

Background:

A. State Policy Issues

TCDD staff will provide an update regarding recent public policy activities.

Discussion topics include:

- Day Habilitation and Community Based Standards (HCBS) Rules
- Autism Program Comments
- Acute Therapy Policies

B. Update on State Supported Living Centers

The Committee will receive updated State Supported Living Center data.

C. Federal Policy Issues

TCDD Public Policy staff will provide an overview of the status and implementation of various federal legislative initiatives that impact people with disabilities.

Discussion topics include:

- Continuing Resolution on Budget
- Keeping All Students Safe Act (KASSA)
- Transitioning to Integrated and Meaningful Employment (TIME) Act

<p><u>Public Policy Committee</u></p> <p><u>Agenda Item 9.</u></p>	<p><u>Expected Action:</u></p> <p>The Committee will receive updates on these items and may make recommendations for consideration by the Council.</p>
<p><u>Council</u></p> <p><u>Agenda Item 14. A.</u></p>	<p><u>Expected Action:</u></p> <p>The Council will receive reports from the Public Policy Committee and consider any recommendations offered from the Committee.</p>

Daytime Terminology

Daytime terms are frequently misunderstood, misused, and evolving. The definition of terms associated with day activities are featured below to spark conversation between self-advocates, decision-makers, service providers, and communities.



social interaction: Although social interaction, inclusion, and participation are used interchangeably, they are different in nature. People with IDD identify six themes critical to social interaction: **1** being accepted as an individual beyond the disability **2** having significant and reciprocal personal relationships **3** being involved in activities **4** having appropriate living accommodations **5** having employment **6** receiving formal and informal supports.



engagement: **1** A positive connection with a role and the role's related activities that motivate and energize individuals. **2** highly focused on the activities associated with a role to the point where other thoughts and distractions melt away and a genuine interest in the role is expressed.



peer support: An emotional and practical approach intended to be mutually beneficial and equal with choice, self-help, self-determination, and positivity being the core values.



independent living: The belief that all people have the same rights and responsibilities in society and that services and supports provided to the public should be accessible and available to achieve the most independence possible.



meaningful day: An approach that consistently offers opportunities to participate in age-appropriate, productive activities at home and in the community. It shifts the focus of direct-care work from traditional caretaking or programmatic tasks to being accountable for the extent of engagement and independence individuals with IDD experience from dawn to dusk.



community-based non-work (CBNW): A non-facility-based option where individuals with IDD spend the majority of their

day in community places where most of the people present do not have IDD doing activities such as volunteering, doing errands, going out to eat, and general community exploration.



day habilitation: An optional, but widely used facility-based service provided in a group setting during weekday work hours. Though widely used, waiver participants are not required to include it in their plan. Services vary, but may include recreational activity, specialized therapy, and life skills training.



adult day care: Facility-based care for individuals age 65 or older and individuals with a physical or cognitive disability to relieve primary caregivers of their duties for the day.



employment: An activity performed in which there is a wage earned for services rendered and the services are primarily for the benefit of the employer.



work: An activity done on a personal basis to enable growth and skills development, and improve social interactions by contributing to society.



productivity: Engagement in activities that contribute to a household or community.



sheltered workshop: A segregated workplace with activities that typically involve repetitive tasks. Workers may be paid below minimum wage.



competitive employment: Work performed in an integrated setting that pays at least minimum wage.



supported employment: Work performed in an integrated setting that includes workers making an informed choice and receive individualized supports to learn and keep the job.



customized employment: Work performed in an integrated setting following a process of discovering a worker's skills and interests and negotiating with an employer find or develop the best fitting role. Outcomes include job carving, resource ownership, and self-employment.

Day Habilitation in Texas

Social integration, inclusion, and community participation are among the stated goals of policies that address services used by people with intellectual and developmental disabilities (IDD), but how individuals spend their days continues to challenge decision-makers and service providers. Texas policymakers must examine meaningful day activities not only within the current day habilitation structure, but also in the context of community based non-work opportunities.

Day habilitation is defined as a facility-based service provided in a group setting during weekday work hours. Although individuals are not required to include habilitation on their service plans, Medicaid community-based waiver participants typically do include day habilitation. Services vary, but may include recreational activity, specialized therapy, and life skills training. It is widely accepted that day habilitation programs require remediation. Many are segregated, involve repetitive tasks rather than skill building activities or employment goals, and some are co-located with sheltered workshops where workers are paid below minimum wage.

HCBS Settings Rule

As a result, day habilitation services are being reformed around the nation to raise standards. These changes are outlined in the Medicaid Home and Community Based Services (HCBS) Settings Rule released by the Centers for Medicare and Medicaid Services (CMS) in 2014. The HCBS Settings Rule presents an opportunity for innovative solutions to emerge so that people with disabilities can have increased community engagement and exercise greater control over their own lives.

The HCBS Settings Rule addresses the quality of HCBS long term services and supports and provides additional protections to people that receive services.

In order to be in compliance with the HCBS settings rule services must be:

- Integrated in the greater community, to the same degree of access as individuals not receiving HCBS, including opportunities to:
 - seek employment and work in competitive, integrated settings; and
 - engage in community life;
- Selected by the individual from a variety of setting options, including non-disability specific settings.
- Service settings presumed to be isolating include day habilitation facilities that:
 - serve only people with disabilities;
 - aim to meet all the recipients needs for habilitation services; and
 - impede integration in the larger community.

HCBS Compliance Deadline Approaching

Day habilitation programs in Texas are widely regarded as out of compliance with the HCBS Settings Rule. States were given five years to bring their systems into compliance.

Senate Bill 204 (2015) would have required a stakeholder workgroup to study and make recommendations to improve day habilitation, but the bill failed to pass. In the absence of statutory direction to convene a new stakeholder workgroup to address day habilitation, the Department of Aging and Disability Services is looking to the already established *IDD System Reform Advisory Committee Employment and Day Habilitation Subcommittee* in response to continued recommendations by advocates to include stakeholders in regulatory and programmatic reform..

The Health and Human Services Commission (HHSC) and Department of Aging and Disability Services are also hosting stakeholder forums around the state to provide information on how the HCBS Settings Rule will impact community based services including day habilitation. Sessions will be held in the following locations on the following dates:

- San Antonio, October 22
- Lubbock, October 27
- El Paso, October 29
- Harlingen, November 3
- Fort Worth, November 6
- Tyler, November 9

More details for the meetings are available: <http://www.hhsc.state.tx.us/medicaid/hcbs/index.shtml>

A Time for Action

The HCBS Settings Rule will require a redesign for how day habilitation services are provided in order to bring the state into federal compliance. Waiver participants, providers and service coordinators will likely need to re-imagine meaningful day activities on an individualized basis. This will include discussions of individual choice and person directed practices, provider rates to adequately support waiver participants, defining outcomes and collecting data to monitor accountability at a state level, and creating a realistic and working transition plan with high expectations to achieve true community integration.

Texas is not the only state struggling with how to modernize day habilitation in terms of how individuals participate and the outcomes to be achieved. 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 also 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. Texas Employment First Task Force has begun discussions about system improvements, but without sustained agency commitment and effort, some are concerned that their work could stall.

Recommended Actions for System Improvement

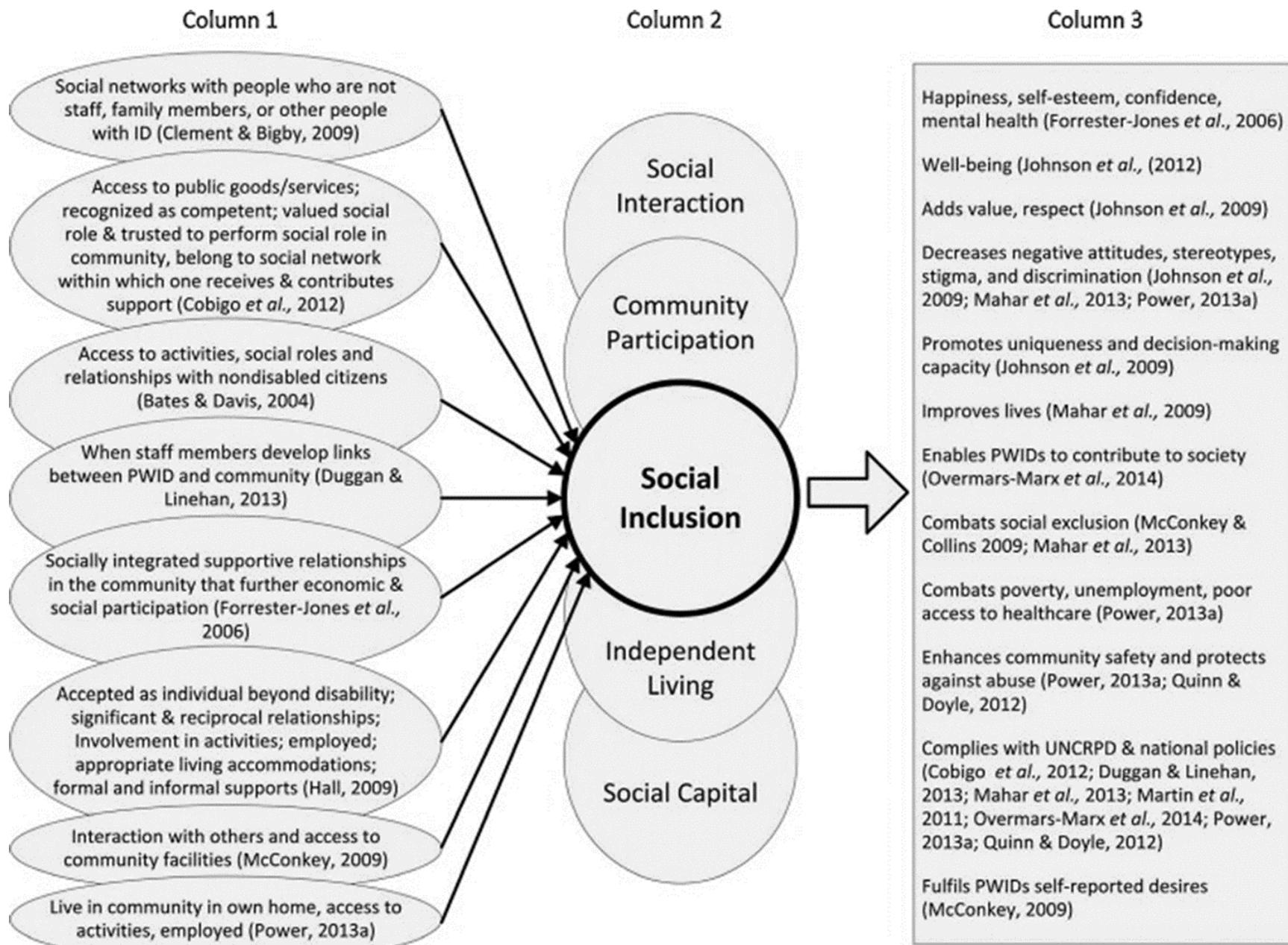
- Modify reimbursement methodologies because the current allocation supports segregated day options and contradicts prevailing service philosophy regarding integration.
- Designate employment supports as the primary method of funding state-financed day services
- Initiate day activity plans before high 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.
- Create basic skills certificate to indicate a person's competitive employment skills and certify qualifications for persons without a high school equivalency diploma.
- Prohibit the co-location of sheltered workshops and day habilitation facilities.
- Expect that the system offers employment as the first and preferred option provided to working age adults who receive public benefits.

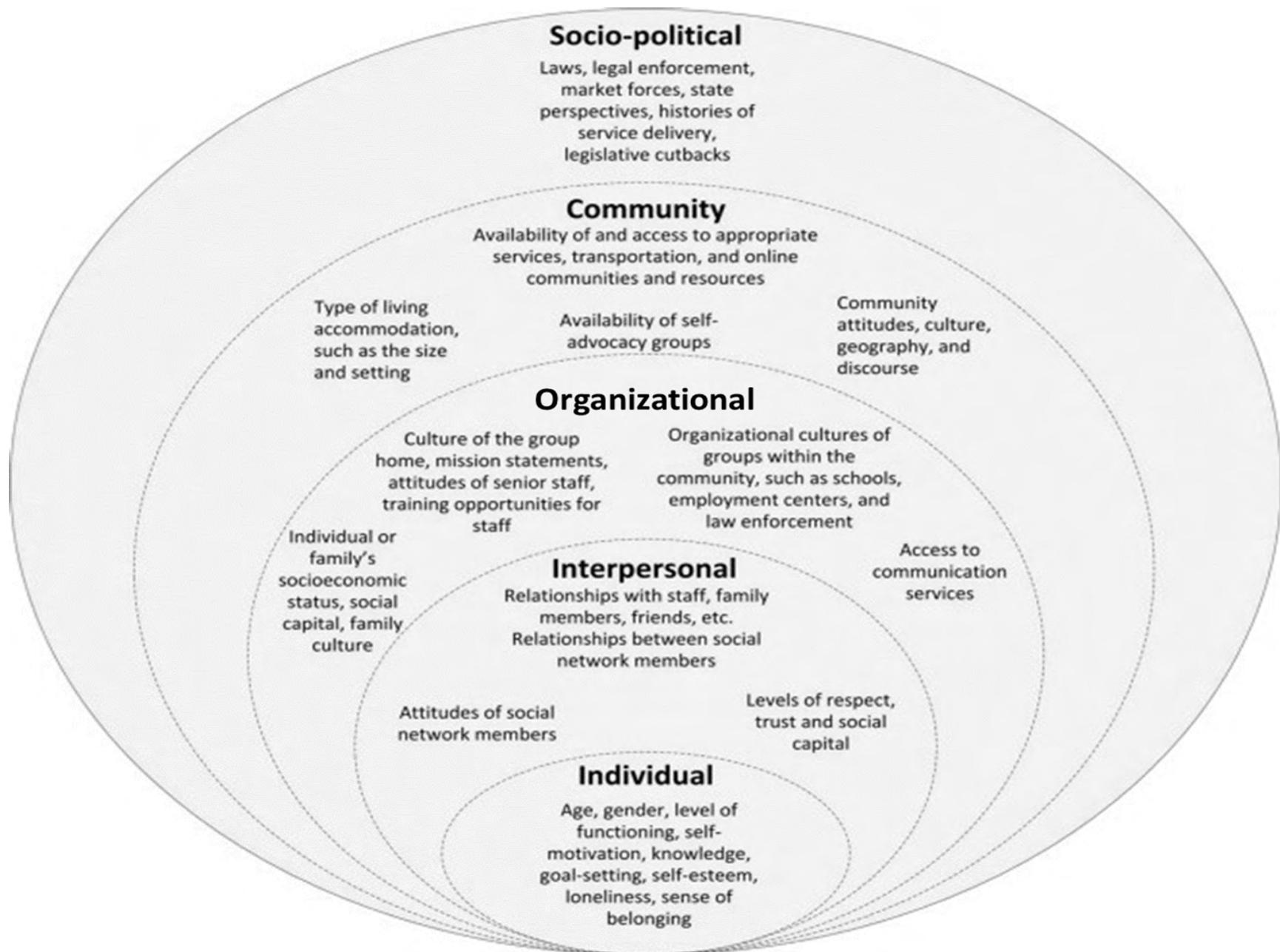
Role of Community-based Non-work

Public policy should focus on eliminating practices that contribute to barriers to the full participation of people with disabilities. By promoting opportunities for people to be engaged in social spaces within their communities, inclusion and productivity can be experienced – not just taught. Successful integration policies must foster meaningful social relationships and build community capacity for systems change. Community-based non-work can offer an opportunity to accomplish just this.

Community-based non-work (CBNW) supports individualization, choice, integration, and independence to individuals in search of meaningful day activities, with the right expectations set. Outcomes must be clear in state policy and provider practice for CBNW to improve the quality of life for people with disabilities. The following are recommended policy expectations for CBNW:

- **Expect employment.**
 - Allow CBNW to supplement employment rather than substitute it.
 - Affirm that if people with disabilities are to be treated as equals in society, then to some extent they should have equal obligations as well-which includes an obligation to contribute to society through working
- **Expect individual choice and life planning.**
 - Emphasize person-centered planning and acknowledge CBNW as simply one aspect of a person's plan to achieve his or her goals and desires in life.
- **Expect that group activities are a matter of choice, not convenience.**
 - Manage program quality by creating CBNW as a separate category of service with clear goals and minimum standards for person directed outcomes.
- **Expect integration and community membership.**
 - Incentivize time spent in integrated spaces that connect people and facilitate quality relationships with a variety of community members without disabilities.
- **Expect the development of strong models of CBNW.**
 - Involve family members, friends, self-advocacy and other peer groups, places of employment, churches, and other community spaces in setting and achieving goals for individualization, integration, choice, and independence.







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September 21, 2015

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Re: Public Comments on Proposed Changes to Rules in the August 21, 2015, *Texas Register*
Texas Administrative Code, Title 40, Part 2, Chapter 105, governing Autism Program

Thank you for the opportunity to provide comments on changes to 40 TAC 105 proposed in the August 21, 2015, issue of the *Texas Register* (40 TexReg 5280-5289). The Texas Council for Developmental Disabilities (TCDD) is established by federal law in the Developmental Disabilities Assistance and Bill of Rights Act and is governed by a 27 member board, appointed by the Governor, 60 percent of whom are individuals with developmental disabilities or family members of individuals with disabilities. TCDD's purpose in law is to encourage policy change so that people with disabilities have opportunities to be fully included in their communities and exercise control over their own lives.

The context for these comments is that, unlike most programs provided through the Department of Assistive and Rehabilitative Services (DARS) and other Texas health and human services programs serving persons with disabilities, the DARS Autism Program is not subject to federal regulation or oversight. Comments on the current proposal take into account unresolved issues raised in public comment on the rules that were adopted one year ago and now in effect, action taken by the 84th Texas Legislature, as well as the reorganization of health and human services agencies.

SUBCHAPTER A. GENERAL RULES

§105.101. Purpose.

The section references "other treatment approaches" but the subsequent sections deal exclusively with applied behavior analysis (ABA). We recommend that the rule define "other treatment approaches" and include them throughout the subchapter or delete the term.

§105.105. Definitions.

(3) Applied behavior analysis (ABA)

Some ABA practitioners use aversive interventions. The definition needs to clearly state that for purposes of the state-funded DARS autism program, ABA relies on positive behavioral interventions and supports and does not include aversive interventions.

This comment was submitted previously by another commenter on the definition of ABA in the rules that are now in effect. The response was that DARS would not prohibit aversive interventions. No explanation was provided (39 TexReg 6681, August 22, 2014).

It is recommended that the DARS Autism Program articulate, explain, and publish for public comment its policy with respect to the use of aversive interventions on children ages 3-15. This potential element of ABA affects the private rights of children with disabilities and their parents (Texas Government Code, §2001.003). Furthermore, a policy that allows aversive interventions or is silent with respect to their use may enable the abridgement of the child's rights under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the Health and Safety Code, Chapter 592.

(28) Treatment plan

The definition has been amended to include "and other" treatment services. Please define these services. The rules currently address only the role of individuals providing ABA. If other services are to be provided, a requirement of collaboration with providers of those services needs to be made here. Otherwise please delete reference to other services.

SUBCHAPTER B. DARS COMPREHENSIVE ABA SERVICES

§105.211. Services Provided.

(6) administer the DARS-designed post-test protocols within 30 calendar days of the child's exit from the DARS Autism Program;

The language here, "within 30 calendar days of," needs to be changed to be consistent with §105.213(f), "no more than 30 days before" to make clear the post-test does not occur within 30 days *following* exit.

Please add a paragraph referencing coordination with providers of “other services” if services other than ABA are to be provided.

The previous proposal of this section included language prohibiting the use of procedures that cause pain or discomfort. A commenter requested that DARS clarify procedures that would not be considered “restrictive” and that a process be put in place for DARS’ approval of such procedures on a case-by-case basis. The commenter also requested that DARS establish a peer review committee to review restrictive procedures.

DARS’ response was to remove the phrase “physically aversive interventions that would result in pain or discomfort are not permitted” from three sections of the proposed rules (§§105.211, 105.311, and 105.409). DARS did not explain this response. It is recommended that consistent with the policies of other health and human service agencies in Texas, and in keeping with both federal and state laws governing rights of disabled persons, DARS should prohibit the use of procedures that cause pain or discomfort. If such procedures are to be permitted, they need to be understood as exceptional and clinically justified and DARS should be involved in and responsible for approving their use, with or without the advice of a peer review committee.

SUBCHAPTER C. DARS FOCUSED ABA SERVICES

§105.309. Enrollment.

(a)(1) The contractor must enroll eligible children in DARS Focused ABA services in accordance with provisions of the contract established between the contractor and DARS;

If any of the provisions of the contract between the contractor and DARS affect the private rights or procedures of nongovernmental parties, e.g., child, parent(s), other providers, please include those elements in the subchapter for public review and comment (Texas Government Code, §2001.003(6)).

SUBCHAPTER E. RIGHTS OF PARTICIPANTS

§105.507. Rights of Children and Families.

(b) The contractor is required to provide the families written notification of their rights during the enrollment process.

For clarity, please amend the sentence to read “During the enrollment process, the contractor is required to provide written notification of the rights of the child and the parent(s).”

“Family rights” are not recognized statutorily. Rights of persons with disabilities confer to the child, not the family. This limits, but does not preclude, extended family involvement.

The only rights listed in this subchapter relate to confidentiality of records, accessibility of records, and filing a complaint. These are important rights but other rights should also be mentioned.

Other rights that should be mentioned include:

- Constitutional and other rights afforded to all individuals under federal or state law
- Rights under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, relating to
 - appropriate treatment, services, and habilitation for such disabilities
 - treatment, services, and habilitation designed to maximize the potential of the individual and provided in the least restrictive setting
 - care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights
 - care that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population
 - prohibition of the use of physical restraint and seclusion unless absolutely necessary to ensure the immediate physical safety of the individual or others
 - prohibition of the use of restraint and seclusion as a punishment or as a substitute for a habilitation program
 - prohibition of the excessive use of chemical restraints and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment, or habilitation for such individuals
 - the ability of close relatives or guardians to visit the individual without prior notice
 - program design that assures the most favorable possible outcome for those served and is appropriate to the individuals served by the programs
- Rights provided under state law (Health and Safety Code, Chapter 592), including
 - the right to protection from exploitation and abuse because of the person's intellectual disability

- to the right to receive for the person's intellectual disability adequate treatment and habilitative services that:
 - are suited to the person's individual needs
 - maximize the person's capabilities
 - enhance the person's ability to cope with the person's environment and
 - are administered skillfully, safely, and humanely with full respect for the dignity and personal integrity of the person
- the right as a person with an intellectual disability, a group of such persons, or a person acting on behalf of a person with an intellectual disability to submit complaints or grievances regarding the infringement of the rights of a person with an intellectual disability or the delivery of intellectual disability services to DARS [the responsible state agency] for investigation and appropriate action

(c) If any record includes information on more than one child, the parent of those children shall have the right to inspect and review only the information relating to their child or to be informed of that specific information.

Please consider revising the language as follows: “A parent has the right to inspect and review information relating only to his or her child. Information about other children must be redacted.”

The parent should have the right to see the record and not have to rely on the verbal interpretation of staff. Redacting information pertaining to other children allows inspection to occur.

§105.515. Staff Requirements.

(b) All direct service staff members must receive training before working independently and on an ongoing basis.

According to the rules referenced in subsection (c) of this section(1 TAC 15, §392.203), direct service staff must have a high school diploma and 40 hours of training to implement behavioral protocols *independently* with young children. In the absence of clear language defining and prohibiting aversive procedures and adopting the additional rights in the comments on §105.507, direct service staff should not work *independently*. Supervision once every two weeks is not adequate.

In rules as originally proposed in 2014, the requirements included having two years of experience with individuals with developmental disabilities. In response to public comment by providers about the difficulty of staffing, DARS deleted the requirement.

Forty hours of instruction are not adequate to address the requirements listed in the referenced rules, which include:

- (1) formalized training on methods for data collection, procedures for implementing discrete trial teaching, prompting procedures, behavior management strategies for addressing problem behavior, and other ABA techniques and program specific methods;
- (2) didactic instruction, workshops, readings, observation of modeling of techniques by supervisors, role-play with supervisors, and training in the natural environment in which supervisors provide specific feedback and additional training as needed;
- (3) written exams (with criteria to determine mastery) or direct observation by BCBA supervisors of therapists working directly with children (with fidelity checklists to determine accurate use of procedures and criteria to determine mastery) to ensure individual acquisition of the skills necessary to accurately implement ABA treatments;
- (4) the tasks in the Behavior Analyst Certification Board's Registered Behavior Technician Task List and Guidelines for Responsible Conduct for Behavior Analysts that have been designated as relevant for behavior technicians;
- (5) ethics and professional conduct training; and
- (6) training on typical child development for children 3 through 15 years of age.

Notably absent from the list is mention of training on the rights of the children being served.

Most people will not understand what “all of the tasks in the Behavior Analyst Certification Board’s Registered Behavior Technician Task List and Guidelines for Responsible Conduct for Behavior Analysts” are.

For purposes of public comment, it would be helpful to either include or describe the content rather than to reference a title that may be inaccessible to many. If the title is in the public domain, please include the content or a link to it so that it can be inspected during the review and comment stage of rule proposal.

The referenced guidelines do not appear to lend themselves easily to adaptation to direct service staff members, i.e., it is not possible to immediately understand which precepts written for behavior analysts would apply to direct service staff, in what form, and to what extent. Guidelines for direct service staff need to be explicit.

In conclusion, in the absence of federal oversight, DARS should provide sufficient guidance for its contractors with respect to aversive procedures and rights. Of keenest concern are the responsibilities of direct services staff who, with minimum education and training, will be authorized to independently work with children following protocols that may include aversive procedures. Reliance on third-party certification is not an adequate surrogate for agency oversight, regulation, and monitoring of potentially harmful practices. Please reconsider how this may constitute a violation of children's rights and represent an area of potential risk to children, contractors, and the agency.

Thank you for the opportunity to comment on these proposed rules.

Sincerely,

Linda Logan, MPAff
Texas Council for Developmental Disabilities