Protect the right of students with disabilities to an appropriate, inclusive, publicly-funded education that provides preparation for life's transitions, supports opportunities for full participation and eliminates the use of inappropriate disciplinary alternatives throughout the educational spectrum — from early education programs to post-secondary schooling.

Guardianship Reform and Supported Decision Making:

Protect and promote the civil rights and well-being of people with developmental disabilities by improving access to alternatives to guardianship and advancing protections and rights for those for whom guardianship is found to be the least restrictive alternative.