



TEXAS
Health and Human
Services

**Texas Department of State
Health Services**

Medical Home Learning Collaborative

FY20, Q3

April 15, 2020



Housekeeping

- All lines are in listen only mode
 - To speak, click the raise hand icon and the organizer will unmute your line
- If your computer does not have a mic, please use the phone for audio (phone is preferred)
 - Dial audio pin to enable audio
- Use the Question box to:
 - Communicate with organizers
 - Ask the speaker a question
 - Get help with technical difficulties
- Today's call will be recorded
- Agenda and PDF of slides are available in the Handouts section



Agenda

1. Welcome & Housekeeping
2. Managing Autism in the Medical Home: Referrals and Supports Following the ASD Diagnosis
3. CSHCN Systems Development Group Updates
4. Upcoming Events
5. Other Member Updates and Events
6. Health Equity
7. Resources
8. Adjourn



Managing Autism in the Medical Home: Referrals and Supports Following the ASD Diagnosis

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Associate Director for Research, Autism Center, Texas Children's Hospital



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Texas Children's Hospital*

Pediatrics



**Texas Children's
Hospital**

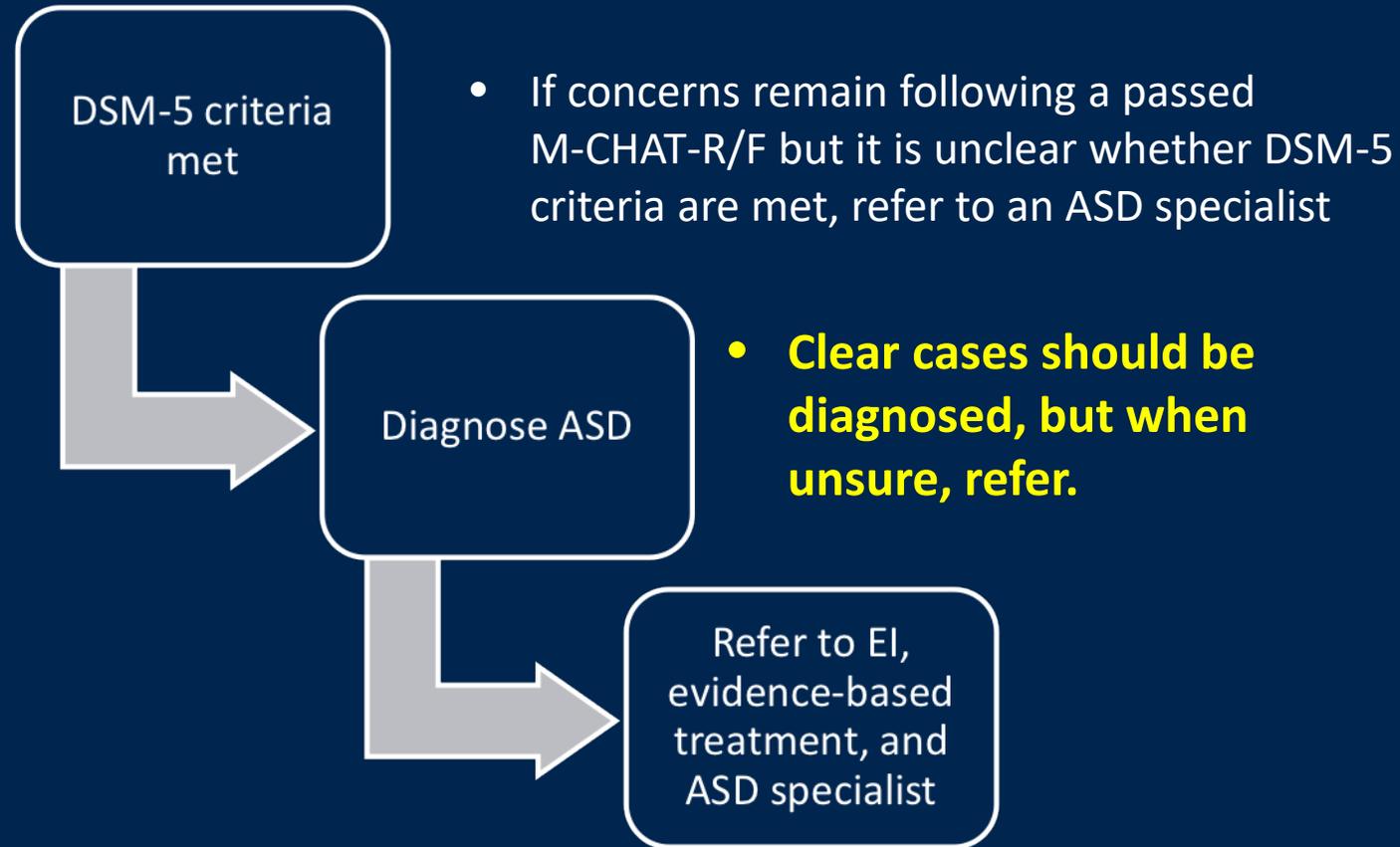
Baylor
College of
Medicine



Overview

1. Referral of complex or questionable cases for ASD specialist evaluation and treatment
2. Educational, therapeutic, and personal-support referrals for families awaiting specialist evaluation and those who receive an ASD diagnosis
3. Medical diagnostic workup in children with confirmed or suspected ASD

Diagnostic Decision Tree





When to Refer for ASD Specialty Evaluation

- Passed MCHAT-R/F but provider or parent still has concerns about the child's social development
- Parent reports concerns consistent with ASD but the provider does not observe concerning behaviors
- Provider observes behaviors consistent with ASD but the parent does not endorse concerns for ASD
- Developmental, behavioral, psychiatric, and/or medical issues that complicate the child's presentation

Locating ASD Specialists/Providers

National Organizations

Autism-society.org

AutismSpeaks.org

Local Universities or Hospitals

UH Clear Lake
(hsh.uhcl.edu/CADD)

UT: Children's
Learning Institute
Autism Center

Texas Children's
Hospital
Autism Center

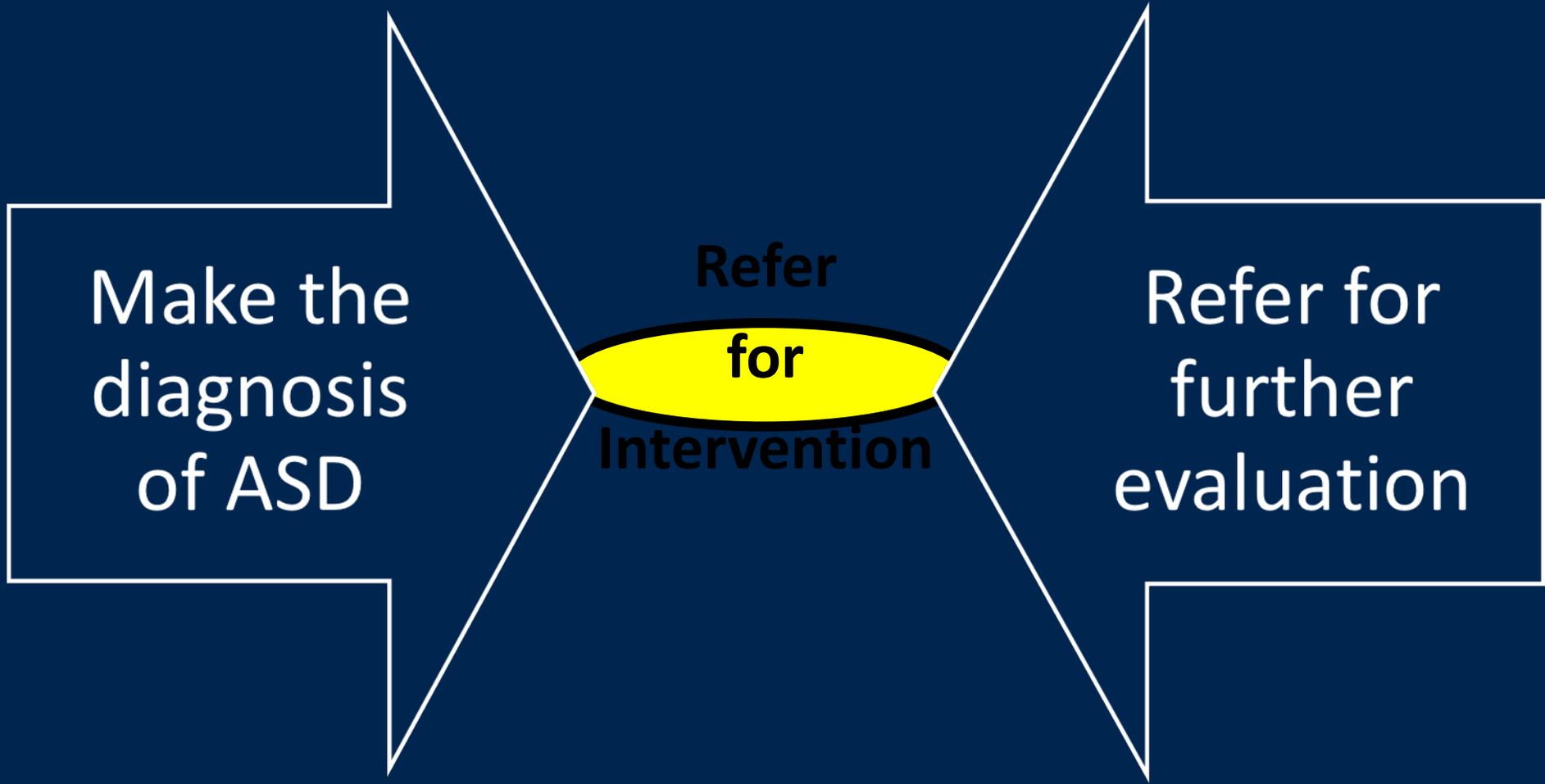
State and Local Organizations

FEAT-Houston.org

The ARC of Greater
Houston (aogh.org)

Knowautism.org

[NavigateLife Texas.org](http://NavigateLifeTexas.org)



Parents' Commonly Asked Questions

“What level of ASD does my child have?”

- Severity of ASD symptoms vs. overall level of developmental functioning
- Schools can evaluate level of developmental/cognitive functioning
- Those with more mild presentations generally require lower levels of support
- Severity may change over time as a function of development, interventions, and individual differences

Parents' Commonly Asked Questions

“Will my child grow out of it?”

- ASD is a pervasive developmental disorder
- Symptoms may wax and wane over time
- Appropriate interventions facilitate skill acquisition
- Most children do not lose the ASD diagnosis



Parents' Commonly Asked Questions

“What can I do to help?”

- Secure evidence-based services
- Specialized school-based services and private therapies
- Avoid non-evidence-based interventions



Recommendations for Suspected or Confirmed ASD Cases

- Early Childhood Intervention (ECI)
- Local public school/PPCD preschool programs
- Applied Behavior Analysis (ABA)
- Speech/Language therapy
- Behavioral family therapy (parent management training)
- Autism Speaks—toolkits
- CDC—Positive Parenting Tips



Early Childhood Intervention (ECI)

- Provides in-home services to children from birth-3 years
- May include developmental stimulation, speech/language therapy, occupational therapy, physical therapy, vision/hearing impairment services
- ECI also helps with transitioning to preschool programs at age 3 years



Obtaining ECI

- To locate local ECI providers:
 - Call 1-800-628-5115
 - Visit <https://dmzweb.dars.state.tx.us/prd/citysearch>
- Families can contact ECI; in Texas, providers are mandated to make referrals to ECI
- ECI has 45 days to complete the evaluation



School-Based Services for Children with ASD

- On their 3rd birthday, children with ASD (and other developmental disabilities) are eligible to receive services through their local public school district
- Services may include a specialized preschool program (PPCD), speech/language therapy, occupational therapy, physical therapy, in-home behavior support
- To determine eligibility for services, a Full and Individual Evaluation (FIE) through the families' zoned school should be requested IN WRITING

The Individuals with Disabilities Education Act (IDEA)

- Federal law that requires schools to serve the educational needs of students with disabilities, including ASD
- Ensures access to a **free and appropriate public education** (FAPE) for all
- Families can request an evaluation to determine eligibility for special education services ***at any time***
- IDEA gives families an equal say in decisions about their child's educational goals

Preschool Programs for Children with Disabilities (PPCD)

- Children ages 3-5 years with ASD eligible for PPCD
- Referral process can begin ~90 days before 3rd birthday (or any time between ages of 3 and 5 years)
- If a child *is* receiving ECI services, his or her ECI service provider can help get the referral process to PPCD started
- If a child *is not* in ECI, **the family** may request an evaluation and initiate the referral process for PPCD



Applied Behavior Analysis (ABA)

- Evidence-based intervention for children with ASD
- Increases prosocial and functional behaviors and reduces maladaptive behaviors
- Based on idea that people are more likely to repeat behaviors that are rewarded (positive reinforcement)
- 1:1 interaction between therapist and child; group instruction also useful



Why do we recommend ABA?

- Widely recognized as safe and effective treatment that can improve:
 - **Basic skills** such as looking, listening and imitating
 - **Complex skills** such as reading, conversing and understanding another person's perspective
- ABA techniques can produce improvements in
 - Communication, social skills, play, self-care and independence, learning

How to Access ABA

- FEAT-Houston (www.feathouston.org) maintains an updated list of in-home and center-based ABA providers
- Some private insurance plans cover ABA. Advise the family to:
 - Review policy and contact insurance company with questions
 - If ABA is not covered, advocate with their HR department to have ABA included as a covered benefit

How to Access ABA (continued)

- Although Medicaid, CHIP and many private insurance plans do not cover ABA, there are other ways to get help with behavior
- Harris Center, UH-Clear Lake and Texana Center offer grant-funded ABA programs (for example, ABA-SKIP)
 - Services provided to children ages 3-15 years
 - Apply early; wait lists can be long!



How to Access ABA (continued)

- Some families pay out of pocket for ABA consultations to help with a specific behavioral concern
- Families can find potential providers through:
 - www.feathouston.org
 - www.bacb.com



Social Skills Training

- Type of intervention often recommended for children with ASD
- Small group and 1:1 activities help children with social and communication difficulties learn to interact more appropriately with others
- May be offered through schools, community agencies, therapy practices



Social Skills Training

- Social skills training providers may offer programs from preschool-age through adulthood
 - Example: Social Motion Skills (www.socialmotionskills.org)
- These services are not usually covered by insurance
- Other options include online programs (example: Model Me Kids), books, and social stories



Other Therapies

- Speech/Language therapy – addresses speech and language delays and difficulties
- Occupational therapy – helps children develop fine motor skills and self-help skills (dressing, feeding, toileting)
- Physical therapy – works on gross motor skill development



Medicaid Waivers

- Refers to several programs that help with long-term needs for people with disabilities
- May provide Medicaid (regardless of family income), respite care, therapies, day habilitation, home modifications, and other services
- All programs have long waiting lists (~8-12 years!)
- Sign up as soon as possible

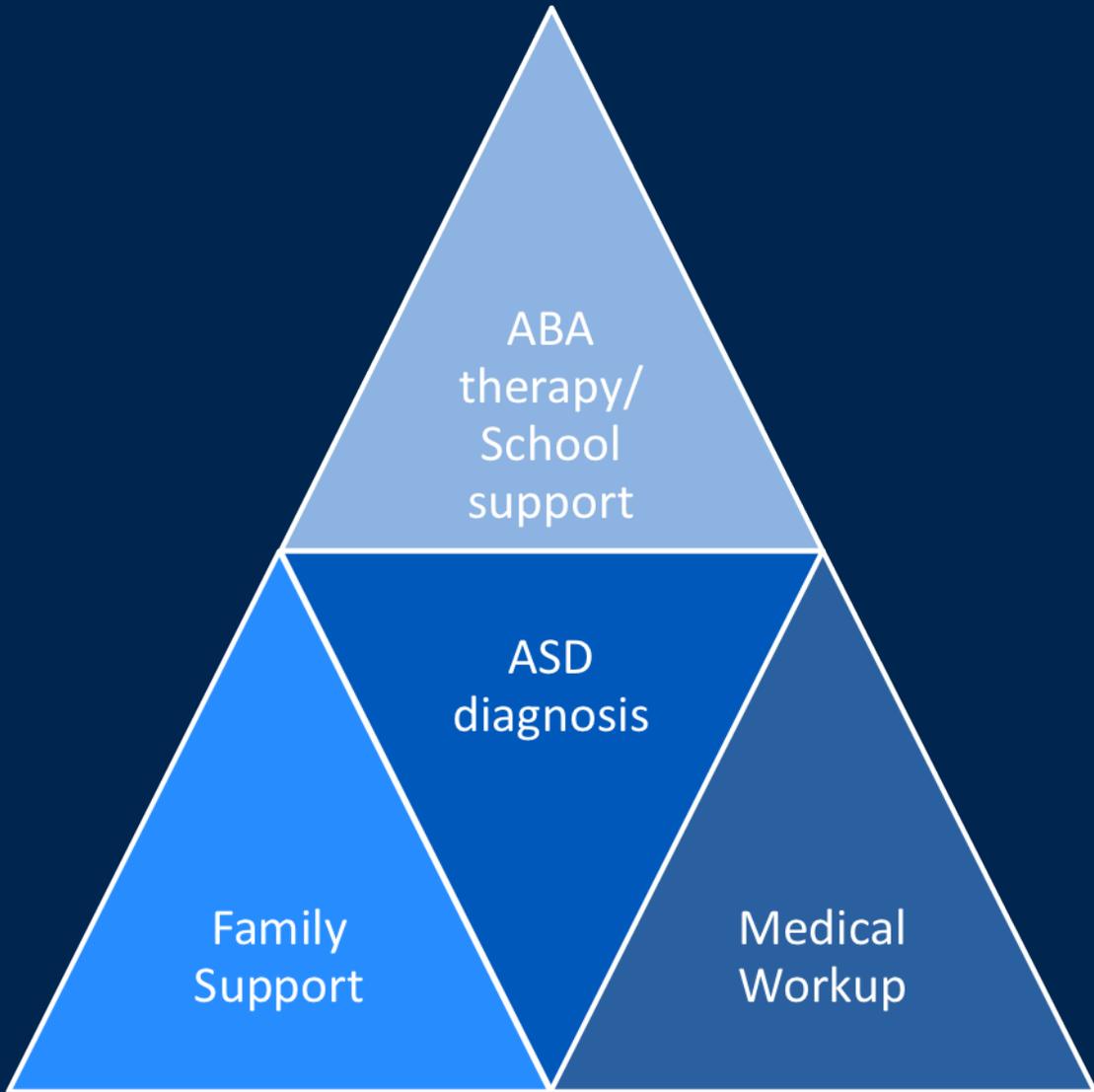
Informational Resources for Confirmed ASD Cases

- Autism Speaks—100 Days tool kit and Family Support tool kit autismspeaks.org/family-services/tool-kits
- Local MHMRA—for example, The Harris Center for Mental Health and IDD mhmrharris.org; Texana Center texanacenter.com
- Centers for Disease Control and Prevention cdc.gov
- Families for Effective Autism Treatment FEATHouston.org
- ARC of Greater Houston aogh.org
- DARS dars.state.tx.us
- Autism Society of America autism-society.org



Personal Support for Parents

- Support Groups and Organizations
 - Facebook groups or Meetup.com
 - Family To Family Network familytofamilynetwork.org
 - Know Autism know-autism.org
 - Project Autism projectautism.org
 - Katy Autism Support katyautismsupport.org
- Community
 - Therapy waiting rooms
 - Schools





Medical Workup

- Consistent biologic markers for ASD do not exist
- Additional medical workup for each child will vary based on medical history and presenting symptoms



Medical Workup

- Consider in all children with ASD:
 - Audiology assessment
 - Genetic testing (Chromosome Microarray Analysis [CMA]; DNA testing for Fragile X syndrome) (Schaefer et al., 2013)
 - Referral for clinical genetics evaluation

Genetic Testing

- Chromosomal Microarray Analysis (CMA) (Shen et al., 2010)
- DNA testing for Fragile X (Hatton et al., 2006)
- Identifying an etiologic diagnosis affords
 - Targeted surveillance for associated medical conditions
 - Genetic counseling
 - Peace of mind for family (knowing what caused their child's developmental disability)

Metabolic Testing

- Indications:

- History of decompensation with mild illness
- Cyclic vomiting
- Seizures
- Global developmental regression

- Physical exam findings:

- Hypotonia or hypertonia
- Course features
- Cleft palate
- Syndactyly



EEG

- Screening EEGs are ***not*** recommended for all children with ASD (AAP, 2012)
- EEG is indicated when:
 - Clinical history of seizures or suspicion of seizures
 - History of isolated language regression



Neuroimaging

- Indications:
 - Microcephaly
 - Midline facial defects
 - Neurocutaneous lesions
 - Seizures
 - Focal neurologic findings on exam



Sleep

- Prevalence of sleep disturbances in children with ASD ranges from 53-78% (Malow et al., 2012)
- Screening for both environmental and medical contributors should be performed
- Need for therapeutic interventions should be determined



Sleep History

- Providers can ask the following questions:
 - 1) Does the child fall asleep within 20 minutes after going to bed?
 - 2) Does the child fall asleep in the parent's or sibling's bed?
 - 3) Does the child sleep too little?
 - 4) Does the child wake up at least once at night?
 - 5) Does the child experience excessive daytime tiredness?

Sleep Resource



<https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/sleep-tool-kit>

Gastrointestinal Symptoms

- Parental report of GI symptoms is higher in children with ASD (Bresnahan et al., 2015)
- No consistent evidence associating GI disturbances and ASD (Ibrahim et al., 2009)
- Children with ASD presenting with GI symptoms warrant the same evaluation as children without ASD



Co-management of Care

- Many medical co-morbidities can be addressed by the pediatrician within the medical home
- The medical home provides coordination and organization of medical care, as well as referrals to appropriate interventions
- Communication between primary care providers and subspecialists is essential to co-management of care



Take Home Messages

1. Refer complex or questionable cases for ASD specialist evaluation and treatment
2. Provide educational, therapeutic, and personal-support referrals for families awaiting specialist evaluation and those who receive an ASD diagnosis
3. Perform the recommended medical diagnostic workup in children with confirmed or suspected ASD

Autism Center at Texas Children's

<https://www.texaschildrens.org/departments/autism>

- ASD diagnostic services
- Treatment/therapy
 - Parent management training, ABA, social skills groups, pharmacotherapy
- Family support
 - Workshops, newsletters, educational resources



Research at the Autism Center

- www.bcm.edu/autism



- *Our mission is to create knowledge about and advance our understanding of autism through research that brings value to families.*
- SPARK for Autism
www.sparkforautism.org/texaschildrens

Next Steps



Questions?

kochel@bcm.edu



CSHCN Systems Development Group Updates



Upcoming Events

- [Route 66 Abilities Conference](#)
 - Postponed due to Covid-19, new date TBD
- [Texas Primary Care Consortium Annual Summit](#)
 - Postponed due to Covid-19, new date TBD
- [16th Annual TxP2P Statewide Conference](#)
 - Postponed due to Covid-19
 - New date August 22-23
- [Project Leadership Training of Trainers](#)
 - November 2-4 in Austin
 - [Sign up for the interest list](#)



Other Member Updates and Upcoming Events

CSHCN Resource Guide: Now Available in Spanish

Apoyo para las familias

Avancemos Juntos Texas

Avancemos Juntos Texas es un sitio web con recursos para familias de niños con discapacidad y necesidades médicas especiales. Incluye herramientas y artículos, así como videos sobre diagnósticos, atención médica, apoyo familiar y otros temas. Para más información, visite la página web: navigatelifetexas.org.

Texas Parent to Parent

Esta es una organización sin fines de lucro dirigida por padres que proporciona apoyo a las familias de niños con discapacidad, necesidades médicas especiales y enfermedades crónicas. Para más información, visite la página web txp2p.org.

Aprenda más sobre los defectos de nacimiento

- Centros para el Control y la Prevención de Enfermedades (en inglés): cdc.gov/ncbddd/birthdefects
- March of Dimes (en inglés): marchofdimes.org
- Texas Birth Defects Epidemiology & Surveillance Branch (en inglés): dshs.texas.gov/birthdefects

Quiénes somos

El Grupo de Desarrollo de Sistemas para Niños con Necesidades Médicas Especiales (CSHCN) se esfuerza por mejorar la atención que reciben niños y adolescentes con necesidades médicas especiales. Colaboramos con organizaciones comunitarias en todo Texas para apoyar a las familias de estos niños. Para ver una lista de nuestros socios en la comunidad, visite el sitio web: dshs.texas.gov/mch/CSHCN/CSHCN-Contractors.aspx.

Póngase en contacto Grupo de Desarrollo de Sistemas de CSHCN

Department of State Health Services
CSHCN Systems Development Group
Mail Code: 1922
PO BOX 149347
Austin, TX 78714-9347

512-776-7373
CSHCNSDG@dshs.texas.gov

dshs.texas.gov/mch/CSHCN.aspx

Niños con Necesidades Médicas Especiales



Texas Department of State Health Services

Guía de recursos para las familias

Saber que su hijo tiene una discapacidad o una necesidad médica especial puede provocar confusión y miedo. Hay muchos recursos en Texas que pueden ayudarle a usted y a su familia a obtener la atención, los servicios y el apoyo que necesitan. Este folleto describe varios de esos servicios y programas.



2-1-1 Texas

2-1-1 Texas es un programa que ayuda a los texanos a encontrar los servicios que necesitan. Para usar este servicio marque 2-1-1 por teléfono o visite la página web 211texas.org (en inglés). 2-1-1 Texas incluye recursos en varias categorías como atención médica, cuidado infantil, discapacidad, alimentos y salud mental. Este servicio es gratuito, anónimo y está disponible todos los días del año y a cualquier hora.

Servicios de atención médica

STAR Kids

STAR Kids es el programa de atención médica administrada de Medicaid de Texas para personas con discapacidad menores de 21 años.

Algunos de los beneficios son:

- Atención primaria, especializada y hospitalaria
- Medicamentos con receta
- Equipo y artículos médicos

Para más información, visite la página web (en inglés):

hhs.texas.gov/services/health/medicaid-chip/programs/star-kids.

Medicaid Buy-In para Niños

Este programa fue creado para ayudar a familias que tienen un hijo con discapacidad, pero que ganan demasiado dinero para recibir Medicaid tradicional. Las familias pueden recibir cobertura de Medicaid haciendo pagos mensuales.

Algunos de los beneficios son:

- Citas médicas y transporte para acudir a ellas
- Servicios médicos para la vista, la audición, dentales y de hospital
- Recetas médicas, pruebas de laboratorio y radiografías

Para más información, visite la página web:

youtexasbenefits.hhsc.texas.gov/es/programas/atencion-medica/ninos/buy-in-ninos.

Programa de Servicios para Niños con Necesidades Médicas Especiales (CSHCN)

El Programa de Servicios de CSHCN ayuda tanto a personas menores de 21 años con necesidades médicas especiales como a personas de cualquier edad que padecen fibrosis quística.

Los beneficios incluyen servicios médicos, de salud mental, dentales y de la vista. El programa también ofrece la administración de casos, equipo médico y servicios de apoyo familiar. Para más información, visite la página web:

hhs.texas.gov/es/servicios/discapacidad/programa-de-servicios-para-ninos-con-necesidades-medicas-especiales.

Intervención Temprana en la Infancia (ECI)

ECI ayuda a las familias con niños desde el nacimiento hasta los 3 años de edad que tienen retrasos en el desarrollo, discapacidades o ciertas condiciones médicas que pueden afectar al desarrollo. Si su hijo llena los requisitos para recibir estos servicios, el equipo de ECI evaluará la rutina de su hijo y la de su familia y desarrollará un plan de servicios basado en la evaluación. Para más información, visite la página web:

hhs.texas.gov/es/servicios/discapacidad/servicios-de-intervencion-temprana-en-la-infancia.



New program brochure includes general health care and family support resources for CSHCN and their families. Order brochures here: <https://bit.ly/38t2cYo>



April is Autism Awareness Month

- [Coach to Communicate Parent Coaching](#)
 - For caregivers of children with Autism Spectrum Disorder age birth to 22
 - Individualized coaching based on child's needs to improve child's communication skills
- [28th Annual Texas Autism Conference](#) - August 6-7, San Antonio
 - Provides parents, educators, and campus leadership with strategies, resources, tools, and evidence-based practices in the education and service of students with Autism Spectrum Disorder.
- [AutFest at Home](#) – April 30, 7pm
 - **Films will be about autism or made by filmmakers with autism.** Through film and video we can raise awareness in a broader community about life with autism. Through film we can show a range of ages and abilities, challenges and triumphs, (however big or small), that living with autism can bring.
- [Parent 2 Parent Autism Listserv](#)
 - For parents with children who have Autism or Asperger syndrome to share information and support.



Trainings and Articles

- New Texas Health Steps Modules
 - [Breastfeeding, Postpartum Health: Screening and Intervention, Management of Overweight and Obesity in Children and Adolescents, and Trauma-informed Care for Children in Foster Care](#)
- New Texas Health Steps Quick Courses
 - [Food Insecurity: What Texas Health Steps Providers Need to Know, Housing Instability: What Texas Health Steps Providers Need to Know, Child Passenger Safety: What Texas Health Steps Providers Need to Know, and How to Recognize and Respond to Child Trafficking](#)



Videos and Webinars

- Primary Care Approach to Prevention – April 16, 12pm
 - [Register Here](#)
- Family Resource Centers and Family Engagement - April 22, 2pm
 - [Register Here](#)
- Reducing Health Disparities through Community Partnerships: Implementation Strategies - Apr 22, 1pm
 - [Register Here](#)
- American Immunization Registry Association: H1N1 Lessons Learned, April 27, 3pm
 - [Register Here](#)
- Supporting Families with Opiate Use Disorder through Family Resource Centers - April 29, 11:30am
 - [Register Here](#)



Additional Information

- [Genetics of Adult Intellectual Disability Research Study](#)
 - Scientists at Baylor College of Medicine are looking for adults with intellectual disability to participate in a genetic study
 - If a family is interested in participating, please direct them to the study web site for eligibility criteria and additional information



2020 Census Reminder

- April 1: Census Day – every home will receive an invitation to participate in the Census by this date
- May – July: Census takers were to begin visiting homes that haven't responded to the 2020 Census
- December: Census Bureau will deliver apportionment counts to the President and Congress
- For more Census info, visit 2020census.gov
- For a "Why the 2020 Census Matters to Texans" Fact Sheet and Toolkit, visit [here](#).



Upcoming Meetings

- Transition to Adulthood Learning Collaborative
 - May 13, 12 pm – 1:30 pm CT
- Medical Home Learning Collaborative
 - June 15, 10 – 11:30 am CT (Date and time subject to change)



Thank you!

Please take the post-call survey. We value your feedback!

Cassandra.Johnson@DSHS.Texas.gov

