

Connecticut Children's CLASP Guideline

Suspected Autism Spectrum Disorders (ASD)

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder characterized by impairments in social interaction, social communication and restricted/repetitive behaviors/sensory issues. The CDC estimates that about 1 in 44 children in the United States have an ASD, with a 4:1 male to female ratio.¹ ASDs affect children across racial/ethnic groups; yet there are disparities in the age of diagnosis with children of color getting diagnosed, on average, more than a year later than white children. Early identification and intervention are essential to optimize outcomes for the affected child and their family.

The Connecticut Children's Autism Spectrum Disorders Program (ASDP), part of the Developmental Behavioral Pediatrics (DBP) division, is designed to identify ASD in children between the ages of 18 months and 18 years. We are located in Farmington and Norwalk. **Children suspected of having an ASD should be referred to DBP.**

INITIAL EVALUATION AND MANAGEMENT FOR CHILDREN < 4 YEARS OLD

INITIAL EVALUATION:

- Complete "autism red flags" checklist
 - No babbling by 12 months
 - No pointing or gestures by 12 months
 - No single words by 16 months
 - No spontaneous 2-word combinations by 24 months
 - Loss of language or social skills at any age
- Parent/Caregiver completion of **M-CHAT-R/F checklist**
 - **See Appendix A: Permissions and Instructions for Use**
 - *Note: The M-CHAT-R/F should universally be administered twice between 16 months and 30 months old (typically at the 18- and 24-month well child visits).*
- Consider use of **Sparkler**, a developmental tracking tool for children under age 5 available for PCPs (utilizes ASQ-3 and ASQ:SE-2), and/or provide families with handout so that they may access Sparkler and its resources. Sparkler connects families directly to CT Help Me Grow/211 Child Development Care Coordinators and well as provides families with activities to promote learning. <https://www.playsparkler.org/sparkler-ct-for-doctors/>

INITIAL MANAGEMENT FOR POSITIVE M-CHAT-R/F SCREENS OR PARENTAL/PEDIATRIC TEAM CONCERNS:

- **Refer** to Developmental Behavioral Pediatrics for ASD evaluation at Connecticut Children's.
- **At the same time**, refer to Birth to Three (B23). Call Infoline – 211 for more information on programs and services (**See Appendix C: Child Development Information Line family handout**)
 - Care Coordination needs are assessed up front by the B23 team. However, you may want to also assess for care coordination needs at the time of the referral to Birth to Three. If care coordination needs identified, refer families to CT Children's Center for Care Coordination via CT Children's One Call Access Center (Phone: 833-733-7669 or Fax: 833-226-2329)
- Refer, as usual, to appropriate Clinical Support Services as needed via One Call (1-833-733-7669)
 - Refer to Audiology for a hearing test, unless already done
 - For speech and language concerns, refer to Speech Language Pathology*
 - For fine motor delays, sensory functioning concerns or delays in activities of daily living, refer to Occupational Therapy*
 - For gross motor delays, refer to Physical Therapy*
- If there are **ALSO** concerns of possible neurologic disorders including seizures, ataxia, muscle weakness/hypotonia, gross motor delay, or otherwise abnormal neurological exam, please also **refer as usual to Neurology**.
 - However, **Neurology does not conduct autism diagnostic evaluations**. If you are seeking an autism evaluation, referral should be made to Developmental-Behavioral Pediatrics (DBP).

**Birth to Three evaluations also assess speech/language, fine and gross motor skills.*

INITIAL EVALUATION AND MANAGEMENT FOR CHILDREN ≥ 4 YEARS OLD

INITIAL EVALUATION:

- Complete “autism red flags for older children” checklist
 - Difficulty with back-and-forth conversation
 - Difficulty understanding & using nonverbal signals (i.e., facial expressions, gestures)
 - Difficulty developing and maintaining friendships with peers
 - Formal-sounding speech
 - Difficulty understanding humor/literal interpretation of other’s speech regardless of context
 - Limited imaginative and/or pretend play
- Administer **an autism-specific screening instrument**
See Appendix B: Autism Screening Instrument for Older Children
Note: An autism-specific screening instrument should be administered whenever red flags are identified by family, pediatric team or school personnel.
- Consider use of **Sparkler**, a developmental tracking tool for children under age 5 available for PCPs (utilizes ASQ-3 and ASQ:SE-2), and/or provide families with **Sparkler handout** so that they may access Sparkler and its resources. Sparkler connects families directly to CT Help Me Grow/211 Child Development Care Coordinators and well as provides families with activities to promote learning. <https://www.playsparkler.org/sparkler-ct-for-doctors/>

INITIAL MANAGEMENT:

- **Refer** to Developmental Behavioral Pediatrics for ASD evaluation at Connecticut Children’s.
- **At the same time**, refer to the local educational agency (LEA) and contact Infoline – 211 for more info on programs and services available (*See Appendix C: Child Development Information Line family handout*)
 - Contact information for LEA can be found on Birth to Three’s website (www.birthe23.org) under “Programs by Town”
- It will be important for you to uncover any unmet family care coordination needs.
 - If care coordination needs identified, refer families to CT Children’s Center for Care Coordination via CT Children’s One Call Access Center (Phone: 833-733-7669 or Fax: 833-226-2329)
- Refer, as usual, to appropriate Clinical Support Services as needed via One Call (1-833-733-7669)
 - Refer to Audiology for hearing testing, unless already done
 - For speech and language concerns, refer to Speech Language Pathology
 - For fine motor delays, sensory functioning concerns or delays in activities of daily living, refer to Occupational Therapy
 - For gross motor delays, refer to Physical Therapy
- If there are **ALSO** concerns of possible neurologic disorders including seizures, ataxia, muscle weakness/hypotonia, gross motor delay, or otherwise abnormal neurological exam, please also **refer as usual to Neurology**.
 - However, **Neurology does not conduct autism diagnostic evaluations**. If you are seeking an autism evaluation, referral should be made to Developmental-Behavioral Pediatrics (DBP).

WHEN TO REFER TO DBP

Referral to DBP for Connecticut Children’s ASD Program if:

- Positive screen on Autism-Specific screening instrument (e.g., M-CHAT-R/F, SCQ)
- Presence of any “red flags”
- Autism concern raised by parents, pediatric team, Birth to Three provider, school personnel, or other community members

HOW TO REFER TO DBP

- Complete our [Referral form](#) and identify referral concerns. Indicate referral reason as “ASD Evaluation”.
- Provide complete health history including results of current audiology and other clinical support services assessments, and any other relevant assessments as available. Please include last visit note from well child care visit.
- FAX information to **1-833-CCMC-FAX**

WHAT TO EXPECT

What to expect from Connecticut Children's DBP Visits:

- Complete Developmental and Medical History
- Review of documents from B23, school district, other consultants
- Assessment for ASD, as indicated
- Discussion of findings with family, including recommendations for services and support
- If diagnosed with an ASD, referral to Neurogenetics or other subspecialty clinics within Connecticut Children's, as indicated.
- Visit notes sent to primary care team
- Follow-up plan for ongoing monitoring and management

APPENDIX A: Permissions and Instructions for Use

Permissions for Use of the M-CHAT-R/F™:

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from www.mchatscreen.com. The M-CHAT-R/F is a copyrighted instrument, and use of the M-CHAT-R/F must follow these guidelines:

- (1) Reprints/reproductions of the M-CHAT-R must include the copyright at the bottom (© 2009 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.
- (2) The M-CHAT-R must be used in its entirety. Evidence indicates that any subsets of items do not demonstrate adequate psychometric properties.
- (3) Parties interested in reproducing the M-CHAT-R/F in print (e.g., a book or journal article) or electronically for use by others (e.g., as part of digital medical record or other software packages) must contact Diana Robins to request permission (DianaLRobins@gmail.com).
- (4) If you are part of a medical practice, and you want to incorporate the first stage M-CHAT-R questions into your own practice's electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request a licensing agreement.

Instructions for Use:

The M-CHAT-R can be administered and scored as part of a well child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from <http://www.mchatscreen.com>. Associated documents will be available for download as well.

APPENDIX B: Autism Screening Instruments for Older Children

NAME OF INSTRUMENT	DESCRIPTION	AGE RANGE	COST/AVAILABLE FROM
Social Communication Questionnaire (SCQ) <i>(Rutter, Bailey, & Lord, 2003)</i>	<ul style="list-style-type: none"> • Designed to screen • Short, easy to do in doctor's office (less than 10 minutes) • Has cut-offs for recommending further evaluation • Parent response scale with 40 yes/no items • Based on the ADI-R 	Can be done for anyone over age 4 (mental age over age 2)	<ul style="list-style-type: none"> • Available from WPS www.wpspublish.com • \$175.00 for autoscore version with 20 current and 20 lifetime forms included • \$56.00 for a pack of 20 current forms or 20 lifetime forms • \$291.00 for unlimited use administration and scoring CD

¹Maenner MJ, Shaw KA, Bakian AV, Bilder DA, Durkin MS, Esler A, Furnier SM, Hallas L, Hall-Lande J, Hudson A, Hughes MM, Patrick M, Pierce K, Poynter JN, Salinas A, Shenouda J, Vehorn A, Warren Z, Constantino JN, DiRienzo M, Fitzgerald RT, Grzybowski A, Spivey MH, Pettygrove S, Zahorodny W, Ali A, Andrews JG, Baroud T, Gutierrez J, Hewitt A, Lee LC, Lopez M, Mancilla KC, McArthur D, Schwenk YD, Washington A, Williams S, Cogswell ME. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. *MMWR Surveill Summ.* 2021 Dec 3;70(11):1-16. doi: 10.15585/mmwr.ss7011a1. PMID: 3485725; PMCID: PMC8639024.

HOW IS YOUR CHILD DOING?



Check in and help spark healthy early growth and learning with

sparkler

SPARK EARLY LEARNING!

sparkler is a FREE mobile app for Connecticut families, helping parents support children's development from birth through 5! Understand your child's development with the mobile Ages & Stages Questionnaires®; learn together through play; track growth; and get tips and answers to questions.

How to Get Started with Sparkler:

- ▶ Download Sparkler from  or  . Or scan the QR Code with your mobile device to go straight to the right place for downloading.
- ▶ Open app and tap Create a New Account.
- ▶ Enter your Sparkler access code to tap into local supports and resources.
- ▶ Create your account.
- ▶ Add a child to your account.

TO DOWNLOAD: USE QR CODE OR PLAYSPARKLER.ORG/CT.

REGISTER WITH ACCESS CODE:



Connecticut Office
of Early Childhood



Help Me Grow
Connecticut

Sparkler is safe and secure, and available in English and Spanish.

¿CÓMO LE VA A SU HIJO/A?

Regístrese en **sparkler** y ayúdele a crecer y aprender de forma saludable.

DÉJESE INSPIRAR Y APRENDAN JUNTOS MIENTRAS JUEGAN.

sparkler es una app móvil GRATUITA para familias de Connecticut ¡que ayuda a los padres a promover el crecimiento saludable de sus hijos de 0 a 5 años! Puede comprender el desarrollo de su hijo/a con los cuestionarios móviles Ages & Stages®; aprender juntos; seguir el crecimiento de su hijo/a; y obtener sugerencias y respuestas.

Cómo empezar con Sparkler:

- ▶ Descargue Sparkler en  o . Visite playsparkler.org/ct o escanee este código QR code para iniciar la descarga.
- ▶ Abra la app y seleccione Crear una Nueva Cuenta.
- ▶ Introduzca su código de acceso a Sparkler para vincularse a su programa/proveedor.
- ▶ Cree su cuenta.
- ▶ Añada su niño/a. Puede añadir tantos perfiles como niños desee registrar.

Para descargas: Use el código QR o entre en playsparkler.org/CT.

REGÍSTRESE CON EL CODIGO:



Connecticut Office
of Early Childhood

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Child development



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