

Understanding Autism

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Developmental & Behavioral Pediatrics

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Developmental & Behavioral Pediatrics

- 1) Clinical Services
- 2) Research
- 3) Community Program: Strong Center for Developmental Disabilities (SCDD)



Strong Center for Developmental Disabilities

University Center of Excellence in Developmental Disabilities (UCEDD) that promotes:

- Independence
- Productivity
- Integration & Inclusion



Department of Health SSIP Project

IFaCT- Improving Family Centeredness Together

This webinar series is part of the New York State Systemic Improvement Plan (SSIP) aimed to improve family-centeredness in the Early Intervention Program



Webinar Series Housekeeping

1. 10 webinars, September 2019 through June 2020
2. Webinars will be recorded and available for viewing after the live presentation through the SCDD website, and on our YouTube channel (PediatricsURMC)
3. To receive a certificate of completion, you must complete the satisfaction survey emailed to you after the webinar
4. Use the chat feature to submit questions during the webinar



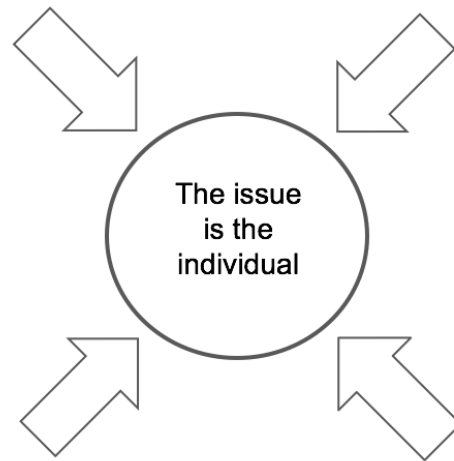
Learning Objectives:

1. Review context of Autism Spectrum Disorder (ASD) diagnosis
2. Describe ASD diagnostic criteria and evaluation process
3. Discuss family/provider interactions around ASD evaluation referrals

Neurodiversity

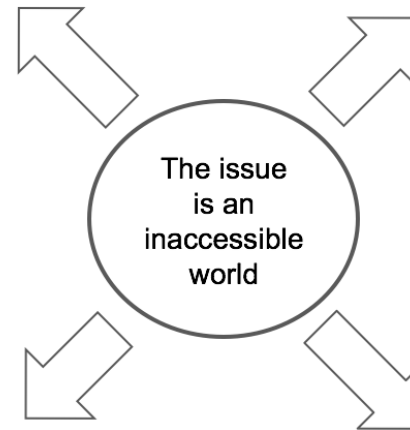


Medical Model of Disability



Medical Model

Social Model of Disability



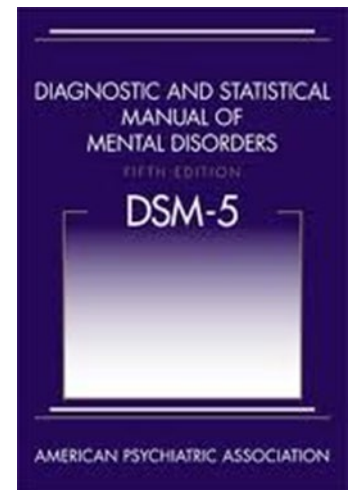
Social Model

Autism Spectrum Disorder (ASD)

- Centers for Disease Control and Prevention (CDC) reports 1 in (59) children
- ASD is more prevalent in males than females (4.5 to 1)

Why the Increase in Prevalence?

- Increased Awareness of ASD
 - contributes to early detection & diagnosis
- Broader Criteria - Diagnostic And Statistical Manual Of Mental Disorders (DSM-5)
- Improved Diagnostic Centers
- Increase in ASD Research



What Causes ASD?

- No definitive cause



ASD

Social-
Communication



Restricted/
Repetitive
Behaviors
and/or Interests



ASD Symptoms

Social- Communication



Reciprocity (back and forth)

Nonverbal Communication

Play and Friendships

Characteristics of Social Communication

- Unusual eye contact
- Unusual or limited facial expressions
- Difficulties with peer relationships & conversations
- Reduced interest in sharing with others
- Difficulties understanding emotions
- Problems understanding other people's point of view
- Language delays
- Repetitive or odd use of language
- Problems with pretend play

Characteristics of Social Communication (continued)

- Concrete and literal
- One-sided, decreased turn taking
- “Little professor” vocabulary

ASD Symptoms

Restricted/
Repetitive
Behaviors
and/or Interests



Repetitive Behavior

Rigidity/Resistance to Change

Intense Interests

Sensory

Restricted, Repetitive Patterns of Behavior, Interests, or Activities

- Stereotyped or repetitive speech, motor movements or use of objects
- Excessive adherence to routines, ritualized patterns of behavior, or excessive resistance to change
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment

Restricted, Repetitive Patterns of Behavior, Interests, or Activities

- Impulsivity, inattention, hyperactivity
 - Over 50% of children
- Unusually intense or odd interests
- Rigidity, inflexibility
- Repetitive movements (e.g., flapping hands)
- Overly focused on parts of objects (e.g., looking closely at wheels of a car rather than playing with the whole car)
- Sensory interests or sensory sensitivity (e.g., disliking certain textures or being touched)

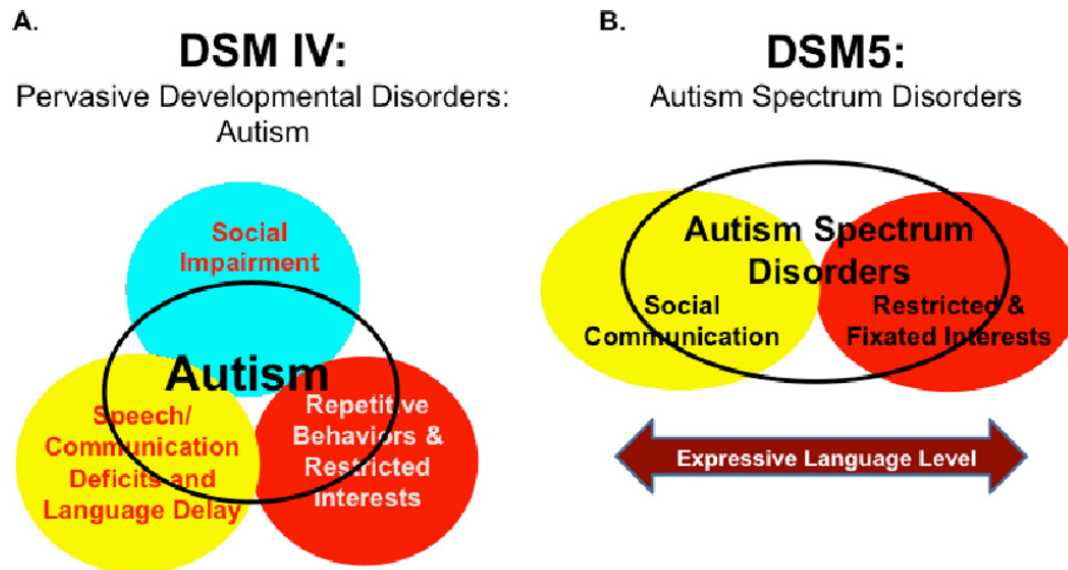
Restricted, Repetitive Patterns of Behavior, Interests, or Activities (continued)

- Symptoms must be present in early childhood (but may not become obvious until social demands exceed their skills)
- Symptoms together limit everyday functioning



Changes within DSM-5

1. Only one category: Autism Spectrum Disorder
2. Two clusters of core symptoms, not three:
 - Social Communication
 - Repetitive Behaviors
3. Language disorders diagnosed separately

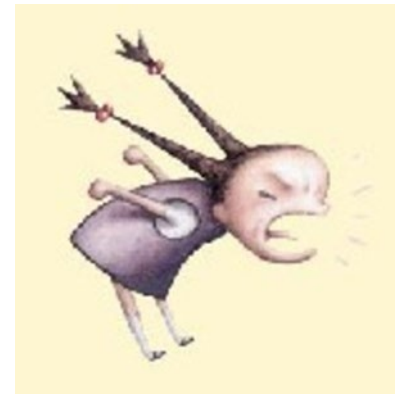


Comorbidities in ASD

- Intellectual disability
- Developmental/ Genetic disability
- Motor and adaptive delays
- Attention Deficit Hyperactivity Disorder (ADHD)
- Anxiety
- Depression
- Executive function problems
- Language delays
- Seizure disorders
- Sleep disorders
- Gastrointestinal (GI) disorders
- Feeding disorders

Some Behaviors We May See

- Noncompliance
- Self-stimulatory behaviors
- Self-injurious behaviors
- Aggression
- Wandering or running away
- Hyperactivity
- Insistence on sameness
- Impulsivity
- Inflexibility
- Hyper or hypo reactivity to sensory input
- Anxiety
- Social withdrawal



Misconceptions of ASD

It is NOT true that individuals with ASD...

- Are not affectionate. Many children with ASD have very strong relationships with family and friends.
- Don't understand what others are saying. Even children with very limited language may have strong comprehension skills.
- All have extraordinary memories or other skills. Superior skills are not more common in ASD than in the general population, although children with ASD certainly can show strengths in some areas.
- Develop skills evenly. Some aspects of a child's skills (such as nonverbal problem-solving) might be much higher or lower than other skills (such as verbal understanding).
- Do not feel or understand emotions. Many children with ASD feel emotions quite strongly and can also identify emotions in others.

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DIAGNOSTIC PROCESS

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First Concerns



First Signs Recalled by Caregivers:

- Regression in milestones (NOT universal)
 - Loss of words, may have loss of social and adaptive skills
- Language delays in second year
- Behavioral difficulties
- Sleep, eating, repetitive behaviors, aggression, self-injurious behavior
- Diagnosis in Western NY community is typically at age 3-4 yrs.

Developmental Surveillance Versus Screening

Surveillance = accomplished through general observation at well child checkups

Screening = routine developmental screening at 9, 18, and 30-month visits and *ASD specific screening* at 18 and 24-month visits

Referral = for diagnostic evaluation

- Very young children may go through the Early Intervention Program (birth to 3 years of age)
- ASD-specific evaluation

Adapted from Susan Hyman (UR Medicine)

Referral to the Early Intervention Program



1. Referral *(Unless parent objects)*

- Referral source or parent suspects child of having developmental delay or disability
- Family informed of benefits of Early Intervention Program (EIP)
- Child referred to Early Intervention Official (EIO) within two days of identification
- EIO assigns Initial Service Coordinator

Gold Standard Evaluation for ASD

ADOS-2 (Autism Diagnostic Observation Schedule)

- Play-based assessment
- Pulls for core features of ASD

Developmental History (with parent)

- Standardized interview (e.g., Autism Diagnostic Interview)
- Clinical developmental history

Evaluation must be completed by a licensed physician, psychiatrist, developmental/behavioral pediatrician) or licensed psychologist

What We Know About the Diagnostic Process

- Parents are often the first to express concern
- In the Western NY community, diagnosis typically occurs at age 3-4 years
- Population surveillance data reveal later age at diagnosis for African American and Hispanic children, suggesting that there are barriers to screening and surveillance and referral for diagnosis in groups with other unmet health needs

Baio J, Wiggins L, Christensen DL, et al.



FAMILY ENGAGEMENT

Involvement versus Engagement versus Partnership

Involvement

- Families come to you or families “let” you in
- Unidirectional sharing of information
- “Change” targeted at family

Engagement

- Families and organizations come to each other
- Open lines of communication
- Families and providers are both changed

Partnership

- Shared vision, goals, and decisions

Person-First Versus Identity-First Language



Photo by Sharon McCutcheon



A Respectful Way to Speak About People Without Defining Them by Their Disability:

- Focus on the individual & not the disability (e.g., "Johnny is a 5 year old child") instead of always naming him as an autistic child or child with autism
- Avoid negative or sensational descriptions (e.g., "Luis is a victim of CP" or "Unfortunate child suffering from intellectual disability")
- Avoid using "normal" to describe people without disabilities; (Use "typically developing")
- Speak to the child/person. Avoid talking over them or only to their parents.

Involving Parents/Guardians

- Ask parents what works best or if anything should be avoided
- Follow the parent's approach to their child
- Ask about strategies for behavior and what has worked in the past



Engage Families in Decision-making

Collaborative decision-making and goal planning

Promoting authentic voice

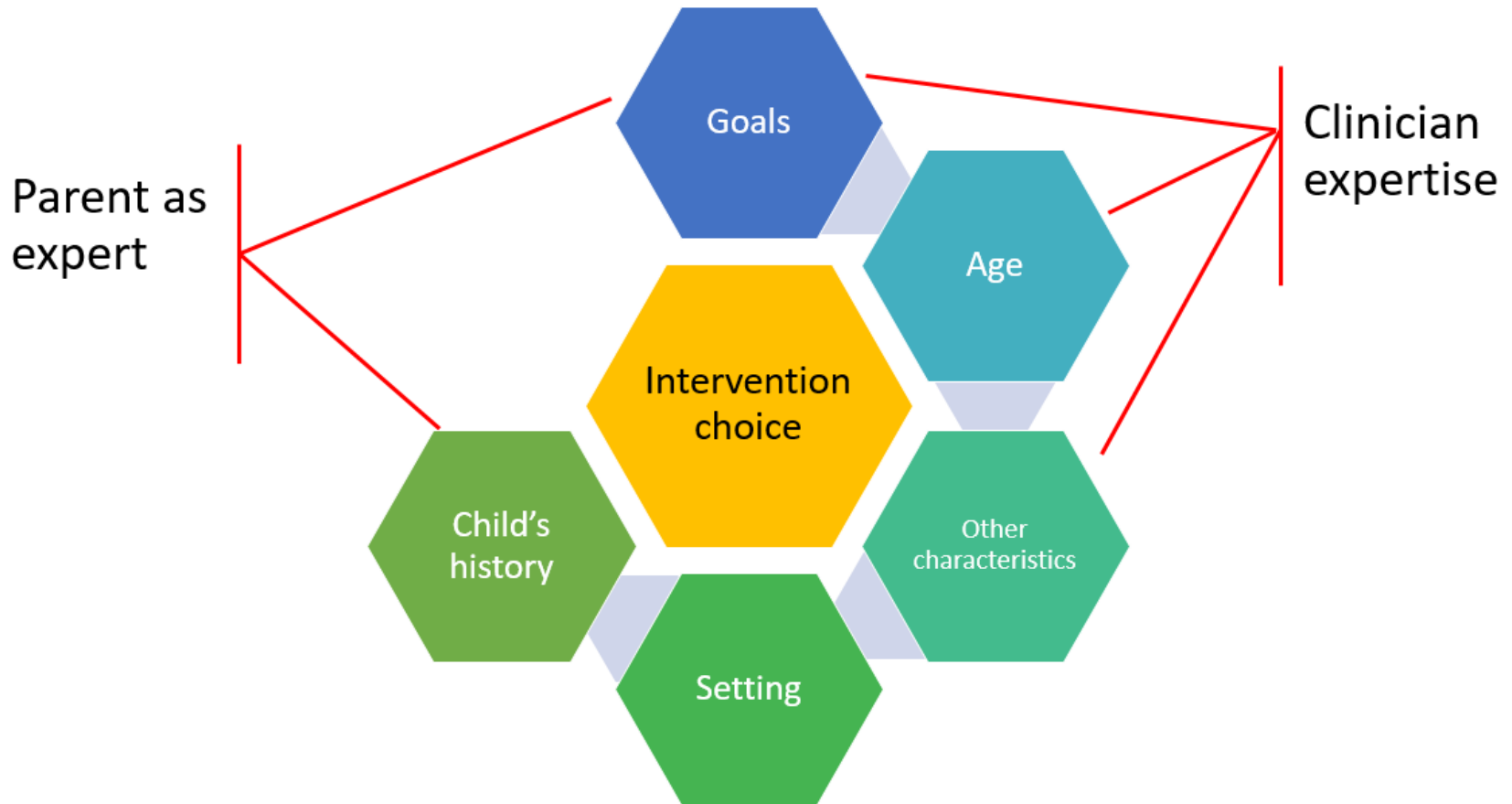
- Includes a setting where families feel comfortable speaking up

How often is the decision already made when the family walks in the room?

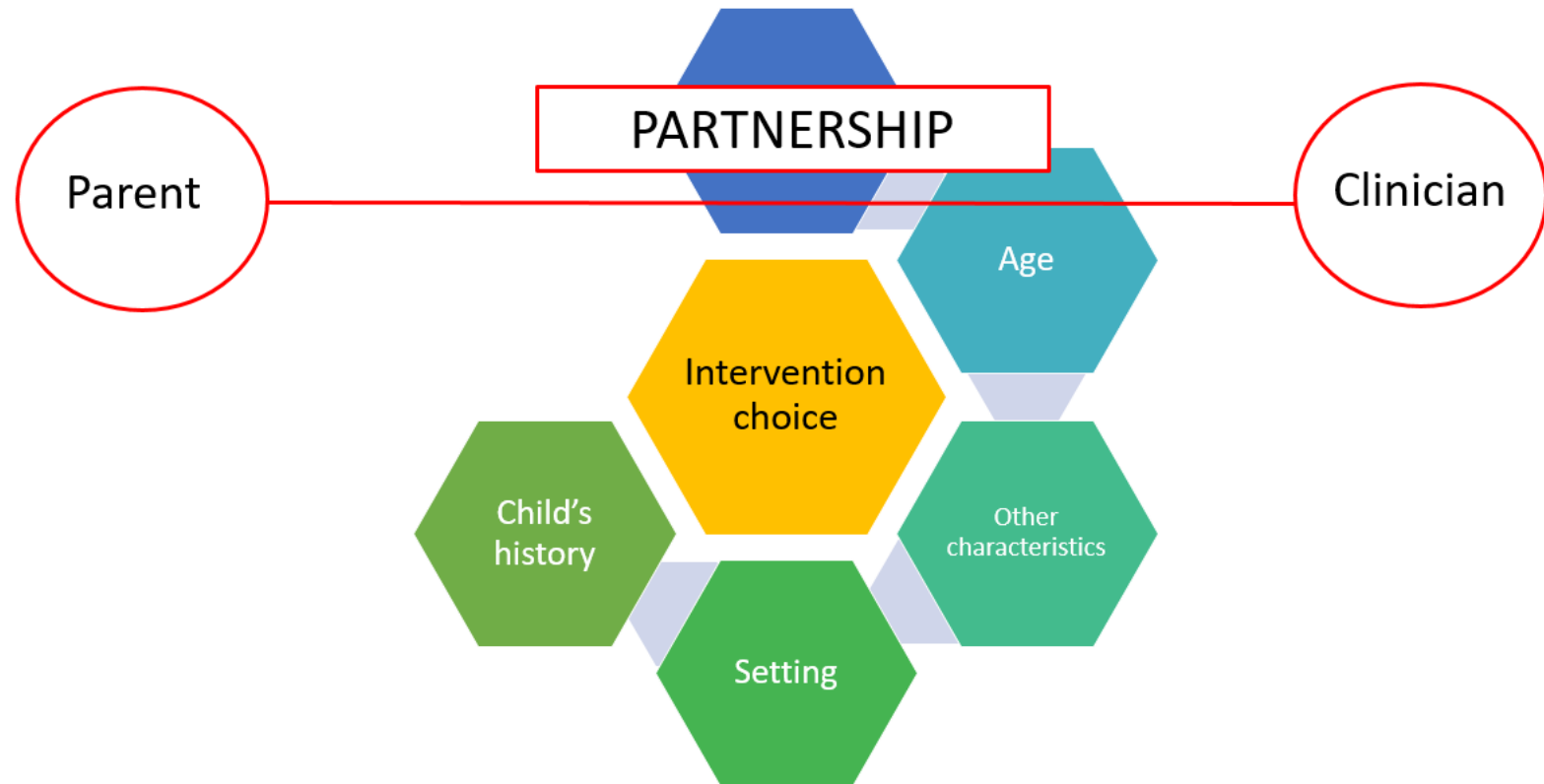


Programs should be matched to each child's and family's needs

Making Informed Decisions



Making Informed Decisions



TALKING WITH FAMILIES

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Finding Common Ground

Framing what you notice in terms of their goals or observations

- Which means you have to ask about their goals and observations

Respecting the family's values and their culture

Always assume good intentions:

- Everyone wants what is best for the child

Separating your Observations from “Fact”

“He does x, y, and z” versus “I’ve noticed that in this situation he does x, y, and z. What do you notice at home?”



Using Neutral Language

“Concerns about a delay” versus “signs of a delay”

Conveying through language that a delay would be a bad thing...how often do we assign judgment or value without realizing it?

- Tone
- Words used



Remembering the Strengths



Photo Credit: Valeria Ushakova

Focusing on the Next Steps

Walking the parent through the process of self-referral

What will the evaluation be like?

http://libguides.urmc.rochester.edu/ld.php?content_id=42929696

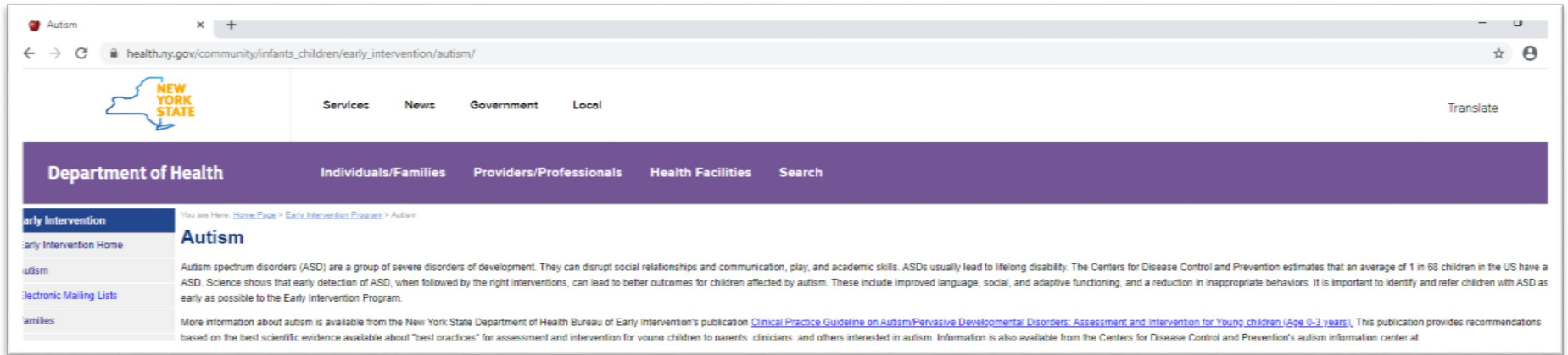
Anticipating wait times and sharing what can be done in the interim

Questions



Early Intervention Program Website: Autism

https://www.health.ny.gov/community/infants_children/early_intervention/autism/



Resources

- Info from CDC on ASD diagnosis:
<https://www.cdc.gov/ncbddd/autism/screening.html>
- Expected milestones and signs that indicate a need for screening: <https://www.autismspeaks.org/learn-signs-autism>
- Information on a standardized ASD screener (the M-CHAT): <https://mchatscreen.com/>
- Municipal/County Contacts for the Early Intervention Program:
https://www.health.ny.gov/community/infants_children/early_intervention/county_eip.htm

Webinar Evaluation!

We want your feedback*

<https://www.surveymonkey.com/r/scddwebinar3survey>



***Complete the online evaluation in order to receive a certificate of completion**



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