

Autism Spectrum Disorder in Primary Care

Supporting Children and Families

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Disclosures

- None



Learner Objectives

1. Define Autism Spectrum Disorder (ASD) in DSM-5
2. Describe 2 strategies used in the early detection of ASD and list 3 ASD screening tools
3. Appreciate the importance of the life course approach in ASD and
4. Name 3 examples of how to support children and families



Agenda

Part 1

- ASD defined in DSM-5
- Prevalence and trends in ASD diagnosis

Part 2

- ASD screening tools
- Observing: “training the eye”

Part 3

- ASD and the medical home



Part 1

Definition and trends



Suggestions Regarding Respectful Autism Language

Traditional terms, concepts, ideas	Suggested alternatives
Disorder	Disability
Autism Spectrum Disorder	Autism, Autism Spectrum Disability
Deficits	Area of challenge, difficulty
Autism symptoms	Autism features, characteristics, traits
Red flags	Signs or indicators of possible Autism
Restricted interests	Focused, intense interests

First person language	Identity first language
Person with Autism	Autistic person

Dwyer MA , 2022



Medical versus Social Model of Disability

Medical

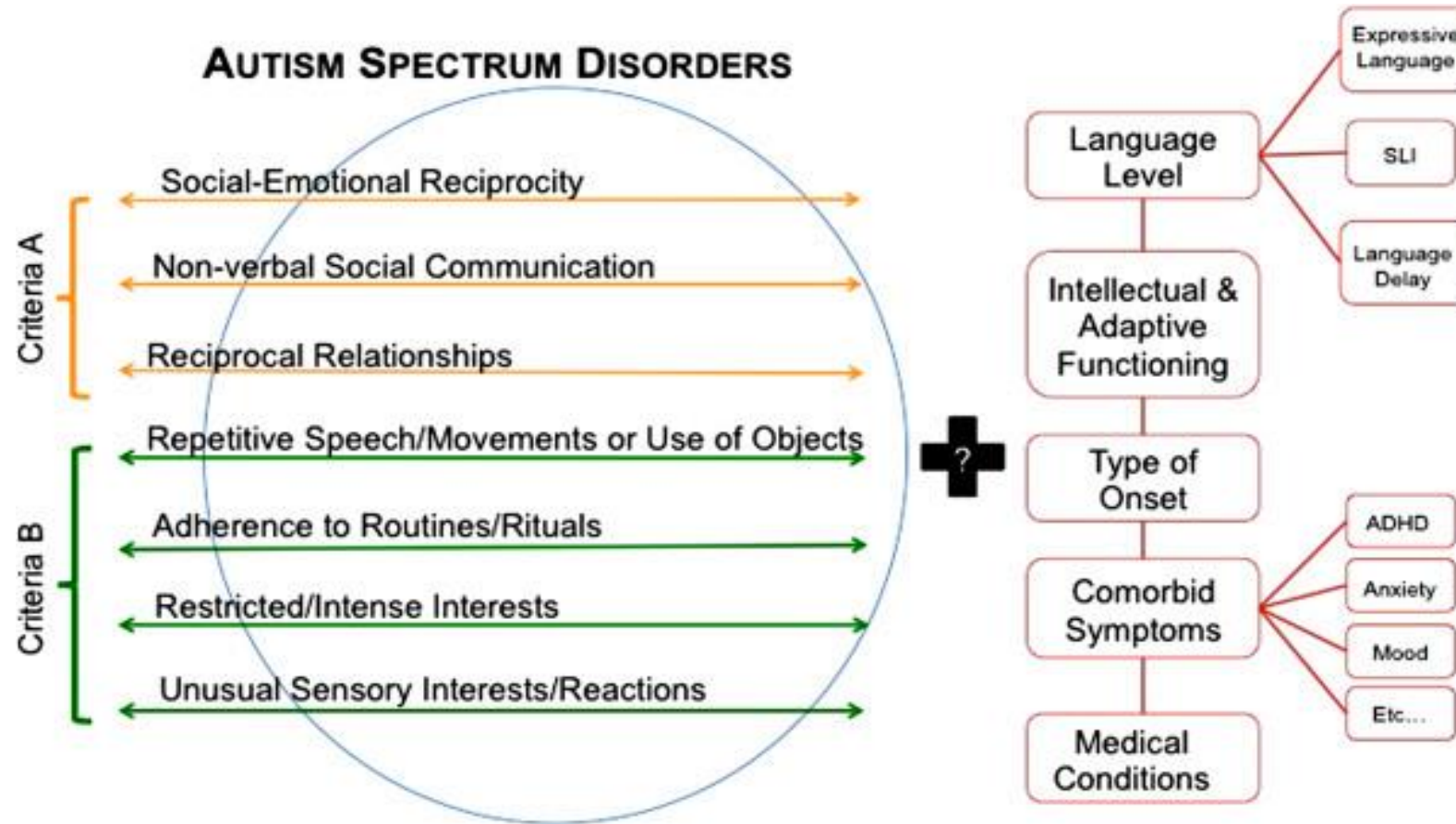
The disability is part of YOU, and the solution to the disability is to fix YOU

Social

This disability is a function of SOCIETY, and the solution is to fix SOCIETY



DSM-5 ASD Criteria



Grzadzinski R, 2013



A: Social Communication

Persistent deficits in social communication and social interaction across multiple contexts

Evidenced by deficits in the following, currently or by history as manifested **by all of the following** :

1. **Social-emotional reciprocity** (e.g., back-and-forth conversation)
2. **Nonverbal communicative behaviors** used for social interaction (e.g., eye contact, facial expressions, body language, gestures)
3. **Developing, maintaining, and understanding relationships** (e.g., modifying behavior to context, engaging in pretend play, showing interest in peers)



B:Restricted, Repetitive Behaviors

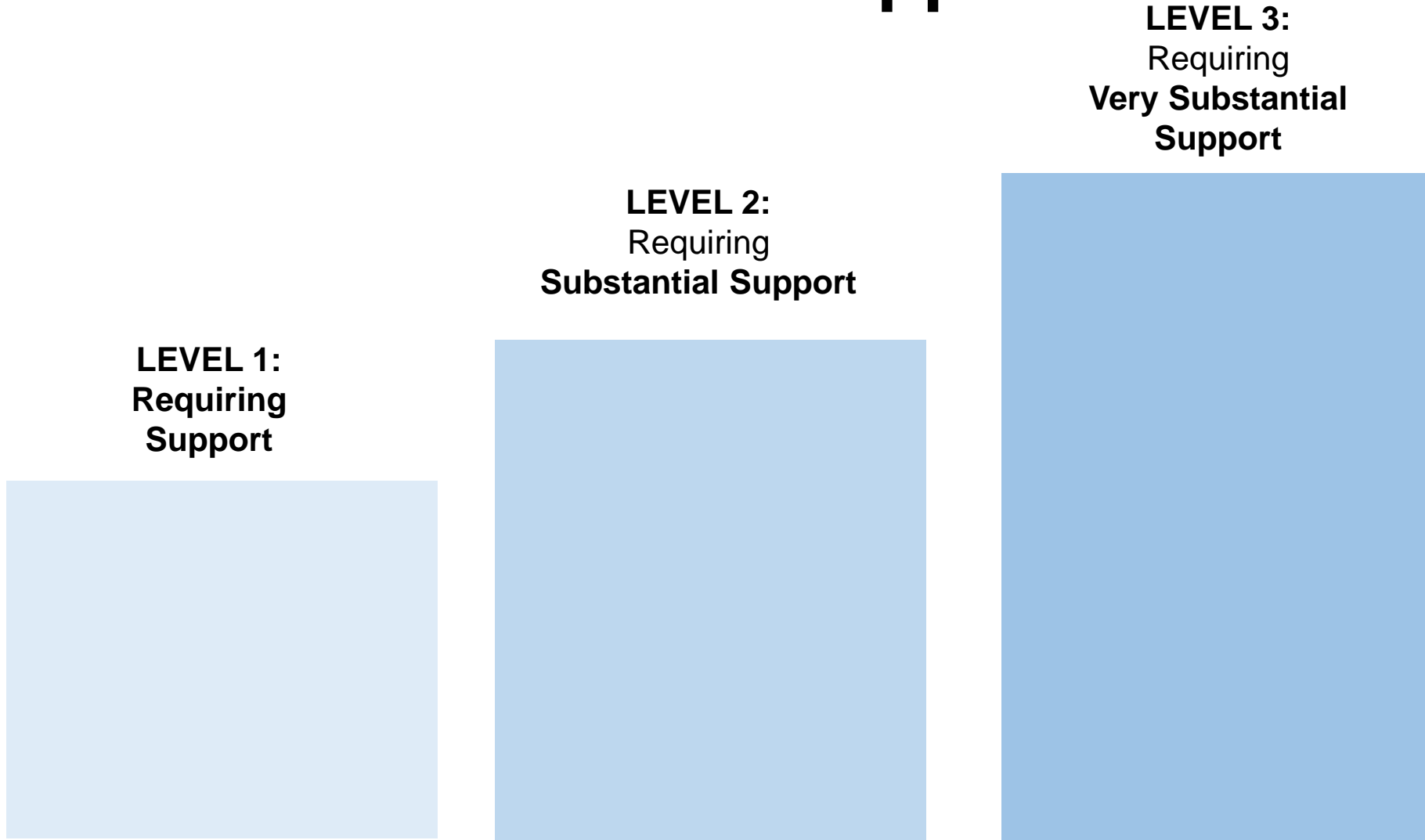
Restricted, repetitive patterns of behavior, interests or activities

Evidenced by **two or more** of the following, currently or by history:

- 1. Stereotyped/repetitive movements, use of objects, or speech**
(e.g., lining up toys, flipping objects, echolalia)
- 2. Insistence on sameness, inflexible adherence to routines, ritualized patterns of verbal or nonverbal behavior**
(e.g., need to take same route or follow same schedule every day)
- 3. Highly restricted, fixated interests – abnormal in intensity/focus**
(e.g., preoccupation with unusual objects)
- 4. Hyper-or hyposensitivity to sensory input or unusual interest in sensory aspects of the environment**
(e.g. , adverse response to specific sounds or textures)



ASD DSM-5 levels of support



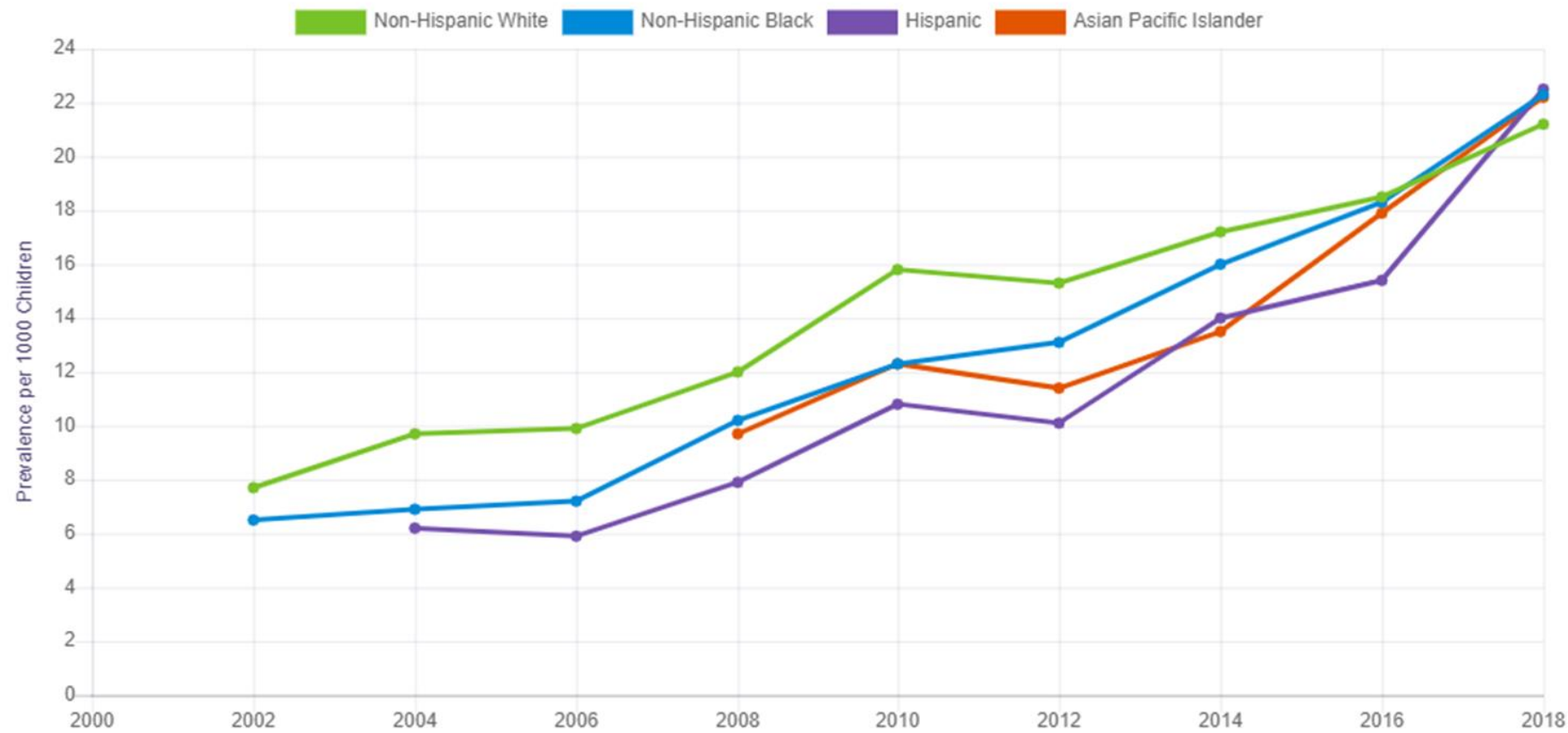
ASD prevalence data and trends

2018	4-year-olds	8-year-olds
Prevalence	1:59	1:44
Sex	3.4 to 1	4.1 to 1
Age of children with ASD who had first developmental evaluation completed by 36 months	72%	47%

Maenner 2021, Shaw 2021



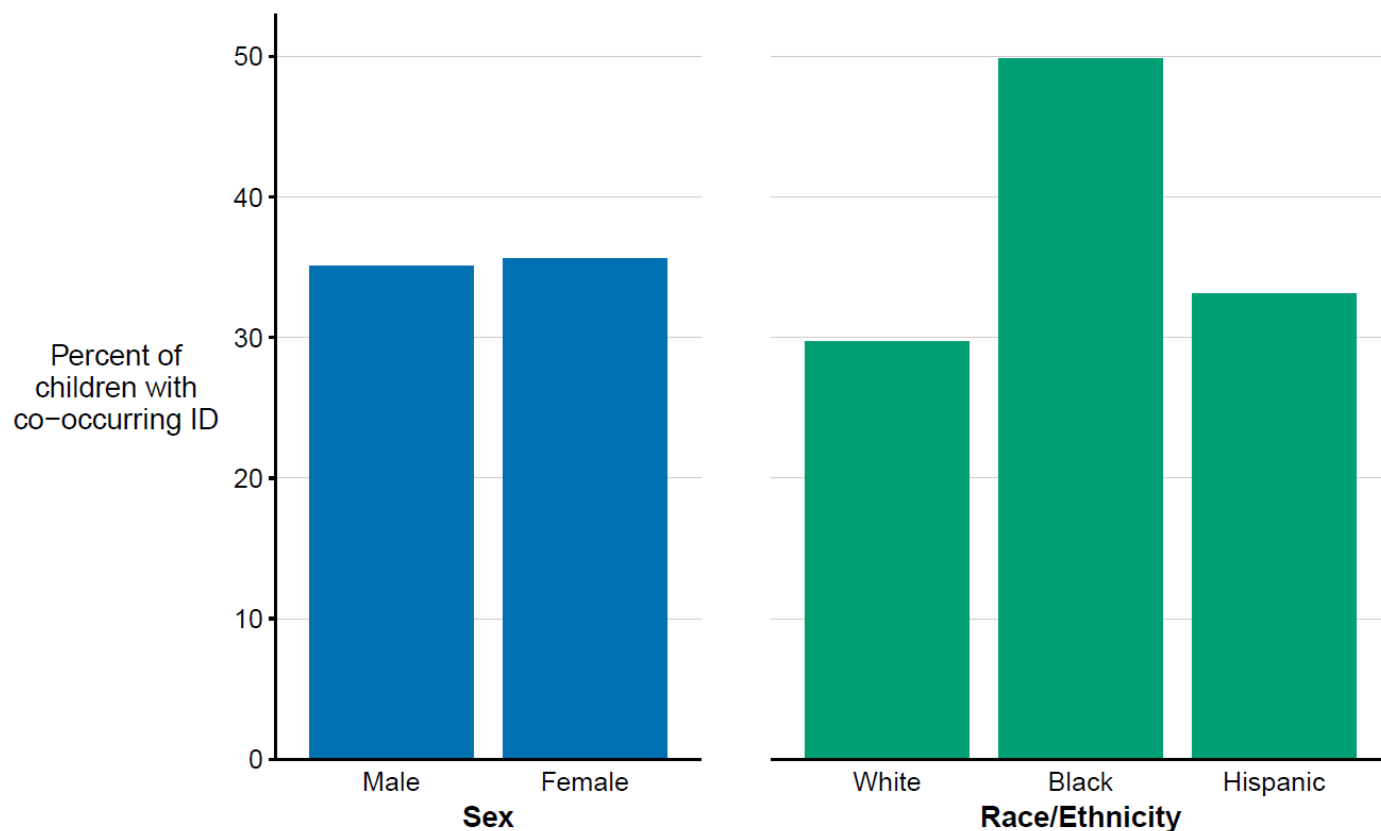
ASD prevalence and trends



<https://www.cdc.gov/ncbddd/autism/data/index.html>



2018 ASD and Intellectual Disability : Racial Discrepancies

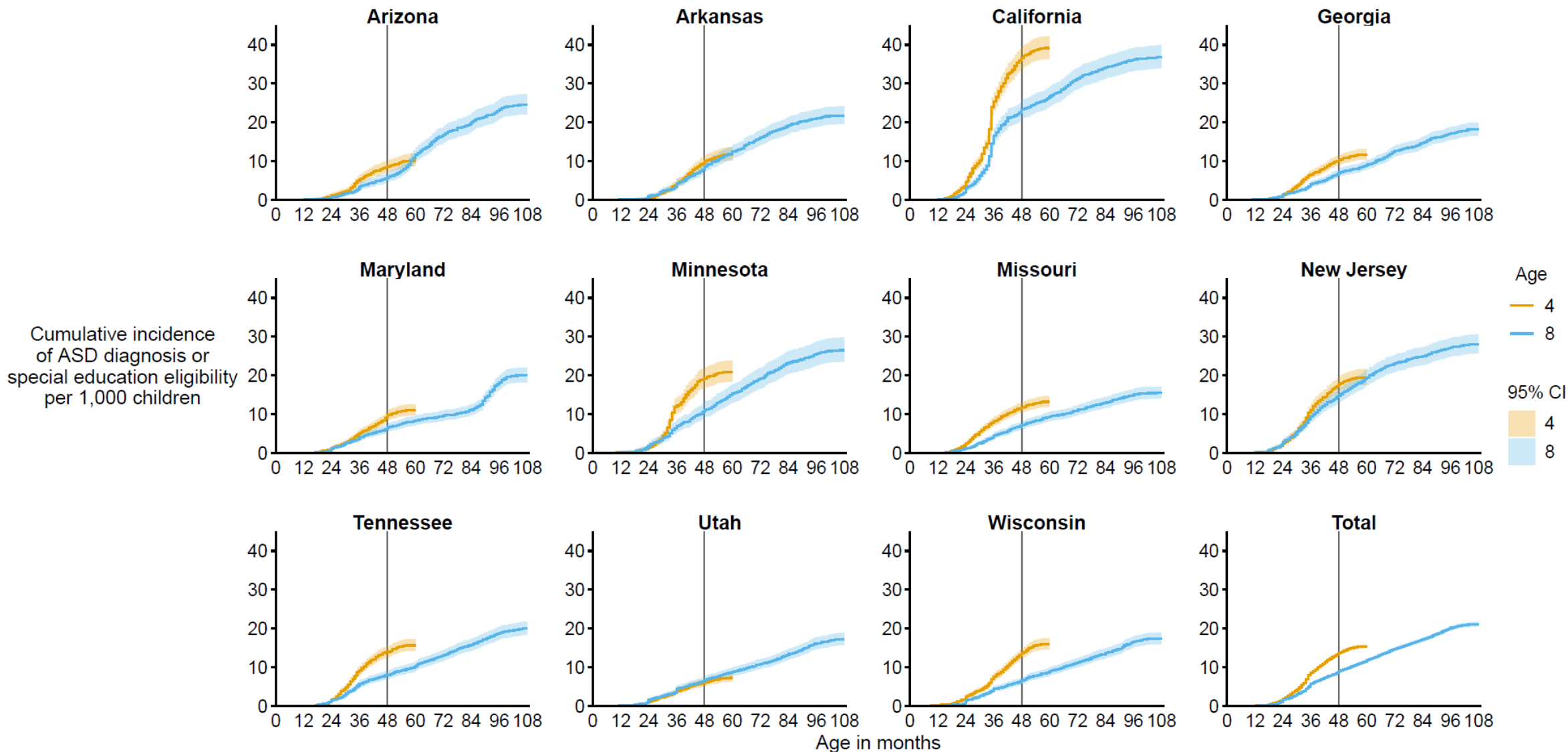


* IQ score ≤ 70 or examiner statement of intellectual disability in a comprehensive evaluation

Maenner, 2021; Shaw, 2021



ASD Prevalence and Trends



Cumulative incidence of autism spectrum disorder diagnosis or eligibility per 1,000 children aged 4 or 8 years, by State
 Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018

Part 2

ASD in primary care- surveillance, screening and training
the eye



Assessing ASD in Primary Care

1. Developmental **Surveillance**
2. Developmental **Screening** :18 months and 24 month screening for ASD
3. “Train the eye” for signs of ASD: **Observation**



Surveillance in ASD

By 9 months

Does not respond to name
Does not show facial expressions like happy, sad, angry and surprised
No sharing of vocal sounds, smiles, or other nonverbal communication

By 12 months

Does not play simple interactive games like pat-a-cake
Uses few or no gestures by 12 months (e.g., does not wave goodbye)

By 15 months

Does not share interest with others (e.g., shows you an object they like)

By 18 months

Does not point or look at what you point to

By 24 months

Does not notice when others are sad or hurt

By 30 months

Does not pretend play (e.g., does not pretend to feed a doll)

Adapted from <https://www.cdc.gov/ncbddd/autism/signs.html>



Surveillance in ASD

Possible signs of ASD

Loss of previously acquired speech, babbling, or social skills

Avoids or does not keep eye contact

Trouble understanding people's feelings or talking about their own feelings

Shows little interest in peers

Does not play games with turn taking

Repeats words and phrases over and over (echolalia)

Gives unrelated answers to questions

Gets upset by minor changes

Has obsessive interests

Makes repetitive movements, e.g. hand flapping, rocking, spinning in circles

Unusual response to sounds, smell, taste, look or feel

Adapted from <https://www.cdc.gov/ncbddd/autism/signs.html>



Screening ASD tools

Autism Screening	Ages	No. Items	Parent Completion Time (min)	Cost
M-CHAT R/F Modified Checklist for Autism in Toddlers Revised-Follow-up	16-30 months	20	5-10	No
SCQ Social Communication Questionnaire	≥ 4 years (mental age >2 years)	40	10	Yes
POSI-SWYC Parent's Observations of Social Interaction Survey of Wellbeing in Young Children	16-35 months	7	< 5	No

<https://screeningtime.org/star-center/#/screening-tools>



Joint Attention

Making Social Connections



“Early signs of Autism Video Tutorial” Rebecca Landa, PhD, CCC-SLP, Kennedy Krieger Institute. June 11, 2013



Joint Attention



Focal Points: ASD

- Hand

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Joint Attention



Focal Points: ASD

- Overly focused on

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Part 3

ASD in the medical home



ASD in primary care (no diagnosis but concerns)

- Listen to parental concerns (always)...
- Use surveillance, screening and clinical skills
 - When MCHAT-R/F **positive (fail)**
 - child may/may not have ASD but further evaluation is indicated: refer for evaluation
 - refer to Early Intervention**
 - if comfortable diagnosis of ASD/long wait list, offer diagnosis (provisional)
 - When MCHAT-R/F is **negative**- continued vigilance is warranted
 - MCHAT- R/F is designed for screening 16-30 months
 - since not all children captured early, continue surveillance



ASD in primary care (after ASD diagnosis)

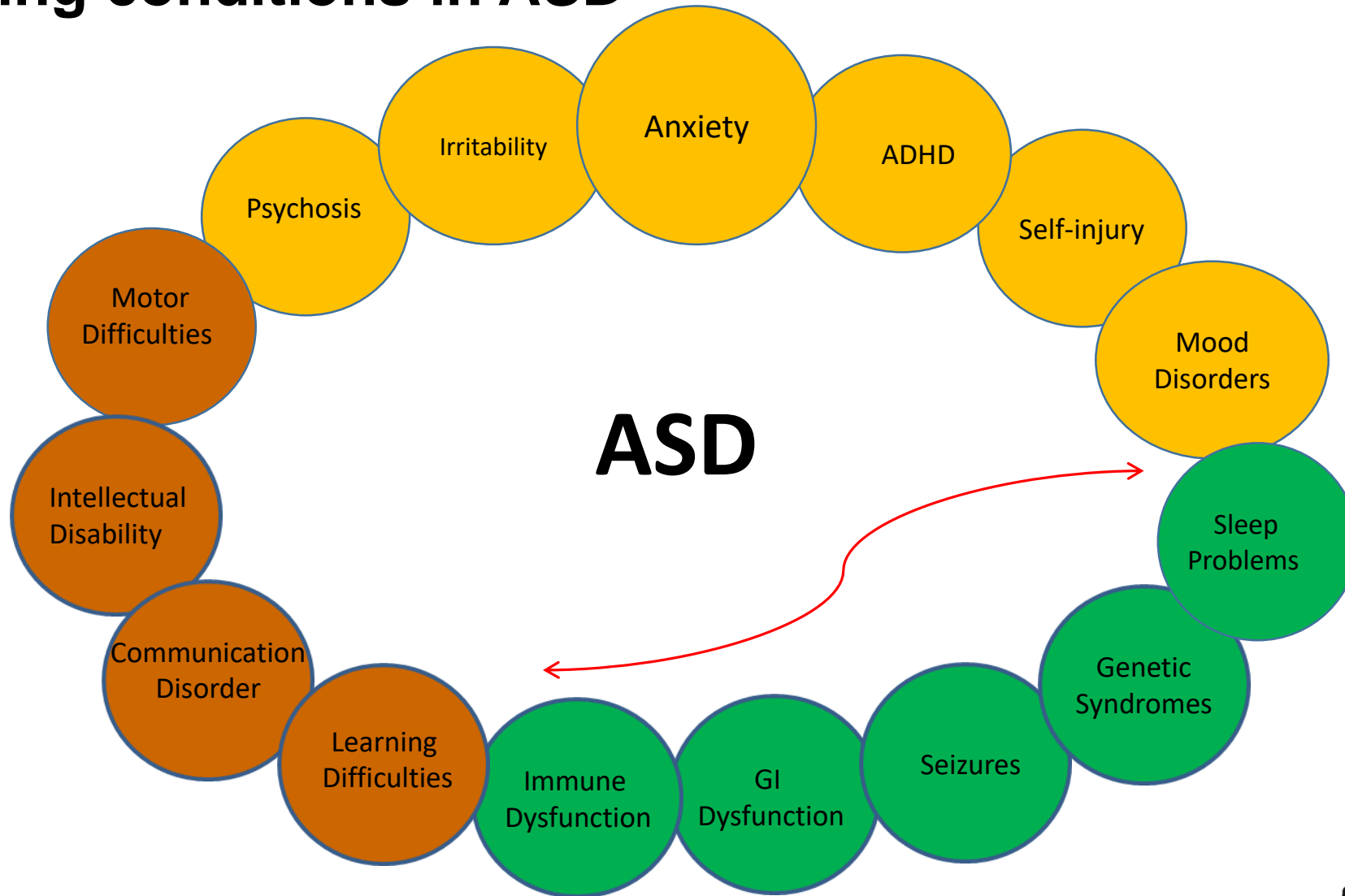
Accommodations

- Prepare for visits to doctor's office (pictures, social story)
- Time of appointment if flexibility exists
- Use of visual supports
- Bring preferred toys
- Limit transitions

- Address co-occurring conditions (look for something you can treat)



Co-occurring conditions in ASD



Challenges (examples)

Challenge

Family stress, waitlists
challenging behavior, school?
Difficulty getting medication,
Disorganized paperwork,
limited family support,
Home modifications, No Time
limited progress on speech,
Summer camp, No sleep
limited finances, Pica,
Toilet training, Fun!?
Allergy, Future Planning
Recreation



Example working plan for concern (sleep)

Main Concern	Related Current Clinical Information	Current plans/ Intervention	People responsible	Date Completed *Date Due
NO SLEEP	<ul style="list-style-type: none">• Rule out Iron deficiency and underlying neurological concerns.• Behavioral Psychology	<ul style="list-style-type: none">• Begin Behavioral Psychology• Attend parent education session• Consult with outpatient OT and school staff.	<ul style="list-style-type: none">• Will call Pathfinders to find new Behavior Psych provider• Contact Jane Doe OT and School team for tips.	<ul style="list-style-type: none">• Pathfinders call completed• Phone conference w/school and outpatient OT scheduled 12/01/14

Slide: courtesy Ellie Sollins LCSW-CARD



ASD in primary care (after ASD diagnosis)

- Ask family to bring information they would like to process
- What is your understanding of the information you were given?
- Address **safety** (wandering, self injurious behaviors) and **scary**
- Family impact: e.g. siblings, work, finances, mental health, long term planning
- Screen siblings

- Identify **STRENGTHS**



Shared Decision Making in ASD

- Topics of shared decision making
 - Therapeutic interventions
 - School placement
 - Complementary and integrated medicines
 - Psychopharmacological interventions
- Tools to aid shared decision conversations
 - Checklists (behavioral, transition, planning)
 - Tool kits
 - Knowledge about complementary and integrated medicine



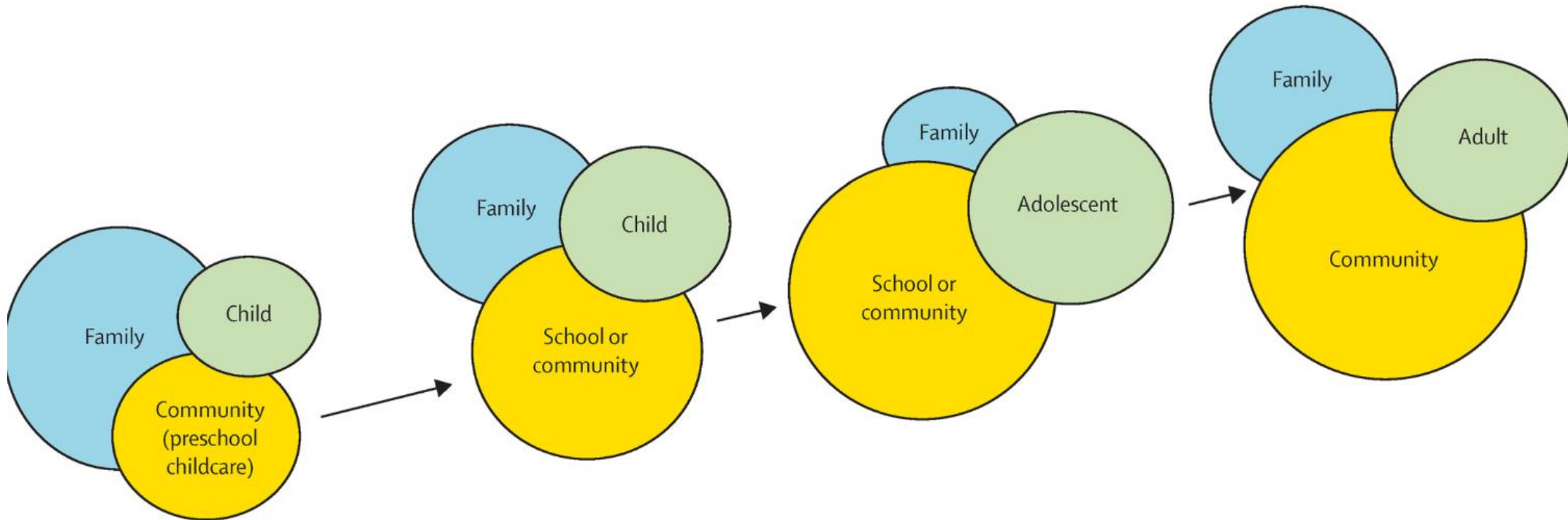
Life course ASD

Preschool age
(before the age of 6 years)

School age
(between the ages of 6 and 11 years)

Adolescence
(between the ages of 12 and 17 years)

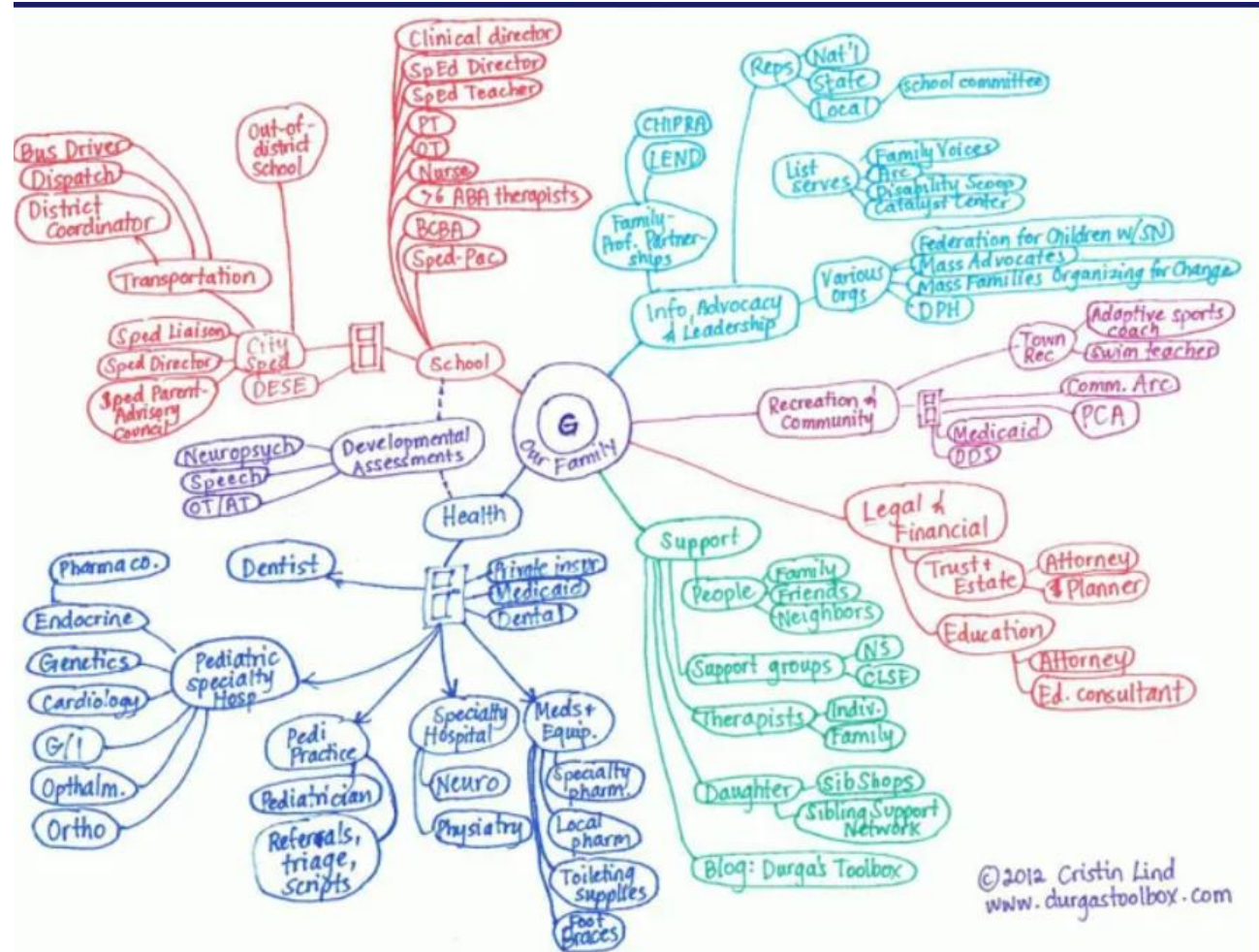
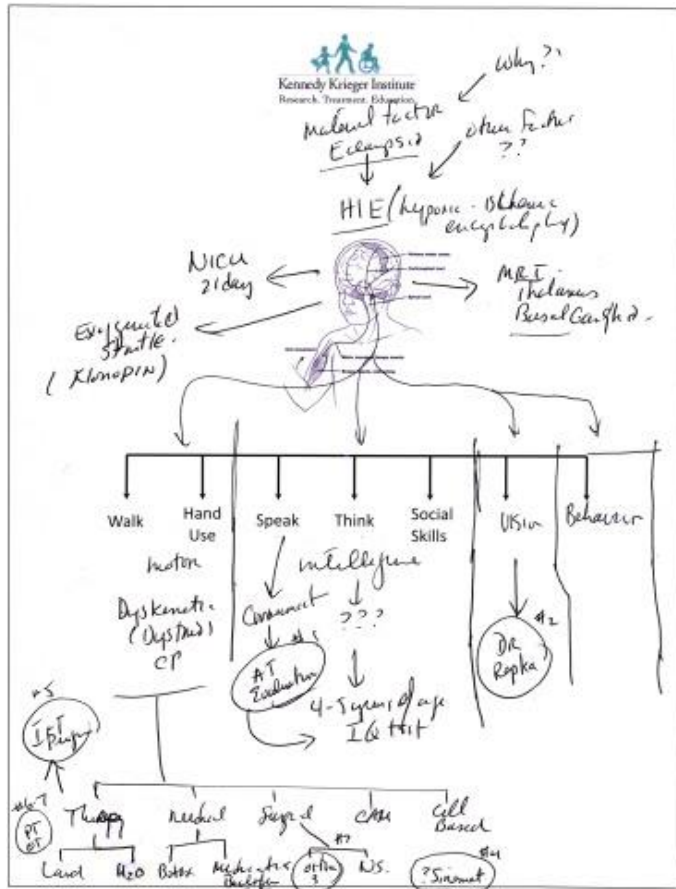
Adults (18 years and older)



Adapted from Lord , 2022



The drawing she kept: road map



© 2012 Cristin Lind
www.durqaustoolbox.com





Looking Into the Future for a Child With Autism

As my son's limitations became clearer, I found it harder every year to write a vision statement for his I.E.P. Then he showed us how.

By CAMMIE McGOVERN AUG. 31, 2017

<https://www.nytimes.com/2017/08/31/well/family/looking-into-the-future-for-a-child-with-autism.html?smprod=nytcore-iphone&smid=nytcore-iphone-share>



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Ethan's vision statement

Not simply because Ethan had articulated his own entirely reasonable vision statement, but because it incorporated every aspect of his present life that brings him joy. After years of fabricating visions for a future we never honestly thought possible, Ethan was offering one that was both optimistic and breathtakingly simple: *I want my life to keep looking the way it does now.*

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COMMENTS

I wish I could tell other parents at the start of their journey what it's taken me two decades to learn. First, that your child may continue to grow and change and, even at the age of 21, may surprise you by doing things you never thought possible. Second, that in the end, success won't be measured by academic performance or job placement. It will have more to do with accumulating small pleasures and filling your life with those. I don't know why it never occurred to me: Your future should look like the best parts of your present.



Pearls

- Identification of ASD requires surveillance, screening and clinical evaluation before and beyond current recommended screening ages at 18 and 24 months
- Medical and mental health co-occurring conditions in ASD are common and often identified and treated in the medical home
- Shared decision making is often an effective approach to discussing therapies and interventions in ASD



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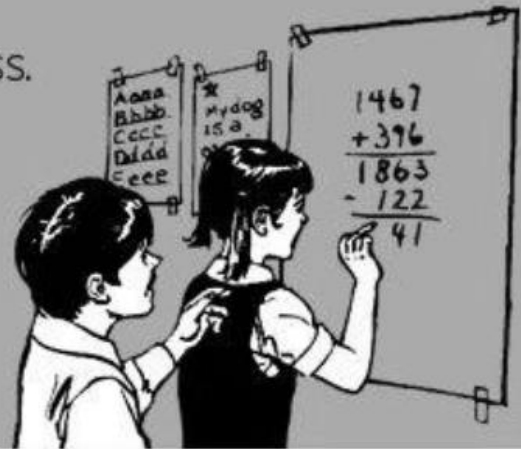
Questions, comments, feedback



Billy has 32 pieces of bacon. He eats
28. What does he have now?

Happiness.

Billy has happiness.

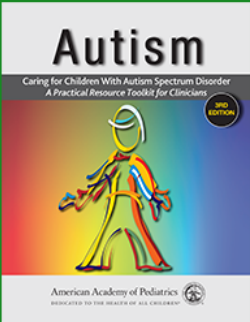


somee cards
user card



Tools and Resources

- Pathfinders for Autism- lifespan checklists
- <https://www.pathfindersforautism.org/wp-content/uploads/2018/02/Ages-checklist-18-to-21.pdf>



Autism
Caring for Children With Autism Spectrum Disorder
A Practical Resource Toolkit for Clinicians
3rd edition
American Academy of Pediatrics
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Caring for Children With Autism Spectrum Disorder: A Practical Resource Toolkit for Clinicians, 3rd edition

Primary care providers play an important role in helping children on the autism spectrum get the assistance and services they need.

Use these fact sheets and family handouts to enhance your comfort with applying new diagnostic criteria, addressing common issues, and incorporating culturally appropriate care into your workflow.

Communicating Visually in Pediatrics
A Step-by-Step Tool for Supporting Patients and Caregivers

Danielle Fleckenstein, MA, CCLS
Alan I. Rosenblatt, MD, FAAP



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CDC TOOL Act Early Milestone track app



Milestones Matter

Track your child's developmental milestones and try brain building tips to add learning to everyday moments!

Track Your Child's Development

Track how your child plays, learns, speaks, acts, and moves with CDC's Milestone Tracker app—and share all progress and any concerns with their doctor during well-child visits. www.cdc.gov/MilestoneTracker



BY 2 MONTHS:
Smiles at you



BY 6 MONTHS:
Laughs with you



BY 12 MONTHS:
Plays games with you,
like "peek-a-boo"



BY 18 MONTHS:
Points to show you
something interesting

Brain Building Tip:

Suggested Age: 0–2 years

Powered by
vroom

We're surrounded by words that are ready for reading. Try reading signs aloud to your child and talk to them about what they mean.

It doesn't matter if it's a book, magazine, or billboard – it all counts! Reading to your child, anywhere and everywhere, helps them develop a rich, diverse vocabulary. Find more tips at vroom.org.



Centers for Disease
Control and Prevention
www.cdc.gov/ActEarly
1-800-CDC-INFO

**Do you have concerns about how your child plays, learns, speaks, acts or moves?
Visit www.cdc.gov/concerned and talk with your child's doctor.**

CDC does not endorse private products, services, or enterprises. Vroom Tips are not a diagnostic tool.



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Note from the AAP:

April is Autism Acceptance Month; AAP Has Online Course on Caring for Children With ASD:

Pediatric clinicians play a critical role in the screening and diagnosis of children with autism and other developmental delays. The AAP provides detailed information on the clinical signs, surveillance, and screening of autism spectrum disorder.

The AAP offers a free self-paced online PediaLink course *Identifying and Caring for Children with Autism Spectrum Disorder*:

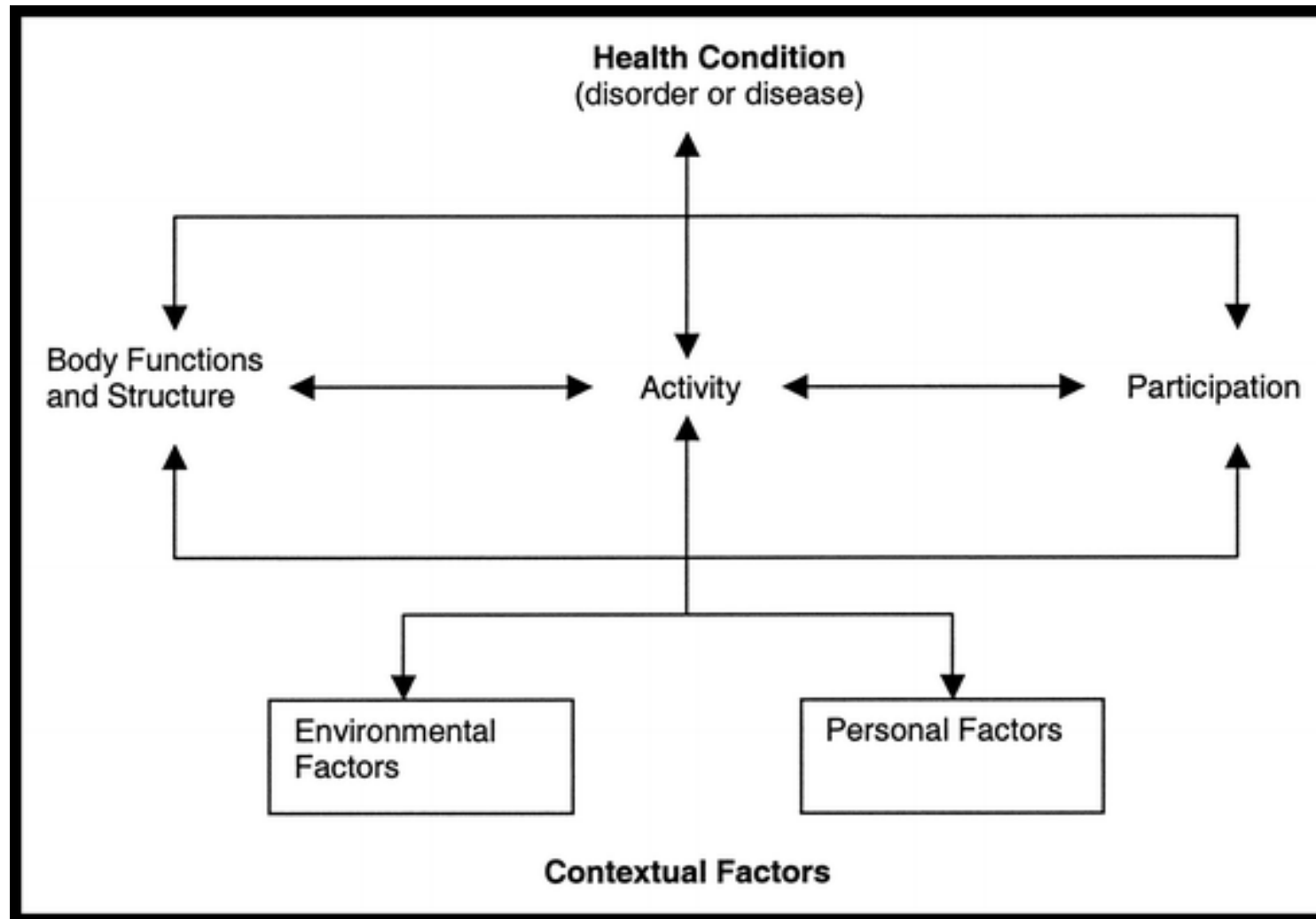
A Course for Pediatric Clinicians. Find the course at [Identifying and Caring for Children with Autism Spectrum Disorder: A Course for Pediatric Clinicians - AAP](#). It is available until **Sunday, April 19, 2023**.



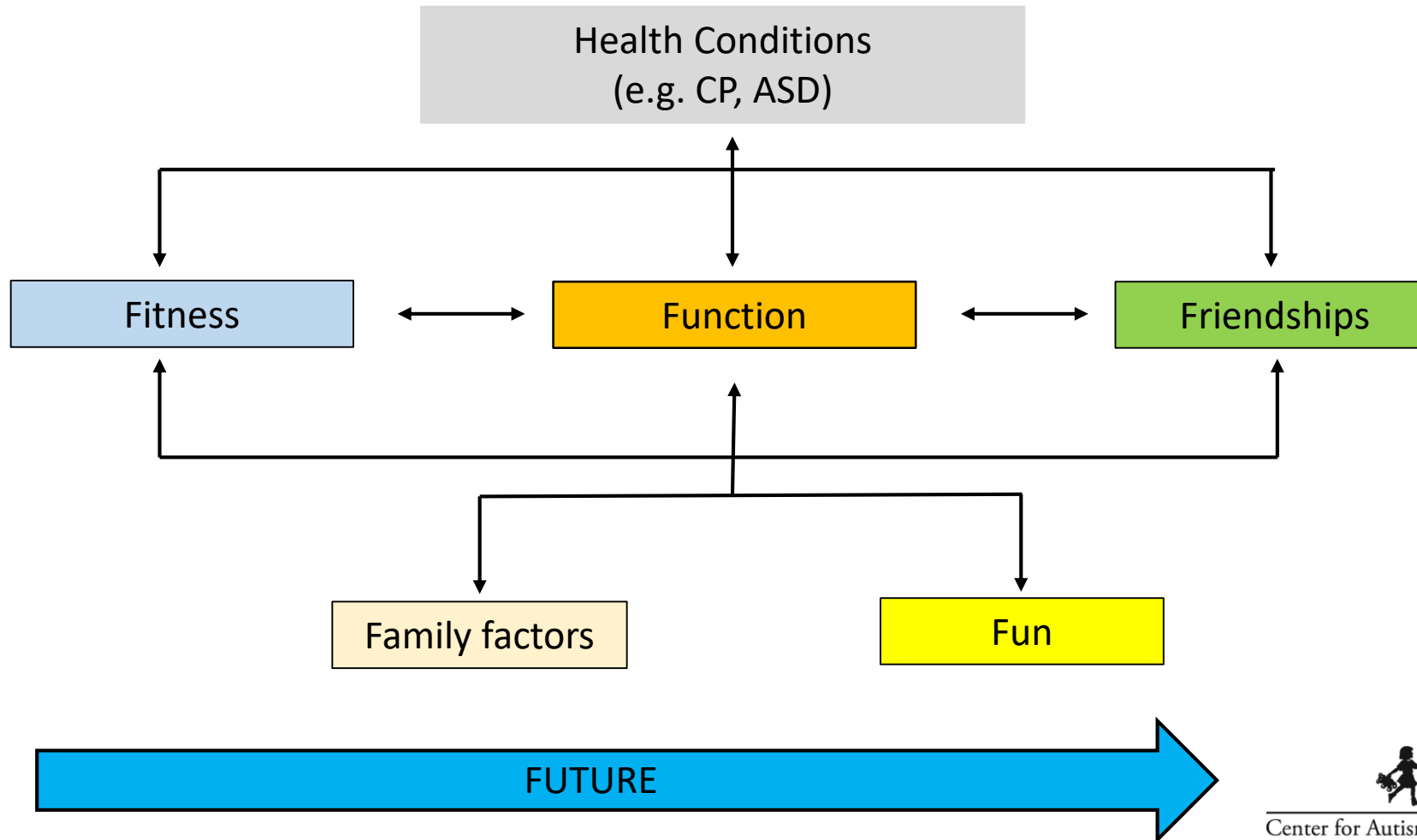
Extra slides on the WHO model



WHO International Classification of Functioning Disability and Health



The WHO model -children



Integrative model of Disability adapted for children

F	Meaning
Function	What people do “how” things are done is not what is important Role-job-task: for children play and school is their work
Family	Family represents the essential “environment” of all children
Fitness	How children stay physically active, include exercise and recreational activities
Fun	Activities children are involved in or enjoy participating in
Friends	Social development is an essential part of childhood
Future	Refers to parents and children’s expectations and dreams for their future

