Autism and the Medical Home: Before, During, and After the Diagnosis

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Accreditation

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Please note:

- This webinar is being recorded. Recording and slides will be made available to participants.
- CME evaluation link will be sent following the conclusion of the webinar.
- Q&A will be held at the end of the presentation. Please enter questions into the Q&A function located at the top or bottom of your screen.

Objectives:

1) review the recommendations for autism screening in primary care

2) discuss the diagnostic process for Autism Spectrum Disorder (ASD)

3) recognize important issues for children with ASD within the medical home

4) learn about the NJ AAP Early Identification and Referral for Autism (EIRA) Project ECHO

Disclosures

I have no financial disclosures.

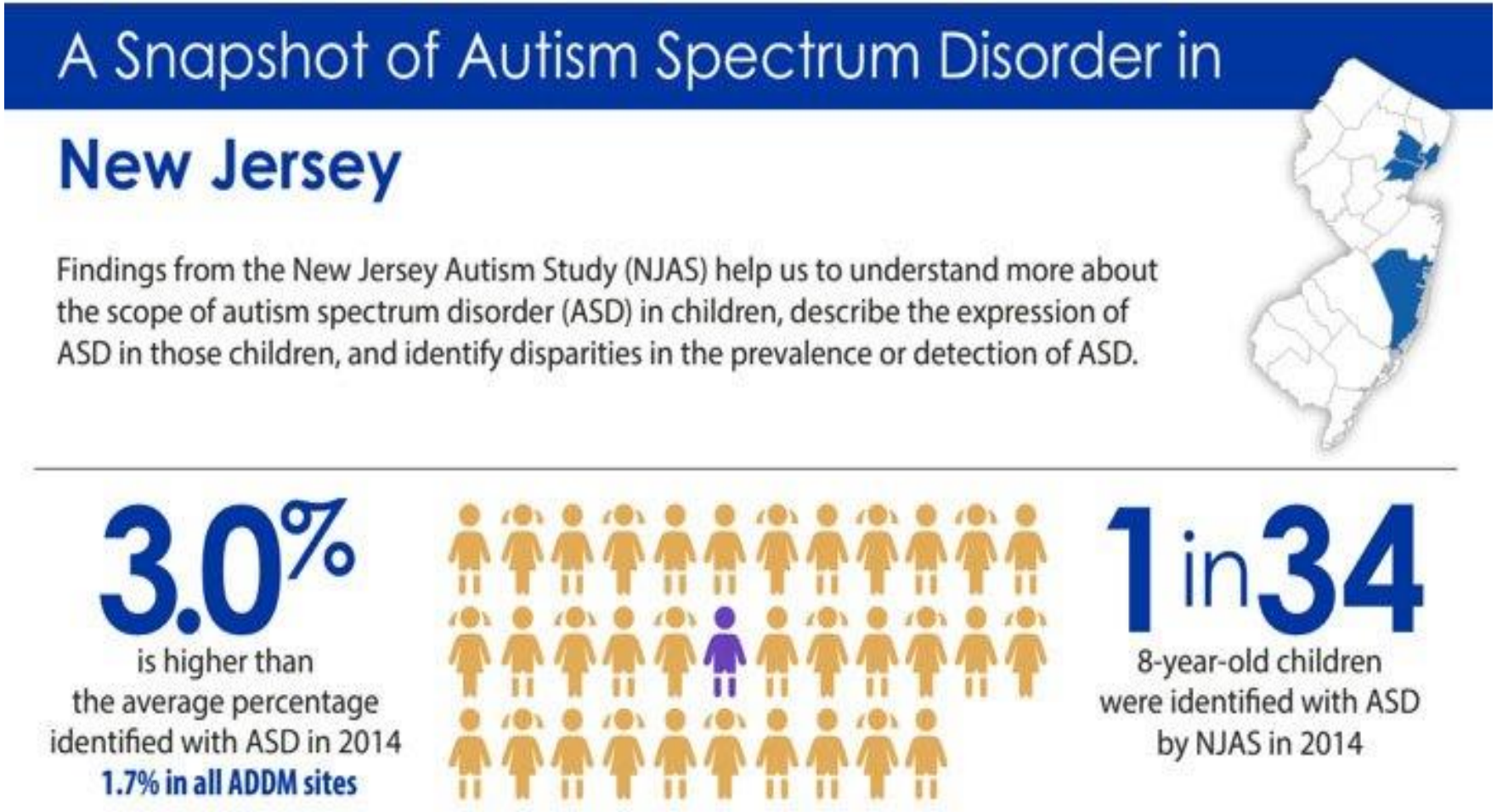
I will be discussing meds using generic and brand names

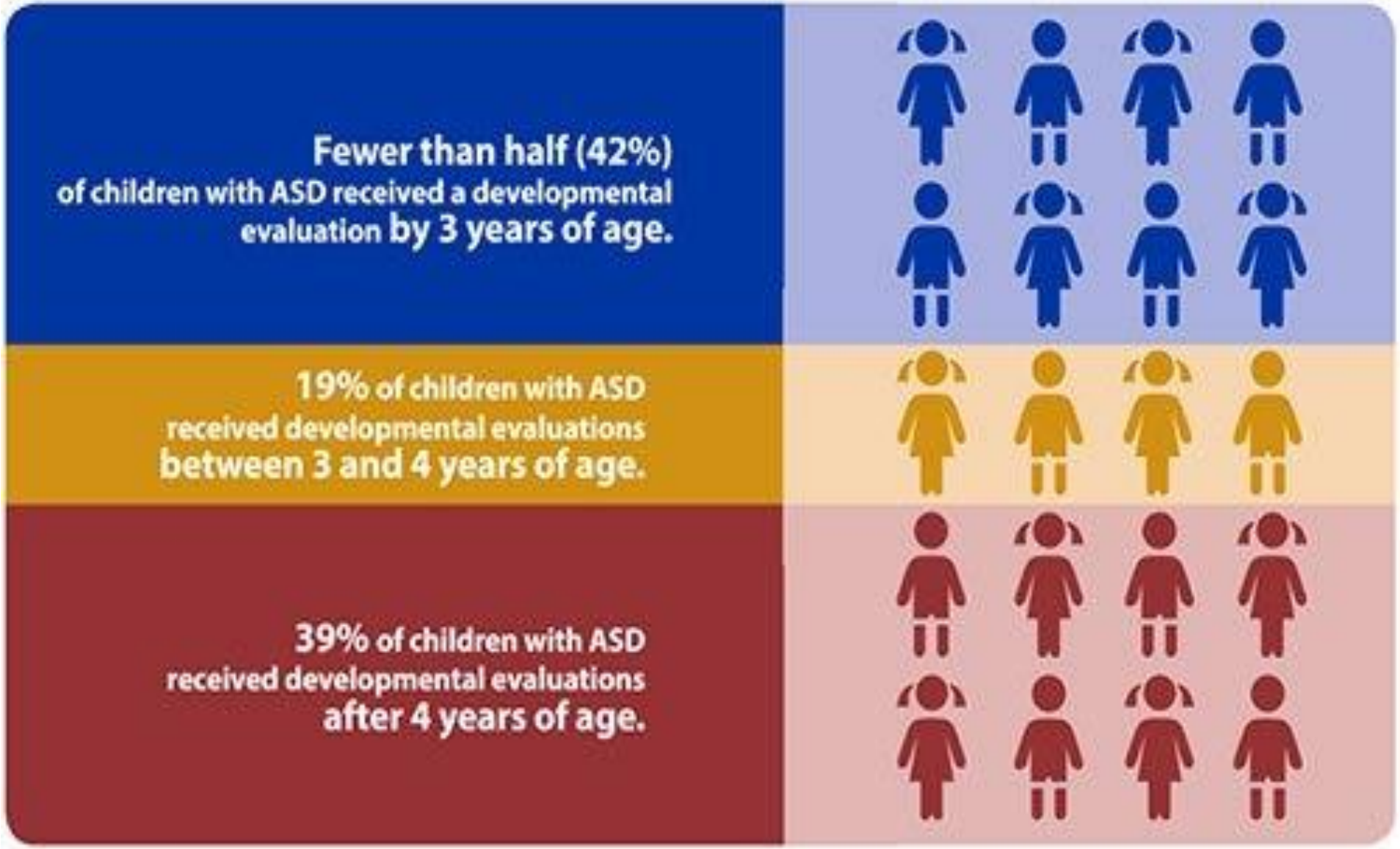
I will be discussing some non-FDA-approved alternative treatments

Autism Facts

And in NJ-
1 in 34

CDC surveillance




Fewer than half (42%)
of children with ASD received a developmental evaluation by 3 years of age.
19% of children with ASD received developmental evaluations between 3 and 4 years of age.
39% of children with ASD received developmental evaluations after 4 years of age.

Why do we all need to know about ASD ?

Because it is relatively common

You will see children in your practice with ASD

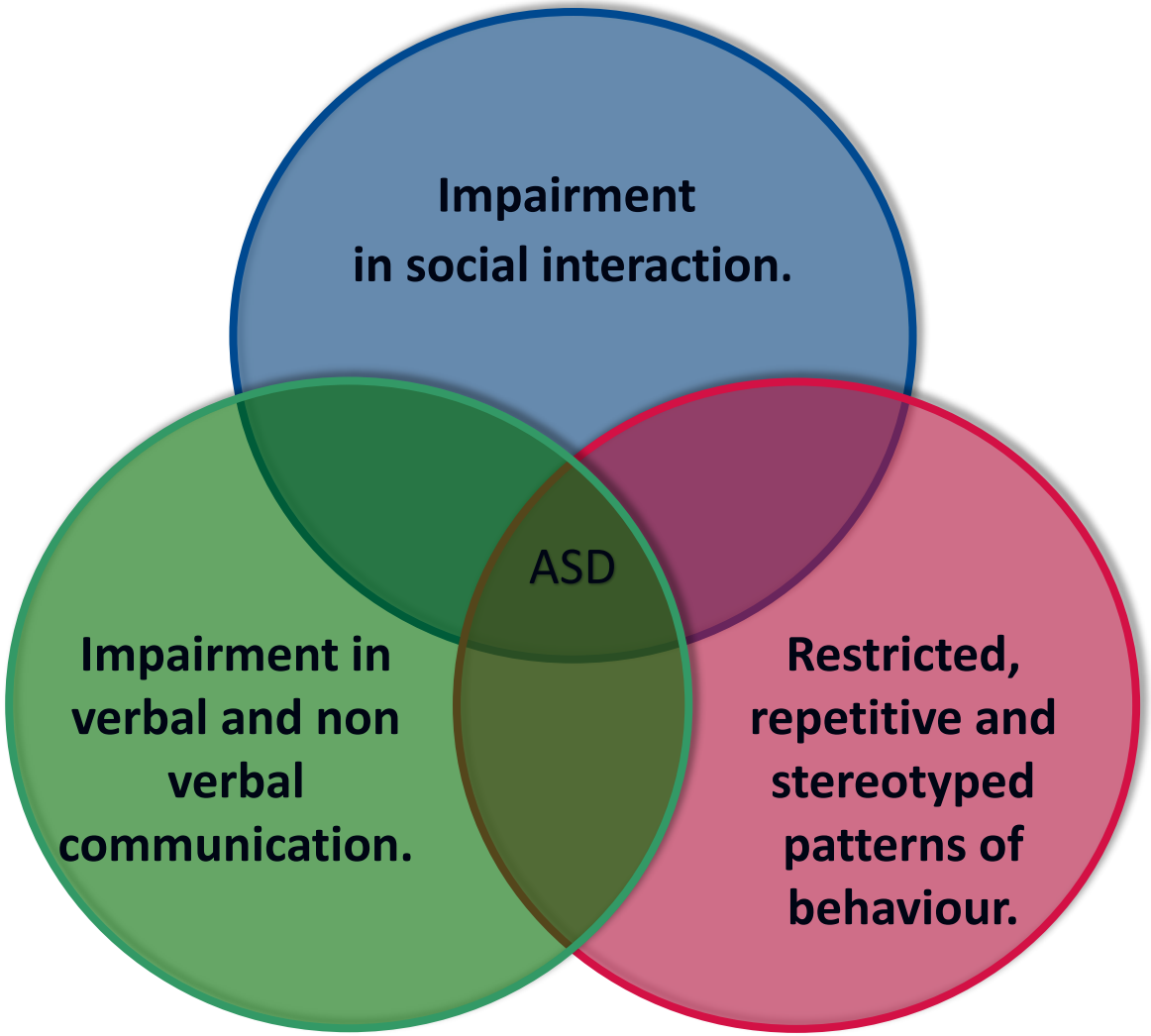
If not yet diagnosed- you can make a **huge** difference- **REFER**

Medical Home is especially needed for children with complex chronic conditions

What is an Autism Spectrum Disorder? DSM IV

A neurodevelopmental disorder characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors.

What Is Autism?



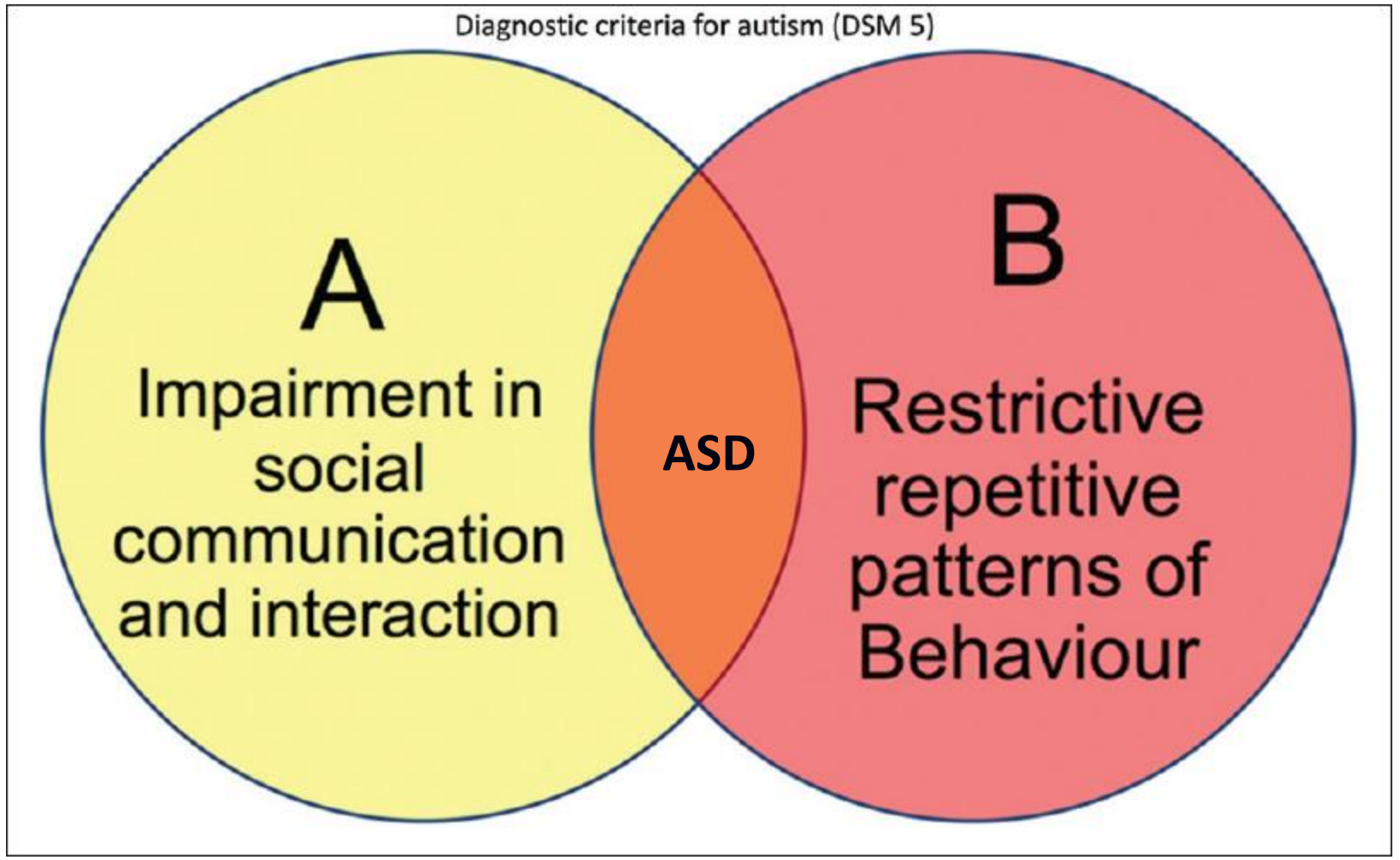
The so-called '***triad of impairment'*** summarises the difficulties of the autistic child but the actual manifestation of these can vary.

(Prior to 2013)

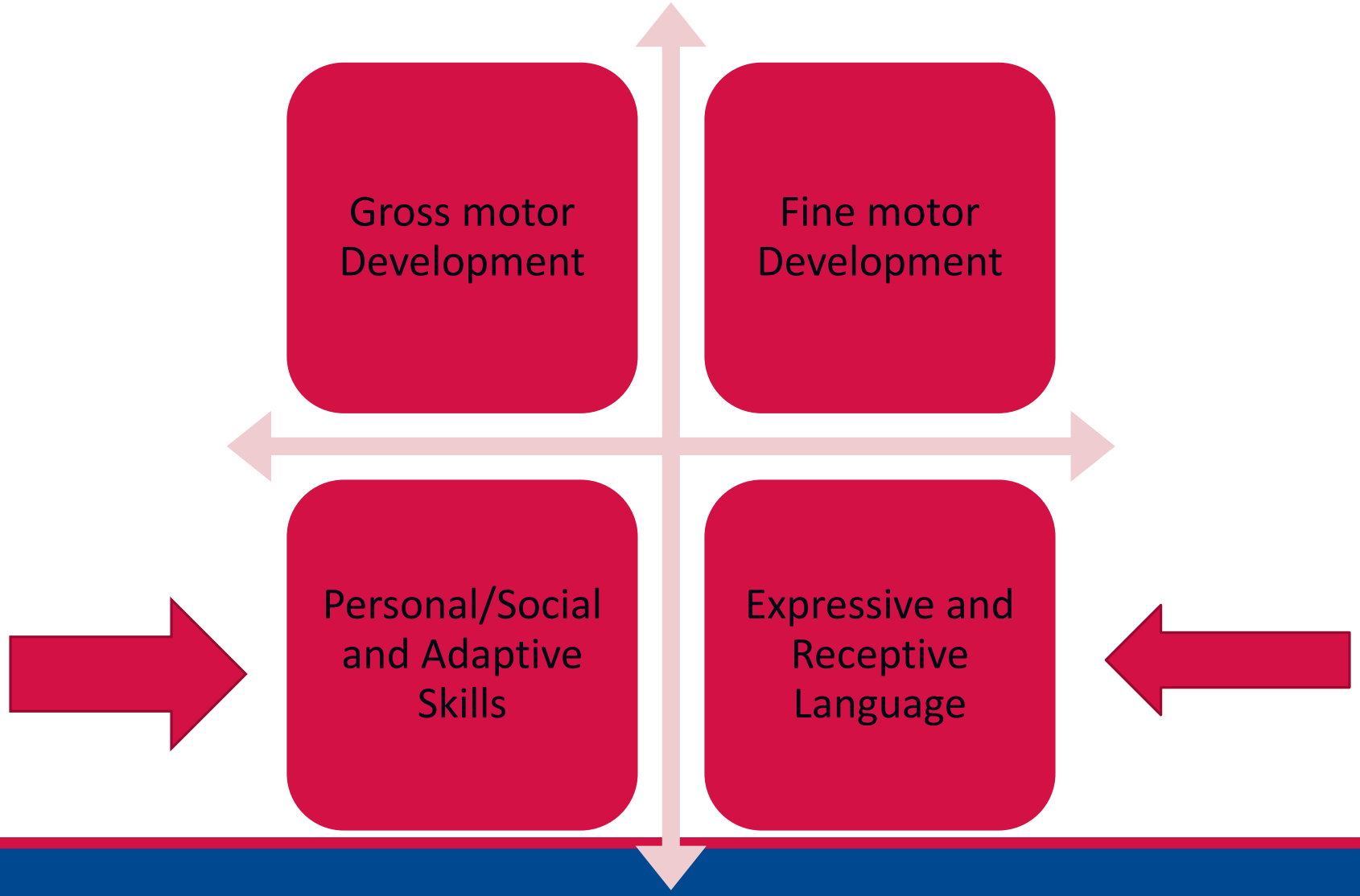
What is an Autism Spectrum Disorder?

DSM IV= A neurodevelopmental disorder characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors.

DSM 5= A group of complex neurodevelopmental disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction. The symptoms are present from early childhood and affect daily functioning.


Diagnostic criteria for autism (DSM 5)
A
Impairment in social communication and interaction
ASD
B
Restrictive repetitive patterns of Behaviour

Development



Early Development

Babies start communicating and relating to other people at birth

Continued social-emotional development is key to forming strong relationships and continued learning

By the end of 3 months

- Begin to develop a social smile
- Enjoy playing with other people and may cry when playing stops
- Become more expressive and communicate more with face and body
- Imitate some movements and facial expressions

Surveillance and Screening in Primary Care

Surveillance for Social and Communication skills (using developmental milestones) at all visits

Screen at 18 and 24 months with specific screening test- M-CHAT

Reassess at well child visits and if concerns arise

- Later age at diagnosis for children with high functioning ASD

By the end of 12 months

Use simple gestures

Imitate actions in their play

Respond when told “no”

Red Flags

- No back-and-forth gestures, such as pointing, showing, reaching, or waving bye
- Not answering to one’s name when called
- No babbling – mama, dada, baba

By the end of 18 months

Do simple pretend play

Point to interesting objects

Use several single words unprompted

Red Flags

- No single words by 18 months
- No simple pretend play
- No pointing

By the end of 2 years (24 months)

Use 2- to 4-word phrases

Follow simple instructions

Become more interested in other children

Point to object or picture when named

Red Flags

- No two-word meaningful phrases (without imitating or repeating)
- Lack of interest in other children

General Red Flags

Avoids eye contact
Delayed speech and language
Repeats words and phrases (echolalia)
Gets upset by minor changes
Has obsessive, atypical interests
Makes repetitive movements such as rocking, spinning, hand flapping
Unusual reactions to sensations- over- or under- reacts to sound, smell, taste, touch, sight
Has trouble understanding others feelings or discussing their own feelings
Doesn't share interests- lack of joint attention

Red Flag: Any loss of speech or babbling or social skills

Regression at any age is cause for immediate referral

ASD Screening in Primary Care:

Children at Higher Risk:

- Siblings of children with ASD: 10 x increased risk
- Premature Infants
- Comorbid Genetic Syndromes: e.g. Fragile X syndrome, Tuberous Sclerosis
- Prenatal Exposures e.g. Valproic acid

Regression in Milestones: 25-30%

- 15-24 months of age
- Change in language, social awareness or behavior

M-CHAT: Does your child…

Like to be swung?

Take interest in other children*?*

Like climbing?

Enjoy peek-a-boo?

Ever pretend to talk on the phone?

Ever use index finger to point to ask? To indicate interest?

Play properly with small toys?

Bring objects to show?

Look you in the eye?

Seem oversensitive to noise?

Smile in response to you?

Imitate you?

Respond to name?

If you point, does he look?

Walk?

Look at things you are?

Make unusual finger movements near face?

Act as if deaf?

Understand what people say?

Stare at nothing?

Look at your face to check reaction?

Robins et al, 1999

http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D._files/M-CHATInterview.pdf

AAP Developmental Screening Guidelines

The American Academy of Pediatrics recommends developmental screening at well-child visits

- All children screened to assess their general development at 9,18 and 24 or 30 months
- All children screened for ASD at 18 & 24 months

1 in 6 children has a developmental disability

9-Month-Old Child

18-Month-Old Child

24-Month-Old Child

Learn the Signs. Act Early.

www.cdc.gov/ActEarly

Table 1.1. Prevalence of Developmental-Behavioral Disorders and Other Chronic Medical Conditions in Children[a]

Condition	Prevalence
Slower learning (IQ between 70 and 89)	23%
Asthma	8.4%
Learning disabilities	7.7%
Attention-deficit/hyperactivity disorder	6.7%
Other developmental delays/intellectual disabilities	4.4%
Autism spectrum disorder	1.5%
Epilepsy	1%
Congenital heart disease	1%
Cerebral palsy	0.4%
Inflammatory bowel disease	0.4%
Juvenile rheumatic diseases	0.4%
Diabetes	0.2%
Cancer	0.02%
Cystic fibrosis	0.04%
Chronic renal disease	0.008%

[a] Data derived from Boyle CA, Boulet S, Schieve LA, et al. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*. 2011;127(6):1034–1042; Christensen DL, Baio J, Van Naarden Braun K, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. *MMWR Surveill Summ*. 2016;65(3):1–23; and Centers for Disease Control and Prevention National Center for Health Statistics. http://www.cdc.gov/nchs. Accessed January 18, 2018.

Board Certified Pediatricians in U.S. = 120,000

U.S. Peds Subspecialists:

Peds Cardiology = 3,218
Peds Heme-Onc = 3,027
Peds Endocrinology = 1,781
Peds Gastroenterology = 1,649
Peds Pulmonology = 1,205
Peds Nephrology = 932

Developmental/Behavioral = 775
Neurodevelopmental Disabilities=255
(Not mutually exclusive, Many double boarded so estimate 900 U.S. total)

(Data from AAP, ABP, CDC)

Diagnostic Evaluation:

Medical History

Developmental milestones
Behavioral History
Family History: Genetic risk factors

Physical

General exam

Neurodevelopmental assessment

Application of DSM V Criteria:

- History
- Observational Measures

Assessment of Parental Understanding, coping skills and resources

Best Practice for ASD Assessment

Early assessment and intervention are crucial to progress

WHO?

- Trained professionals (Field less important than expertise)

  Neurodevelopmental Pediatricians, Neurologists, Pediatricians, Psychiatrists, Psychologists
- Interdisciplinary is best

WHAT?

- Developmental history, observations, direct interaction, parent interview, evaluation of social, communication, sensory, emotional, cognitive and adaptive behavior.

WHERE?

- Multiple settings

WHEN? As early as possible

DSM 5 **(ALL must be present)**

A) Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):

1) **Deficits in social-emotional reciprocity**, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2) **Deficits in nonverbal communicative behaviors used for social interaction**, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3) **Deficits in developing, maintaining, and understand relationships**, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

DSM 5 (at least 2 of 4 must be present)

B. **Restricted, repetitive patterns of behavior, interests, or activities**, as manifested by **at least two** of the following, currently or by history (examples are illustrative, not exhaustive):

1) **Stereotyped or repetitive motor movements, use of objects, or speech** (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2) **Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior** (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

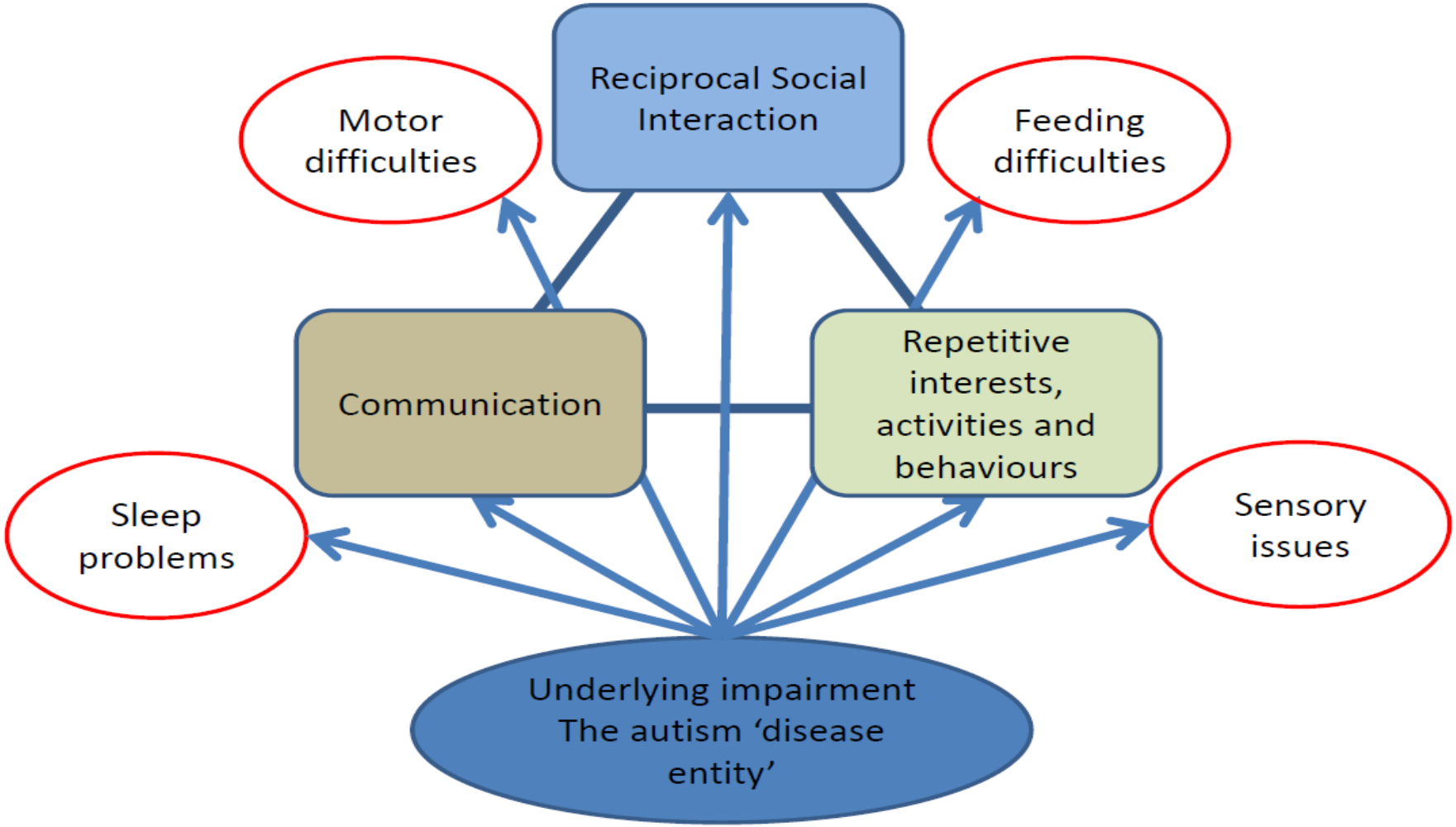
3) **Highly restricted, fixated interests that are abnormal in intensity or focus** (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4) **Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment** (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Medical Work Up- (may include)

Genetic Testing	**Karyotype-** 5% yield **Microarray**- 6-27% **Fragile X-**1-2%	
Metabolic Testing	Amino Acids-<1% Organic Acids<1%	Only if indicated
Neuroimaging	MRI, any lesion-up to 48%	Only if indicated
EEG	Any abnormality-16-68% Seizures- 25% lifetime	Only if indicated
Other	**Lead**- low	

A broader conceptualisation of ASD



Specific aspects of medical history to target in children with ASDs:

GI concerns:
- Diarrhea/constipation/bloating/pain

Sleep problems:
- Night waking, delayed sleep onset

Feeding behaviors:
- Aversions based on taste/texture/appearance
- Monitor growth and nutrition

Treatment

- Goals
  - Minimize core features and associated deficits
  - Maximize functional independence and QOL
  - Alleviate family stress
- Educational intervention
- Developmental Therapies
  - Communication
  - Sensory, fine motor, gross motor
- Behaviorally Based treatments
  - Core and associated symptoms
  - Social skills
- Medical or biologic treatments
- Support family in home and community

Evaluation and Intervention Services

- Birth to 3 years: Early Intervention
- 3-5 Years: School district
- 5-21 Years: School district
- Transition age planning and young adult service referrals

Assessment includes: IQ, Speech and Language, Adaptive, Motor, Social and Emotional, and Hearing

Educational Interventions:

1- **Applied Behavioral Analysis (ABA):** works to systematically change behavior based on principles of learning derived from behavioral psychology and encourages positive behavior as well teaching new skills.

2- **Speech Therapy:** with a licensed speech-language pathologist is important in helping to improve a person's communication skills, allowing better expression. Some individuals with ASD are nonverbal, so the use of gestures and sign language are useful.

Educational Interventions:

3- **Occupational Therapy (OT):** used as a treatment for the sensory integration issues associated with ASDs. Improves the individual's quality of life and ability to participate fully in daily activities.

4- **Physical Therapy (PT):** to improve gross motor skills and handle sensory integration issues, particularly those involving the individual's ability to feel and be aware of his body in space.

5- **Social Skills Training**

Psychopharmacology

Symptoms/ Disorders	Freq	Treatments
Attentional, impulsivity, hyperactivity	59%	Behavioral intervention Psychopharmacotherapy – stimulants, atomoxetine, alpha agonists, anti-anxiety
Anxiety	43-84%	Behavioral treatment – relaxation, cognitive Psychopharmacotherapy – SSRI, alpha agonist
Depression	2-30%	Psychotherapy Medication – anti-depressants
Obsessive compulsive symptoms	37%	Behavioral treatment, supportive counseling; Medication – SSRI, others
Disruptive, irritable or aggressive behavior	8-32%	Behavioral intervention Medication – atypical neuroleptics (risperidone, arapiprazole (Abilify), others)
Self-injurious behavior	34%	Behavioral intervention Medication (e.g., naltrexone, risperidone, others)
Tics	8-10%	Medications; Alpha agonist (clonidine, guanfacine), others
Sleep disruption	52-73%	Sleep diary; sleep hygiene; behavioral supports; investigate possible medical comorbidity/ies as cause(s)

Biologically Based CAM

Supplements
- B6/Magnesium, B12
- DMG/ TMG
- Vitamin A, Vitamin C
- Folate
- Omega 3 Fatty Acids

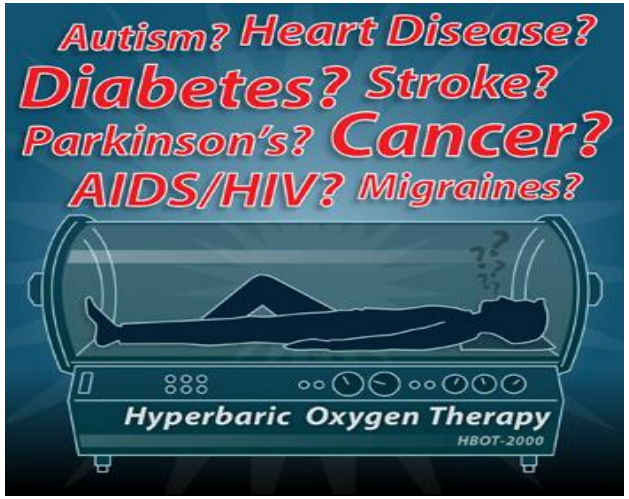
Elimination Diets
- Casein/ gluten free

Off-label medications
- Secretin

Immune
- Antifungal therapy
- Immunotherapy, steroids
- Antibiotics/Antivirals
- Stem cell transplantation

Immunization-related
- Withhold immunization
- Chelation

Hyperbaric oxygen therapy (HBOT)



Always others coming along…

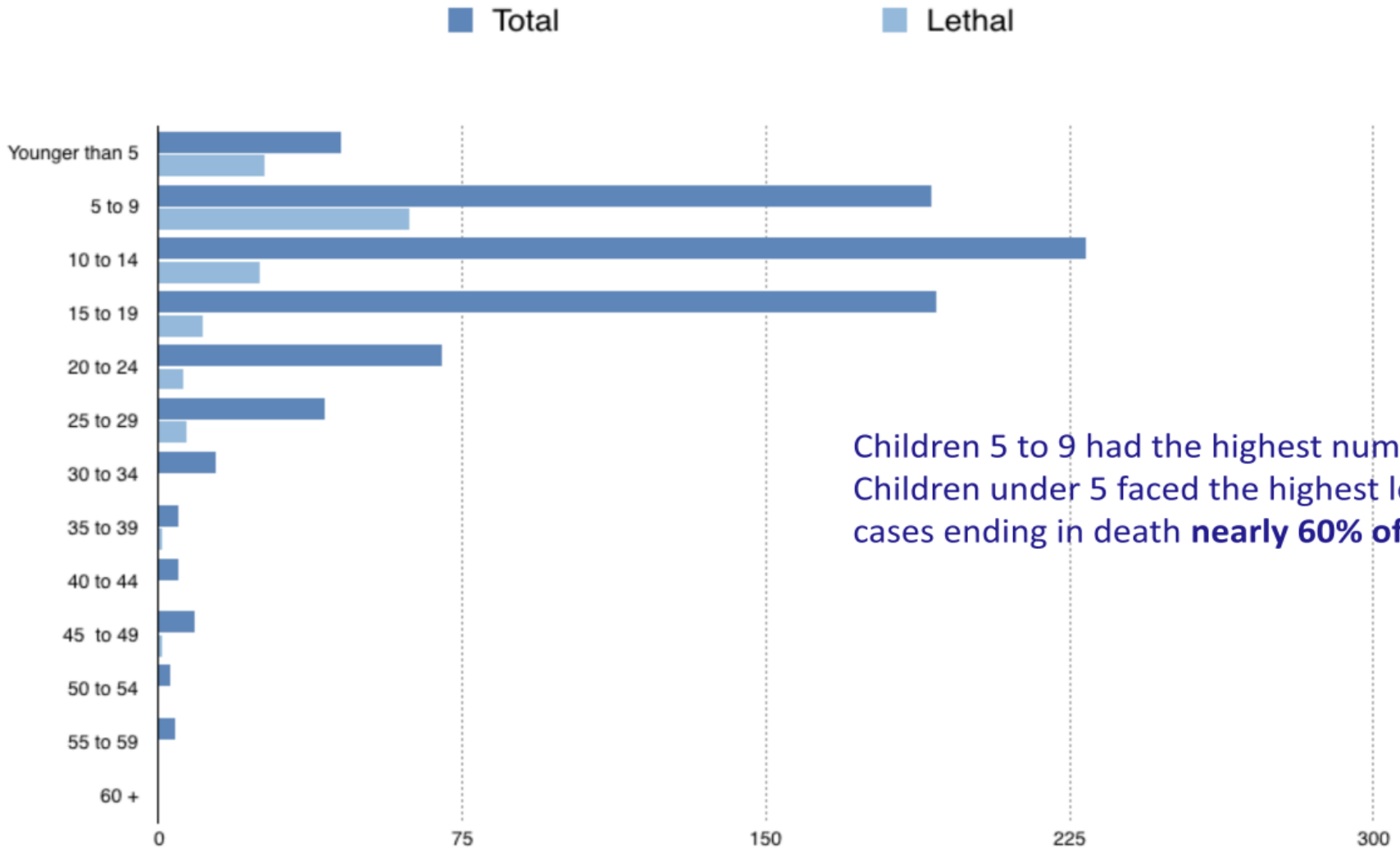
Wandering /Elopement

Prevalence

- ***29% to 49%*** of children with autism have parent-reported wandering

US surveys; 526-2077 families; 2012-2019

Outcomes by Age Group, 2011 to 2016



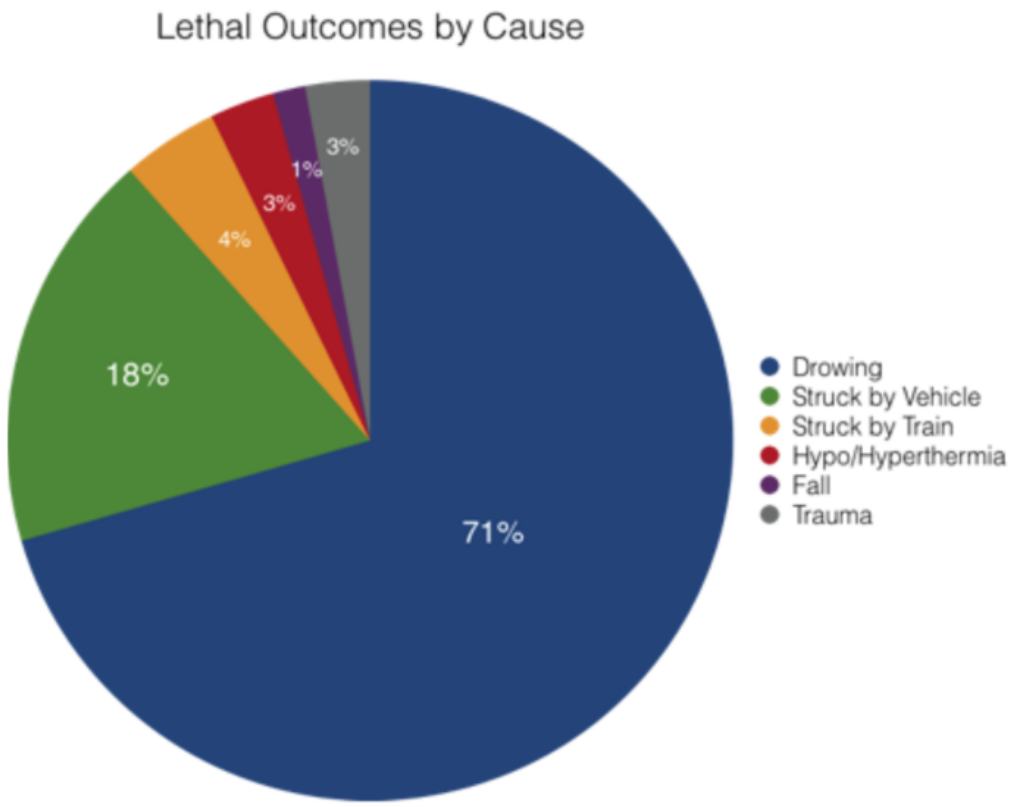
Children 5 to 9 had the highest number of deaths. Children under 5 faced the highest lethal risk with cases ending in death **nearly 60% of the time.**

NATIONAL AUTISM ASSOCIATION

Lethal Outcomes by Cause, 2011 to 2016

The vast majority of deaths were caused by **accidental drowning**, followed by traffic and train injury.

Of drowning deaths, 76% occurred in a natural body of water, or drainage water.



NATIONAL AUTISM ASSOCIATION

Elopement Patterns: Situations

Avoidant/Anxious Situations

- Escape anxious situation (43%)
- Stressful environment (39%)
- Conflict-laden environment (24%)

Sensory

- Noisy (38%); Uncomfortable sensory experience (34%)

Goal-Directed

- Pursue special interest (27%); Reach play he/she enjoys (18%); Reach favorite food (11%)

Impulsive

- Under-stimulated (27%): “Boring” environment (27%)

Andersen, Law, Marvin, and Lipkin, J Autism Dev Disord. 2020

Keeping Kids with Autism Safe from Wandering: Tips from the AAP (HealthyChildren.org; Hyman & McIlwain)

- Know wandering triggers
- Secure your home (regardless of age)
- Reinforce water and swimming safety
- Work on communication and behavior strategies
- Set expectations with the child when going out
- Consider monitoring technology and identification
- Rest (child and parent)
- Family wandering emergency plan

The AWAARE Collaboration Working to prevent wandering incidents and deaths within the autism community

https://nationalautismassociation.org/big-red-safety-box/

This program is supported by grant 2020-J1-BX-0009 provided by the Office of Justice Programs (OJP), U.S. Department of Justice (DOJ)

Three digital safety toolkits

- Caregiver Toolkit
- First Responder Toolkit
- Teacher Toolkit

http://awaare.nationalautismassociation.org/

WHAT TO DO IF SOMEONE WANDERS

- Stay Calm
- Call 911
- Search Nearby Water First
- Implement your Family Wandering Emergency Plan (FWEP)

SAFETY ALERT
PERSON WITH
AUTISM
MAY NOT
RESPOND TO
VERBAL COMMANDS
Safety Alert!
I HAVE AUTISM
CHILD ID KIT
BIG RED SAFETY BOX
NATIONAL AUTISM ASSOCIATION
AUTISM & WANDERING
PREVENTION TIPS
STOP
STOP
1
HAPPY!

Annually (or more frequently) complete and share with school staff, family, friends, neighbors, caregivers, police, fire, and rescue professionals.

PERSONAL EMERGENCY PROFILE

DATE: _____

NAME: _____ AGE: _____

ADDRESS: _____

PHYSICAL DESCRIPTION: _____

PLACE PHOTO HERE

TRACKING FREQUENCY # (If applicable)

EMERGENCY CONTACT(S) IF LOST, MAY BE FOUND AT: _____
(Likely places to go)

NAME: _____ PHONE NUMBER: _____

NAME: _____ PHONE NUMBER: _____

RESTRICTIONS (Allergies and diet)

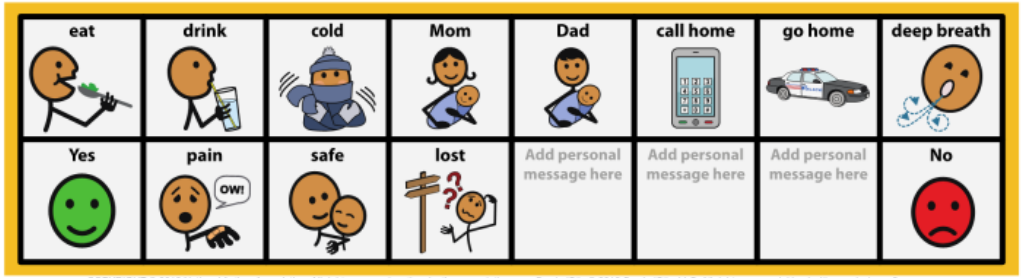
MEDICAL NEEDS (Diagnosis, health concerns)

SIGNS OF ESCALATION (Changes in behavior that show increased or decreased anxiety, anger, etc. Recommendations for do's and don'ts.)

LIKES (Attractions, favorite things, hobbies, interests, foods, drinks, verbal exchanges, etc.)

DISLIKES (Triggers, sensitivities, fears, things to avoid, foods, drinks, verbal exchanges, etc.)

Symbols aid understanding and communication for everyone. Show and point to symbols when talking with a rescued person.



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awaare.org

family wandering emergency plan

AUTISM WANDERING AWARENESS ALERTS RESPONSE EDUCATION

AWAARE COLLABORATION

Make sure your family has a plan in case of a wandering emergency. Before an emergency happens, sit down together and decide how you will get in contact with each other, where you will go and what you will do in an emergency. Keep a copy of this plan in your emergency supply kit or another safe place where you can access it in the event your child is missing.

critical information

CHILD'S NAME _____

CHILD'S TRANSMITTER TRACKING NUMBER (if applicable) _____

CHILD'S OFFICIAL DIAGNOSIS _____

CHILD'S IDENTIFYING MARKS, MEDICATIONS & MEDICAL NEEDS _____

emergency steps:

- ☑ **ALWAYS CALL 911 IMMEDIATELY IF YOUR LOVED ONE IS MISSING FROM YOUR HOME.**
- ☑ Clearly state your child's name.
- ☑ State that they have a cognitive impairment, provide the diagnosis, state they are endangered and have no sense of danger.
- ☑ Provide your child's radio frequency tracking number (if applicable).
- ☑ Provide your child's date of birth, height, weight, and any other unique identifiers such as eyeglasses and braces.
- ☑ Tell them when you noticed that your child was missing and what clothing he or she was wearing.
- ☑ Request an AMBER Alert be issued (if your child is a minor) or a Silver Alert be issued (if your child is an adult)
- ☑ Request that your child's name and identifying information be immediately entered into the National Crime Information Center (NCIC) Missing Person File.
- ☑ Search known areas your child would likely be, or attracted to. If you have an emergency point person assigned to contact neighbors, pick up your other children from school, watch your children, etc., alert them while searching known areas your child would likely be. *If you have other small children, never leave them unattended.*

TIP: create an emergency point person who can contact neighbors, fax your alert form to local law enforcement, and assist in making arrangements for your other children.
Should your child go missing, make sure this contact has a cell phone, knows what your child is wearing, any identifying features, where you child was last seen, how long your child may have been gone, any medical needs or allergies your child may have, your child's likes and dislikes and main attractions. Ideally, the emergency contact will be a relative or close friend. Provide your emergency contact with a copy of this plan and ask them to keep it in a safe, accessible place.

EMERGENCY CONTACT NAME: _____

EMERGENCY CONTACT NUMBER: _____

The Only GPS Tracker *Designed for* Kids With Autism

Keep Your Child Safe From Wandering, Bullying & Mistreatment with **AngelSense**

Monitoring Plan Includes:

•Unlimited Notifications & Email Alerts

- Unlimited Users
- Unlimited Location Updates
- Real-time Tracking App: iOS, Android, Web
- Listen-in with a Single Click (60 minutes/mo)
- Expert and Caring Support

AngelSense

Important Roles of Primary Care Physicians and the Medical Home

Early recognition

- Knowledge of signs and symptoms
- Developmental surveillance and screening

Guiding families to diagnostic resources and intervention services (simultaneously)

Being part of the medical evaluation

Providing ongoing health care including anticipatory guidance

Supporting and educating families

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

From the American Academy of Pediatrics:
Clinical Report

Identification, Evaluation, and Management of Children With Autism Spectrum Disorder

Susan L. Hyman, Susan E. Levy, Scott M. Myers and COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS

Pediatrics January 2020, 145 (1) e20193447; DOI: https://doi.org/10.1542/peds.2019-3447

CDC- Learn the Signs Act Early. https://www.cdc.gov/ncbddd/actearly/index.html

NJ Department of Human Services- A Family Guide to Navigating the NJ Service System for Individuals with Autism
Spectrum Disorder and other Developmental Disabilities.
www.state.nj.us.humanservices/ddd/home/ooa

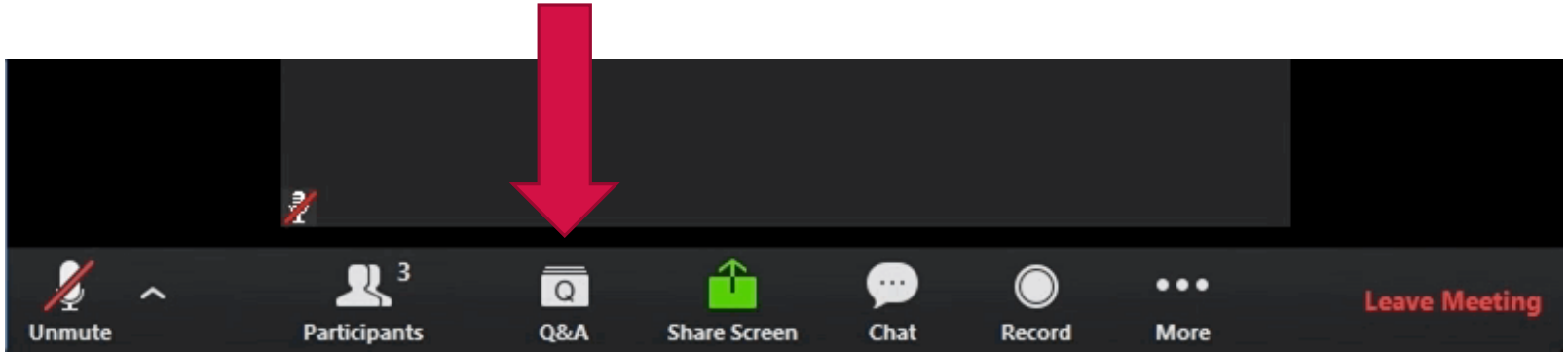
NJ Department of Health- Child Evaluation Centers.
www.nj.gov/health/fhs/specialpediatrics/child-evaluation/

SPAN- Statewide Parent Advocacy Network www.spanadvocacy.org

Autism Speaks – 100 Day Kit. www.Autismspeaks.org

Questions?

Please type questions in the Q&A function located on the control bar at the top or bottom of your screen.



Early Identification and Referral for Autism (EIRA) Project ECHO

Goal to advance recommended Autism specific screening at 18 and 24 months and link families to resources and services.

Early Identification and Referral for Autism (EIRA) Project ECHO

- Collaboration with Cognoa, Inc.
- Partnership with SPAN
- ABP approved MOC Part 4 QI program utilizing the Project ECHO® model
- Now recruiting up to 12 pediatric practices to participate!
- March-October on 3rd Thursday 12-1 pm
- 5 targeted at-risk communities: Camden, Cumberland, Essex, Middlesex and Passaic

EIRA Project ECHO

Aims to improve screening and referral for ASD and strengthen the pediatric medical home in care coordination for children with ASD by:

- Enhancing knowledge of recommended screening guidelines
- Improving utilization of MCHAT and other screening tools
- Increasing confidence in performing screening and identification of at risk individuals
- Improving communication with families about findings
- Growing knowledge of referral networks for ASD

Interested in signing up?

- Regina Grazel, Program Director
  rgrazel@njaap.org
- Sharleen van Vlijmen, Program Manager
  svanvlijmen@njaap.org