Policy Council for Children and Families
August 31, 2021

Policy Council for Children and Families works to improve the coordination, quality, efficiency, and outcomes of services provided to children with disabilities and their families through the state's health, education, and human services systems. Members:

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Advocacy Organization Representative
Austin

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Elizabeth Tucker
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Austin

Lori Urbina-Patlan
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Edinburg

Welcome and introductions The meeting was convened by Lisa Brodie, Vice Chair. A quorum was present.

Consideration of February 10, 2021 and April 12, 2021 meeting minutes.

The minutes were approved as drafted.

Follow-up from 87th Texas Legislative Session. Scott Daigle Public Policy Director Texas Council for Developmental Disabilities

Texas State Budget, SB 1 : Total Expenditures, All Funds = $248.6 billion. This is about $13.6 billion less than the current budget, and that difference is due to the inclusion of fewer federal dollars. However, lawmakers are currently in Special Session with a call to appropriate federal COVID relief dollars, boosting that total.

SB 1 provides funding for an additional 1,549 waiver slots over the biennium. By program:

- CLASS: 381
- DBMD: 6
- HCS: 542
- MDCP: 42
- STAR+: 107
- TxHmL: 471

Note that HHSC's original request was 3,512. M

SB 1 does not include an increase in the rates for community attendants. This leaves the rate at $8.11 per hour. There is hope that some of those COVID relief dollars could be used to increase the rate.

Education

SB 89, Menéndez – IEP Supplement for COVID-19
SB 1716, Taylor – Establishment of the Supplemental Special Education Services Grant Program
HB 159, M. González – Teacher Training/Staff Development.
HB 2256, Guerra – Bilingual Special Ed Certification
HB 785, Allen - Behavioral intervention plans for certain public-school students and notification and documentation requirements regarding certain behavior management techniques.
~~HB 2125, M. González – Extending Special Education Eligibility for Students 21+ Impacted by COVID19 School Closures (Failed to Pass)~~

Early Childhood Intervention (ECI)

HB 2658, Frank – Will address continuing eligibility for kids on Medicaid (based on amended text from HB 290, Cortez)
Article II of Appropriations Bill,
~~SB 1 HB 843, Lopez/HB 908, Johnson – ECI Private Health Insurance Benefit (Failed to Pass)~~

Accessibility

SB 776, Lucio, Jr. – UIL Adaptive Sports Program

~~HB 24, Dominguez – Inclusive & Accessible Playgrounds (Failed to Pass)~~

~~HB 168, M. González – Inclusive Day Care (Failed to Pass)~~

~~HB 2309, Dominguez – Enforcement of Accessible Parking Violations (Failed to Pass)~~

Guardianship

~~HB 1675, Allison – Caregiver Parents as Independent Guardians (Failed to Pass)~~

10 GUARDIANSHIP BILLS THAT PASSED

- SB 41 by Sen. Zaffirini, consolidation and allocation of state civil court costs
- SB 615 by Sen. Zaffirini, probate and guardianship matters
- SB 626 by Sen. Zaffirini, guardianships, management trusts, and other procedures and proceedings for incapacitated persons
- SB 692 by Sen. Zaffirini, access to financial records by the guardianship abuse, fraud, and exploitation deterrence program
- SB 1129 by Sen. Zaffirini, guardianship, alternatives guardianship, and supports and services for incapacitated persons
- SB 1697 by Sen. Paxton, allowing parents and guardians to elect for a student to repeat or retake a course or grade
- HB 79 by Rep. Murr, associate judges for guardianship and protective services proceedings
- HB 1156 by Rep. Thierry, financial abuse of elderly person is criminal offense
- HB 1296 by Rep. Metcalf, certain notices in guardianship proceedings
- HB 3394 by Rep. Metcalf, determining incapacity of proposed guardian or guardian

Criminal Justice

HB 2107, Wu - Outpatient Services for Juveniles w/ IDD

HB 2831, White – Advisory Committee on IDD Confinement in County Jails

Employment

SB 50, Zaffirini – Competitive, Integrated Employment Initiative for Waiver Recipients

Emergency Management

SB 968, Kolkhorst - Public health disaster and public health emergency preparedness and response

Contains language from HB 3711, Bucy, establishing a wellness check for medically fragile individuals during an emergency

Health Care

HB 3720, Frank – Interest lists and eligibility criteria for certain Medicaid waiver programs

SB 642, West – Mental health services for certain children at risk of relinquishment

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HB 119, Landgraf – Ban on Organ Donor Discrimination Against People with Disabilities
HB 797, Howard – Vaccine Administration by Home Health Nurses
HB 1535, Klick – Texas Compassionate Use Program (TCUP) Expansion

Constitutional Amendments (November 2nd)

- HJR 99, Canales – County financing of infrastructure in underdeveloped areas
- HJR 125, Ellzey – School property tax limits for surviving spouse of a person who is disabled, if spouse was 55 or older at time of person's death
- HJR 143, Geren – Charitable raffles at rodeo venues
- HJR 165, Jetton – State Commission on Judicial Conduct enforcement of standards for judicial candidates
- SJR 19, Kolkhorst – Right to Essential Caregivers for in-person visitation
- SJR 27, Hancock – Prohibition on limits to religious services conducted by a religious organization
- SJR 35, Campbell – Property tax exemption for surviving spouse of a member of the U.S. armed services who is killed or fatally injured in the line of duty
- SJR 47, Huffman – Enhanced requirements for candidates to certain judicial offices

SJR 19 – Right to Essential Caregiver

Sec. 35. (a) A resident of a nursing facility, assisted living facility, intermediate care facility for individuals with an intellectual disability, residence providing home and community-based services, or state supported living center, as those terms are defined by general law, has the right to designate an essential caregiver with whom the facility, residence, or center may not prohibit in-person visitation.

(b) Notwithstanding Subsection (a) of this section, the legislature by general law may provide guidelines for a facility, residence, or center described by Subsection (a) of this section to follow in establishing essential caregiver visitation policies and procedures.

Special Session Update

The Governor's 1st Special Session call included 11 items:

- Bail Reform
- Transgender Athletes
- Elections
- Abortion Meds
- Border Security
- TRS 13th Check
- Social Media
- Critical Race Theory
- Article X Appropriations

- $$$ for Property Tax Relief,
- Family Violence Prevention Foster Care, Cybersecurity

The 1st Special Session ended on August 6.

Special Session Update 2

The Governor immediately called a 2nd Special Session, which began at noon on Saturday, August 7, to consider the following:

- Each of the items from 1st Special Session
- Federal COVID relief appropriations
- Legislative quorum requirements
- State laws governing radioactive waste
- Filing & election dates for 2022 primaries
- Education during Pandemic
- Pre-empting Local Labor Laws

The 2nd Special Session will end no later than September 5.

PCCF Bills of Interest That Did Not Pass - Medicaid

- ~~SB 2028 (Kolkhorst) Medicaid managed care~~
- ~~HB 3679 (Parker) Reimbursement of durable medical equipment providers in Medicaid managed care~~
- ~~HB 3705 (Krause) and SB 1243 (Perry) Medicaid buy-in for children~~
- ~~HB 3678 (Parker) Insurer's obligation for continuity of care for certain Medicaid recipients~~
- ~~HB 3677 (Parker) Coordination of Medicaid and private health benefits for Medicaid recipients with complex mental needs PCCF Bills of Interest That Did Not Pass – Medicaid~~

PCCF Bills of Interest That Did Not Pass – Education

- ~~SB 688 (Lucio) Development of a special education services matrix~~
- ~~HB 1163 (Mary González) Prohibiting certain restraints on students receiving special education services~~
- ~~HB 877 (Mary González) Educational representative for students with disabilities~~
- ~~HB 742 (Burns) Alternative assessment of students receiving special education services and alternative accountability plans for campuses serving the students~~
- ~~HB 411 (Julie Johnson) Term referring to individualized education program team~~
- ~~HB 3450 (Lucio III) Justified use of force by a school employee or volunteer on a student~~

- ~~SB 1101 (Creighton) Creating bilingual special education certification to teach students of limited English proficiency with disabilities~~

PCCF Bills of Interest That Did Not Pass – Misc

- ~~HB 4571 (Rose) Statewide intellectual and developmental disabilities coordinating committee~~
- ~~SB 2074 (Menéndez) Establishment of the Mental Illness and Intellectual or Developmental Disability Advisory Council~~
- ~~HB 1050 (Romero, Jr.) Relating to a study on employing mental health professionals or mental health response teams to assist when responding to a behavioral health-related emergency call~~
- ~~SB 1457 (Zaffirini) Peer services to individuals with an intellectual or developmental disability including provision of those services under Medicaid~~

Questions/Answers/Comments No discussion

Presentation: Texas Architectural Barrier (free) Law

The Architectural Barriers Program is part of the TDLR RPM Division. TDLR and AB staff administer compliance with the following: Act--Texas Government Code, Chapter 469, Elimination of Architectural Barriers (the Texas Architectural Barriers Act).

Rules--Title 16, Texas Administrative Code, Chapter 68, the administrative rules of the Texas Department of Licensing and Regulation promulgated pursuant to the Act.

TAS--The 2012 Texas Accessibility Standards which were adopted by the Commission and became effective March 15, 2012.

Americans with Disabilities Act: ADA Federal Accessibility Law is administered by the U.S. Department of Justice (DOJ).

➢ Civil rights law intended to prevent discrimination against people with disabilities in employment, public services, commercial facilities, public accommodations, and transportation & telecommunication services.

➢ Enforcement is driven by private lawsuits and complaints from people with disabilities.

➢ Generally, there is no requirement for plan review, or inspection; although federally-funded projects may require review or inspection prior to release of federal funds.

➢ Applies to existing as well as newly constructed, renovated, modified, or altered buildings including:

- public and government entities (Title II);
- private entities:

➢ public accommodations (Title III); and
➢ commercial facilities (Title III).

Texas Government Code, Chapter 469 Texas Accessibility Act is administered and enforced by the Texas Department of Licensing and Regulation.
➢ Construction law that is applicable only when a subject building or facility is newly constructed, renovated, or altered except in the case of state leases.
➢ Enforcement is driven by consumer, industry, and Department complaints.
➢ Requires project registration with the state, plan review, and inspection of subject facilities.
➢ Accessibility and enforcement of compliance is pursued throughout the process.

Rule 68.100 Technical Standards & Technical Memoranda
a) The Texas Commission of Licensing and Regulation adopts by reference the 2012 Edition of the Texas Accessibility Standards (TAS), effective March 15, 2012.

The International Symbol of accessibility leads people to believe that accessibility laws and standards only relate to persons with mobility impairments. However, the population to which Chapter 469 and TAS relates is much broader and is identified in the following provisions of Chapter 469.001.

(b) This chapter relates to: Non-ambulatory & Semi-ambulatory Disabilities
Examples of Application of TAS:
▪ Aisle seats with folding armrests
▪ Ambulatory and wheelchair accessible toilet compartments

This chapter relates to: Sight Disabilities, Hearing Disabilities, Disabilities of Coordination, Aging.

The public policy of TDLR addressed in the following provisions of Chapter 469 identify why this Act is so important to the population of persons identified in Chapter 469.001.

Chapter 469.001(c) Scope of Chapter; Public Policy-- This chapter is intended to further the policy of this state (which is) to encourage and promote the rehabilitation of persons with disabilities and to eliminate, to the extent possible, unnecessary barriers encountered by persons with disabilities whose ability to engage in gainful occupations or to achieve maximum personal independence is needlessly restricted.

The original 1969 Act was applicable only to public buildings and facilities. The standards adopted under this chapter apply to: 1. A building or facility used by the public that is constructed, renovated, or modified, in whole or in part, on or after January 1, 1970 using funds from the state or a county, municipality, or other political subdivision of the state.

106.5.48 Public Building or Facility-- Public Building or Facility. A building or facility or portion of a building or facility designed, constructed, or altered by, on behalf of, or for the use of a public entity* subject to the Texas Architectural Barriers Act, Chapter 469, Texas Government Code.

Excerpt from Title II, § 35.104 Public Entities-- (A) any State or local government; (B) any department, agency, special purpose district, or other instrumentality of a State or States or local government.

State Leases. In 1971, a statutory change to the Act by the 62nd Legislature added buildings and facilities leased by state agencies and added provision for plan reviews. In 1997, the 75th Legislature required that state leases be inspected prior to occupancy.

Public - We've now discussed public buildings and facilities which are those that constructed, renovated, or modified with public funds, including, state leases in which there is no construction. Private - Now we need to discuss private buildings and facilities which are defined in the following provisions of TAS.

Public Accommodations/Private Funds
Compliance with the Act for these categories/types of buildings and facilities was initially applicable only to counties of 50,000 or more population. The county population limit was reduced to 45,000 in 1981 and removed completely in 1991. In 1991, public accommodations - as defined by the ADA - were added to the Act and compliance became effective 1992.

Chapter 469.003(a) Applicability of Standards. The standards adopted under this chapter apply to: (4) a privately funded building or facility that is defined as a "public accommodation" by Section 301, Americans with Disabilities Act of 1990 (42 U.S.C. Section 12181), and its subsequent amendments, and that is constructed, renovated, or modified on or after January 1, 1992.

The (1991) ADA definition of "public accommodation" is incorporated into Rule 68.20(c). This Rule identifies the types of buildings and facilities that DOJ (and TDLR) considers to be public accommodations.

(1) an inn, hotel, motel, or other place of lodging except for an establishment located within a building that contains not more than five rooms for rent or hire and that is occupied by the proprietor of such establishment as the residence of such proprietor;

(2) a restaurant, bar, or other establishment serving food or drinks;

(3) a motion picture house, theater, concert hall, stadium, or other place of exhibition or entertainment;

(4) an auditorium, convention center, lecture hall, or other place of public gathering;

(5) a bakery, grocery store, clothing store, hardware store, shopping center, or other sales or rental establishment;

(6) a laundromat, dry-cleaner, bank, barber shop, beauty shop, travel service, shoe repair service, funeral parlor, gas station, office of an accountant or lawyer, pharmacy, insurance office, professional office of a health care provider, hospital, or other service establishment;

(7) a terminal, depot, or other station used for specified public transportation;

(8) a park, zoo, amusement park, or other place of recreation;

(9) a museum, library, gallery, or other place of public display or collection;

(10) a nursery, elementary, secondary, undergraduate, or postgraduate private school, or other place of education;

(11) a day care center, senior citizen center, homeless shelter, food bank, adoption agency, or other social service center establishment; and

(12) a gymnasium, health spa, bowling alley, golf course, or other place of exercise or recreation.

Commercial Facilities/Private Funds

Commercial facilities typically are not open to the public but provide employment and a product or service. In many cases, they are both commercial facilities and public accommodations. For example, a power plant is a commercial facility, however… the building where you go to make utility payments is a public accommodation. Both are subject to TAS although each building will have

areas and spaces that are exempted by Rule 68.30 or TAS 203. A Walmart that operates as a sales and service establishment is a public accommodation, however… the Walmart distribution center that is not open to the public is a commercial facility.

The standards adopted under this chapter apply to: (5) a privately funded building or facility that is defined as a "commercial facility" by Section 301, Americans with Disabilities Act of 1990 (42 U.S.C. Section 12181), and its subsequent amendments, and that is constructed, renovated, or modified on or after September 1, 1993.

Rule 68.30 identifies exemptions for the following: 1. Federal Property 2. Places Used Primarily for Religious Rituals 3. Van Accessible Parking at Garages Constructed Prior to April 1994 4. Residential Facilities, (private residences).

General exceptions. 203.1 General. Sites, buildings, facilities, and elements are exempt from these requirements to the extent specified by 203. (where structurally impracticable); 203.2 Construction Sites; 203.3 Raised Areas; 203.4 Limited Access Spaces; 203.5 Machinery Spaces; 203.6 Single Occupant Structures; 203.7 Detention and Correctional Facilities (common use areas); 203.8 Residential Facilities (common use areas); 203.9 Employee Work Areas; 203.10 Raised Refereeing, Judging, and Scoring Areas; 203.11 Water Slides; 203.12 Animal Containment Areas; 203.13 Raised Boxing or Wrestling Rings; 203.14 Raised Diving Boards and Diving Platforms.

Plan Reviews and Inspections

Building owners have an obligation to comply with both federal and state accessibility Acts and Standards. Plan reviews and inspections are not required or performed by DOJ to verify compliance with the 2010 ADA or the ADA but TDLR requires plan reviews and inspections for subject buildings and facilities.

All plans and specifications for the construction of or for the substantial renovation or modification of a building or facility must be submitted for review and approval if:

(1) the building or facility is subject to this chapter

(2) the estimated construction cost is at least $50,000.

A person may not perform a review or inspection function of the commission on behalf of the owner of a building or facility unless the person holds a certificate of registration issued under this subchapter. (469.201). Previously, attendance at the Texas Accessibility Academy was required to be eligible to take the RAS exam. Although not required it is highly recommended.

Questions/Answers/Comments

What about the old building built prior to 1970 and that are not up to standard. The speaker stated that existing building are not subject to the requirements, but they are to be covered under the ADA. Renovations create the entity to fall under the standards.

Any one can file a complaint with TDLR through their website. .

Autism Spectrum Disorder therapy services provided by Allied Health Professionals

Speech and Language Therapy

Diagnosis of Autism Spectrum Disorder (ASD)

- Recognition of the dichotomy of Educational Model and Medical Model
- Under the Educational Model, testing and ultimately a diagnosis/non-diagnosis answers the question, "Does this child demonstrate an educational need for services as a student with _____?"
- Under the Medical Model, testing and ultimately a diagnosis/nondiagnosis answers the question, "Does this child require medically-necessary intervention to better communicate his/her wants, needs and preferences across environments?"

In the educational model, Diagnosis is made by LSSP (Licensed Specialist in School Psychology), now with the component of testing by Speech Language Pathologist. Historically, the component testing by SLP was not required. This component testing is determined to be an important piece of a diagnosis because of the information assessed on the social usage of language (pragmatics), a key identifier of ASD. In the medical model, diagnosis is generally made by psychologist with expected components of evaluation

1. Clinical interview
2. Behavioral observations
3. Standardized assessments, which may include
    a) Clinical Assessment of Behavior Parent Extended Form,
    b) Kaufman Brief Intelligence Test, 2nd Edition (K-BIT 2),
    c) Wide Range Achievement Test—5,
    d) Childhood Autism Rating Scale –2 (CARS-2)

(This is not an exhaustive list of standardized tests appropriate for this population)

According to the Diagnostic and Statistical Manual of Mental Disorders 9DSM-5) revised by the American Psychiatric Association in 2013, the core symptoms of ASD fall into 2 categories

1. Difficulty with social communication (such as poor eye contact and not pointing, giving or showing to share their interests with others).
2. Restricted interest and repetitive behaviors (such as focusing excessively on a specific object or saying or doing the same thing again and again).

Importantly, a diagnosis of ASD requires symptoms in both categories. In addition, these symptoms must significantly affect the child's day-to-day functioning and they must occur early in development.

Under the educational model, an SLP's role may be direct or indirect

1. Direct services through intervention
2. Indirect services through recommendations made by SLP of accommodations (agreed to in Admission Review Dismissal meeting)

Under the medical model, an SLP's role is generally direct through provision of intervention services (therapy)

Because communication is one of the two core symptoms of ASD, treatment naturally should come under the purview of the communication specialist, the Speech Language Pathologist. The SLP is the communication expert and is in the unique position to discuss and indeed, treat children having social/pragmatic deficits associated with ASD. SLP's have emerged as central figures in autism services, as they possess a strong background in the neurodevelopmental basis of communication, language and other critical aspects of child development (Barry Prizant, 2014). Given the increasing prevalence of diagnosis of ASD and the high cost associated with the resulting treatment, it is most prudent and more practical to consider a team approach (multi-disciplinary) to treatment. While social communication deficits are a core feature of ASD, certified and licensed SLP's are particularly well qualified to provide services for these deficits. The training and knowledge of board-certified behavior analysts (BCBA's)also make them highly qualified to serve children with ASD, particularly for addressing the needs of children with ASD who present with challenging behaviors. (LSHSS, Oct. 2014).

Therapy Intervention for Children with ASD. SLP examines/assesses/observes communication across the continuum:

1. Utterance act (articulation, vocal intensity, voce quality, fluency)
2. Nonverbal communication(physical proximity, foot/leg movements (restlessness), eye contact/gaze, facial expression
3. Propositional Act (specificity/accuracy of vocabulary, word order, ability to change communication style based on situation and listener)

4. Perlocutionary Acts(appropriateness of verbal response, topic maintenance, turn-taking, initiation of topic, repair/revision, quantity/conciseness of either too much or too little information or detail)

(Prutting Pragmatic Protocol, C.A. Prutting, UCSB, 1982)

Intervention Strategies

- Teach the relationship their actions have on those around them i.e., what is it that repels or is off-putting to others)
- Use social stories
- Use social "autopsies" (analysis of "disasters" and discuss options in a nonjudgmental manner) × Teach how to wait in line
- Teach perspective taking (barrier games)
- Teach sharing skills
- Teach negotiation skills
- Teach responsibilities and roles for given situations
- Establish routines (visual schedules, calendars)
- Teach how to transition
- Teach conversational skills (initiate, turn-take, expand)
- Teach recognition of facial features

Questions/Answers/Comments

A comment was made about too much carbohydrates and diet. Sometimes with diet we have to cut down on medication. The speaker stated that as a speech language pathologist then they can suggest diet issues to parents.

Speech and Language pathologists have feeding within their scope.

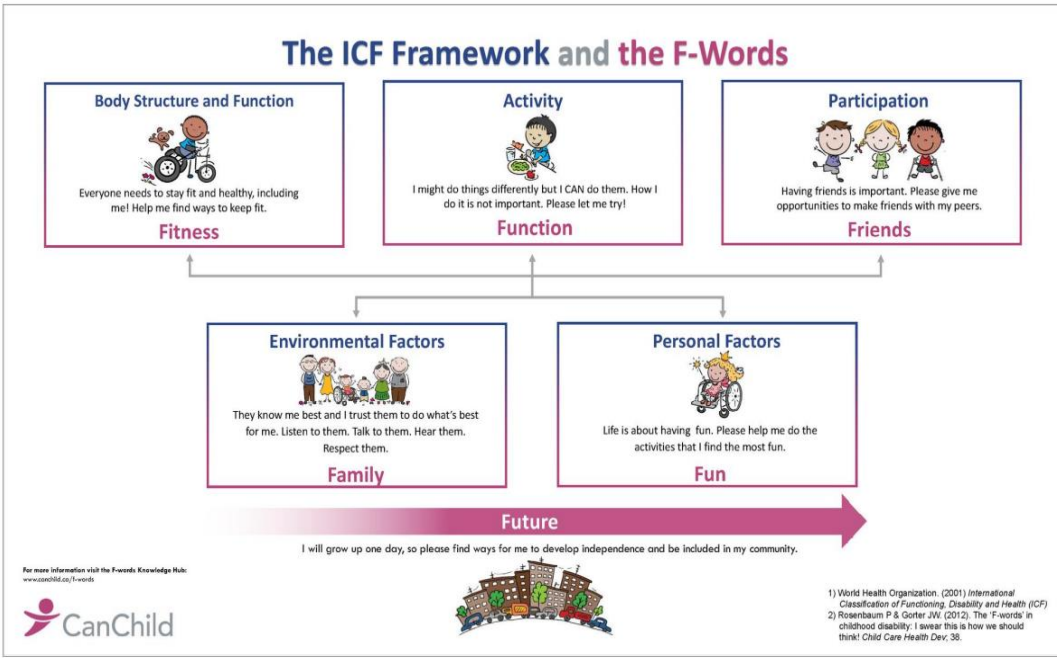
Bringing in a Nutritionist would be a good resource for future meetings or for the work group.

Educational need can be defined very narrowly at local school districts. Demonstration of an educational need is often supported by external assessments.

What age can a child or toddler be diagnosed? The speaker stated that by the time the SLP sees the child, the diagnosis is usually made. This is about the age of three. Sometimes the therapist may not agree with the diagnosis.

Physical Therapy & Autism Spectrum Disorder.
Physical therapists are experts in: Movement, Motor development, Body function.

6 F-Words & Childhood Disability



ASD Prevalence & Diagnosis ~1 in 54 children diagnosed per CDC

- 1 in 34 boys
- 1 in 144 girls 5 years is average age of diagnosis in US. Diagnosis based on DSM-5 criteria:
    - Deficits in social communication
    - Delay or lack of language development • Restricted and repetitive patterns of behavior

ASD Comorbidities

- Childhood anxiety • Attention deficit hyperactivity disorder (ADHD)
- Obsessive compulsive disorder (OCD)
- Developmental coordination disorder (DCD)
- Depression • Sleep disturbances
- Epilepsy
- Gastrointestinal (GI) dysfunction
- Immune dysfunction

ASD Characteristics & Features

- Deficits in Social Communication & Interaction
- Restricted & Repetitive Behaviors
- Self-injurious behavior: head banging, biting
- Anxiety or depression
- Large gap between intellectual ability & adaptive/self-care skills
- Significant delays/impairments in performing routine, daily caregiving tasks

Physical Therapy Related

- Unusual gait, toe walking
- Balance deficits, clumsiness
- Poor postural control
- Low postural tone
- Poor bilateral coordination
- Decrease eye-hand coordination
- Limited movement variability ASD Characteristics & Features
- Difficulties planning & imitating movements of others
- Limited participation in physical activity even with high functioning ASD
- Lower scores in gross & fine motor skills vs. peers
- Delays in motor skills increase with age
- Significant impairments in more complex motor skills

Impairments to Body Functions & Structures, Activity Limitations, and Participation Restrictions

Systems	Impairments	Activity Limitations	Participation Restrictions
Sensory-perceptual	•Atypical/enhanced auditory and visual perception •Sensory modulation difficulties (hyper- or hypo-responsiveness to auditory, visual, olfactory, tactile, and vestibular stimuli) •Atypical pain responses	•Sensory seeking or avoidance behaviors •Sensorimotor stereotypies •Unexplained loss in abilities	•Need for caregivers to interpret behavioral changes as indicators of underlying discomfort, pain, or change in health status
Motor	•Uncoordinated gait •Atypical weight bearing during toe-walking •Balance •Strength and muscle tone •Endurance and physical activity levels •Apraxia/dyspraxia: Difficulty completing complex movement sequences during imitation, on verbal command, or during everyday tool use.	•Motor delays •Motor incoordination •Imitation difficulties •Difficulty performing functional tasks, including activities of daily living	•Participation in extra-curricular interests •Inability to care for self in home & community settings •Inability to complete daily routines independently

Each child's (Physical) therapy plan, goals & intervention will be different:

Individualized based on:

- Specific presentation of child
- Child/family goals
- Identified barriers to activities and participation.

Treatment interventions:

- Meaningful activities
- Age appropriate activities
- Natural, meaningful environment may produce better outcomes

Focus is on activities & participation limitations affecting typical skill development & age appropriate participation with peers.

Early Intervention, PT & ASD

- Complete motor assessments of infants and toddlers with ASD
- Look for signs of motor delays in at risk infants
- Encourage motor play to address delays, low postural tone, and lack of movement variability.
- Educate caregivers on how to engage in motor play to encourage infant-caregiver interaction
- Advocate for early motor interventions for infants, toddlers, and preschoolers at risk for autism.
- Early Childhood Intervention has positive effect on developmental & functional outcomes
- Early motor/adaptive interventions facilitate improved social communication performance
- Significant early intervention following diagnosis showed a significant reduction in autism symptoms.

School-based PT & ASD

- Include PT in IEP team.
- Recommend motor evaluations for children with ASD and share motor treatment ideas.
- Recommend adaptive modifications.
- Motor skills training to promote focus in class, transitions, and peer play.
- Apply a variety of motor-learning principles.
- Identify themes that work best for each individual child.

Guiding Principles of Effective Intervention

- Earliest possible intervention
- Family involvement helps children meet outcomes faster
- Individualized Programming
- Systematic Intervention
- Structured/Predictable Environments
- Functional Approach to Behavior

Why physical activity & exercise?

- Children with autism typically participate in more sedentary activities
- Typically prefer individual physical activities to group
- 75% of pts with high functioning autism don't participate in physical activity

Exercise Decreases

- Stereotypic behaviors
- Aggression
- Off-task or unwanted behavior
- • Elopement

Exercise Increases

- On-task behavior
- Improvement in motor skill acquisition
- Social communication, interaction & attention • Self-worth
- • Overall health & weight management

Long Term Considerations.

- Significantly lower quality of life across lifespan
  - 3-14x more likely to be socially isolated
  - Loneliness & depression more prevalent with age
- Increased risk of obesity with age (25.7%)
  - Inactivity
  - Poor nutrition & food habits
  - Medications
  - Lack of knowledge/awareness
  - Environment

Early involvement with transition & employment programs. IDEA mandates starting at age 14 Increase resources for recreation, leisure, supported vs. independent living and employment after high school; 14% of adults with autism who had received state developmental disabilities services held paid jobs in their communities.

Financial Costs--Average medical expenditures are 4-6x more ~$3.2 million across the lifetime of the individual. Majority of expenses:

- behavioral interventions ($40,000-60,000 per year)
- other outpatient or home-based interventions
- inpatient care
- costs related to caregivers' loss of employment.

In Summary:

- Early intervention is key.
- Physical activity can improve focus, participation, socialization and decrease negative behaviors.

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- Important to educate and empower families for carryover at home & in community.
- Physical therapy needs vary based on each child and across their lifespan.
- Multidisciplinary collaboration is important in all settings.

Questions/Answers/Comments

How do you empower families to carryover activities at home? Caregivers are actively engaged in every treatment session. Parental goals are a focus to encourage therapy participation.

How do you address parental burnout and self care for parents? We work on a set of goals and then take a break for the parents. We encourage family members to talk through issues.

Occupational Therapy

Our expertise in the area of activity analysis makes us skilled in the evidence-based strategies to address sensory needs, self regulation, adaptation, motor development, and self-care skills. OT establishes a foundation for developing the skills to participate in life activities throughout the lifespan. It helps to provide strategies to cope in an ever-changing environment with an otherwise rigid routine, i.e. auto flush toilets, auto hand dryers.

The OT process includes:

- Evaluation
- Treatment
- Caregiver education/training
- Community Resources

Evaluation: Assess each child as an individual existing in a family with unique dynamics (strategies and techniques used/taught could vary based upon family dynamics alone). This evaluation, based upon observation, parent report, and standardized testing, helps determine the plan of care, and ultimately, how to best help our patient as well as the caregiver/family. Goals are established based upon what is most meaningful to the caregiver/family. Through evaluation, OT also plays a role in early detection of autism and making recommendations for services.

While each child diagnosed with Autism/ASD is a unique individual, as you know, there are common presentations.

- Repetitive movements such as spinning, rocking, head banging.
- They deal with an inconsistent environment with a routine behavior.
- Unusual or inconsistent response to sensory stimulation in one or more areas: visual, auditory, tactile, etc.
- And more...

Treatment is guided by these common presentations.

Treatment Strategies

- Maintain instruction at concrete level.
- Use of visual pictures and/or gestures with spoken language.
- Keep instruction or treatment routine and predictable (at least initially, slowly incorporating change) – important to include into HEP (home exercise program) for caregiver to work on in home and community.
- Use multi-sensory approach (helps identify individual needs, i.e. deep pressure, joint compressions, vibration, assists with readiness for therapy and increasing attention to task)
- And through evaluation determining each individual's strengths to be able maximize their potential. (i.e. strength, ability to focus attention to a task for 2 minutes)

HOH (hand over hand) assistance

- Repetition
- Modeling from caregiver or sibling
- Multisensory approach
- Interdisciplinary collaboration
- *Overall effort to establish a routine

Treatment

- Often the first few steps are to learn the individual's needs for self-regulation and determine how to teach the child/caregiver to self-regulate.
- The next step is typically to utilize this ability to self regulate, even if it is just for a few minutes, to increase attention in order to learn new skills.
- Attention to task is a common goal early in intervention.
- Self-regulation
- Attention to task
- Play
- Fine Motor skills
- ADLs (Activities of Daily Living)
- IADLs (Instrumental Activities of Daily Living)

Self-regulation/Attention to task

- Multi-sensory approach (Sensory seeking vs. sensory avoiding)
- Gross motor/ joint compressions
- Wilbarger brushing

- Vestibular input
- Vibration, and others

Play is important alone but is often the method of developing fine motor skills for children but fine motor skills, developed through play, carryover into ADLs/selfcare. ADLs include:

- Eating: both Self feeding and our "picky eaters"
- Dressing
- Grooming (oral care, brush hair, haircuts)
- Potty training education/strategies

As ASD is a spectrum, with variance in ability to participate, IADLs may also be included.

- Making a simple meal/kitchen safety
- Cleaning room/making bed
- Laundry
- Managing bills
- Preparing for life in college
- Other life skills

Caregiver Education/Training

- Support families by providing typical developmental milestones and promoting their engagement in age appropriate activities
- Attend sessions
- Teach back
- Empowering the caregiver
- Establishes this new routine in the environments where they are most often (home/school/community)
- Provide community resources

Summary

- As stated earlier, OT establishes a foundation for developing the skills to participate in life activities throughout the lifespan.
- OT practitioners are distinctly qualified to promote productive and meaningful activity and enhance the quality of life of these individuals and their families.
- We are able to help children perform better in the school, home, and community environment.

- This starts with recognizing that each child is an individual existing in a family, learning their specific needs for self-regulation, increasing attention in order to learn new skills, and empowering the caregiver to engage in these strategies outside of therapy.

Question/Answers/Comments

There can be a real challenge for families when children have extreme behavior. The speaker stated that because they are out patient, they would refer to ABA.

Workgroup reports: Autism Spectrum Disorder The workgroup had its formal kickoff meeting. They had 7 subject matter experts and two council members. Objectives:

- Ensure a continued discussion for persons with Autism Spectrum Disorders
- Monitoring the Behavioral analysis benefit including rates and other issues identified by stakeholders
- Address professionals who work alongside of ABA

Mr. Blanton stated that a professional position will be appointed to the council knowledgeable on Autism Spectrum Disorders.

2021 planning

PCCF Legislative Report Timeline

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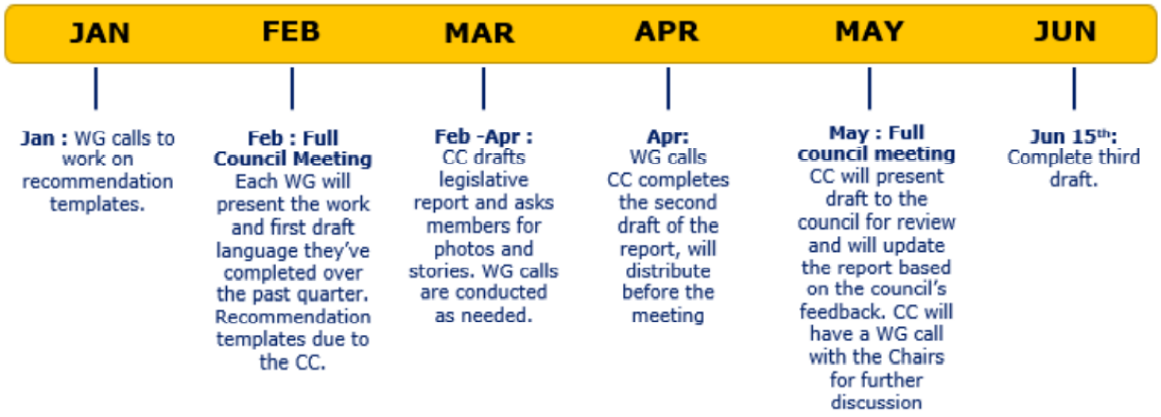
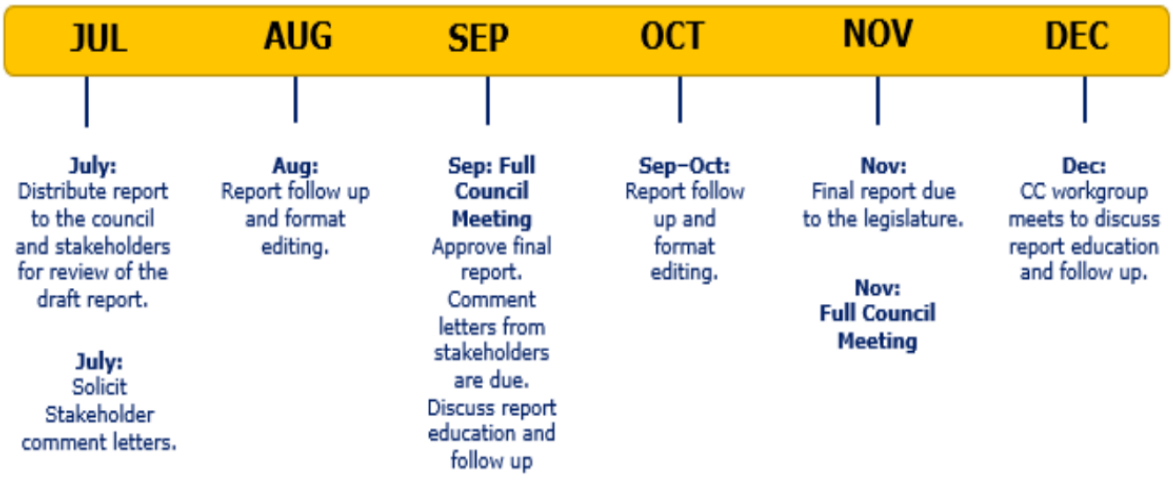
2022 Milestones (Proposed)



2022 Milestones (Proposed)



The main early goal is to select the topics to be focused on. Initial draft recommendations appear below. In addition to the list below it was suggested to include issues related to adults. Also, to include young adults with mental health conditions and IDD and postsecondary transition.

1. **Recommendation: Pay parents who are trained certified nurse aides to care for their children, which will solve nurse shortage issue and save cost to HHSC.**

    - Amend the Texas Medicaid State plan to allow for Parents as Certified Nurse Aids. This is being done in other states like Colorado, Arizona, Missouri, etc. and is a good option for Texas. There is an extreme nursing shortage in the state and allowing parents who are trained as certified nurse aides to be paid to care for their children would not only assist in solving the nursing shortage crisis but would also save the state money by using a middle tier person instead of a nurse.

2. **Recommendation: Pay parents who care for their children, which will solve attendant care crisis, and will financially support family who cannot seek outside home due to need of their children with disability.**

    - Texas should request a waiver from the Centers for Medicare and Medicaid Services to allow parents of minor children to be a paid Medicaid provider for Personal Care/Community First Choice services. A number of other states allow parents of minors to be the paid under Medicaid through a waiver with CMS. Texas is experiencing an attendant care crisis and parents are not able to seek work outside of the home due to the needs of their children with disabilities. The assessment of hours a child qualifies for is determined using a standardized tool administered by a third party. It should not matter who delivers the service.

3. **Recommendation: Fund Medicaid waivers for children to help them come off Interest list**

    - Continue to support children to grow up in families through the funding of Medicaid waivers for children to leave facilities, be diverted from admission, or come off the Interest List.

4. **Recommendation: Increasing the threshold allowance for Medicaid Buy-in for Children and Adults to 300 percent of federal poverty level**

    - Apply the Family Opportunity Act's family income limit of 300% Federal Poverty Level to the Texas Medicaid Buy-In for Children program and improve outreach so that more families can contribute to the cost of their children's care

5. **Recommendation: Amend the MDCP waiver to allow for a reserved capacity of nursing facility diversion waivers for children with medical fragility that are at risk of facility admission and do not require a nursing facility stay.**

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6. **Recommendation: Treatment Foster Care for children with significant mental health concerns who cannot live at home and are not in the conservatorship of CPS in lieu of in-patient psychiatric hospitalization and/or a Psychiatric Residential Treatment Center.**

7. **Recommendation: Healthcare Transition planning in schools. Recommending schools to include health in the Individualized Education Program (IEP).**

   Got transition site has resources to support this with a readiness assessment for students and sample IEP goals. Various stakeholders across Texas thinks it's important to include health in IEPs. Recently there was a data directly from students supporting the importance. It is anticipated that there is a no significant cost to make it a requirement to include health in IEPs. Including health in IEP is another option in addition to the recommendation made earlier which is creating similar set-up as in Houston transition medicine clinic.

8. **Recommendation of newborn screening (and/or developmental screening) for early detection and intervention for kids with disability.**

   Texas Early Hearing Detection and Intervention program (TEHDI), provided information that Texas has room for improvement in terms of outcomes such as follow up, referral to early intervention for newborn. The stakeholders recommend allotting resources in the screening program and changing policy around.

   Action item: Inviting TEHDI to identify more issues identified and potential recommendation as a solution.

9. **ASD Workgroup Recommendation: Including dieticians and feeding therapist as part if interdisciplinary team while providing holistic approach to treating kids with Autism Spectrum Disorder.**

   Action item: Johnson Center for Child Health and Development can provide details for holistic approach in treating kids with ASD.

10. **Trauma Informed Care, for children identified as trauma victims [abuse; neglect; witnesses; bullying; cyberbullying] (based on diagnosis; familial abuse; foster care placement; education related issues; negative law enforcement contact; inappropriate justice related dispositions).**

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Public comment

Ronnie Thowman, TxABA suggested that a behavior analyst be invited to speak. She commented on the legislative session and the rules that are being developed for ABA services under Medicaid. They have concerns:

- Autism Diagnosis being reconfirmed every three years
- Reauthorization should be at 6 months, not 3
- Rates are too low to maintain a network of services

Rhona Statman, Every Child stated that they support the recommendations that were drafted above. In addition:

- Allowing parents to be certified nurse aids
- Paying parents to provide attendant services
- Medicaid waivers for children funding
- Medicaid Buy-in
- Treatment foster care

Action items for staff and member follow-up.

- Invite early hearing detection program
- Johnson Center for Child Health and Development
- Role of Board certified behavioral analysis
- IDD carve in status and strategy plan
- Family certified as specialists as in other states

Adjourn. There being no further business, the meeting was adjourned.

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