

# 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

<b>Traditional terms, concepts, ideas</b>	<b>Suggested alternatives</b>
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

<b>First person language</b>	<b>Identity first language</b>
Person with Autism	Autistic person

Dwyer MA , 2022



# Medical versus Social Model of Disability

## **Medical**

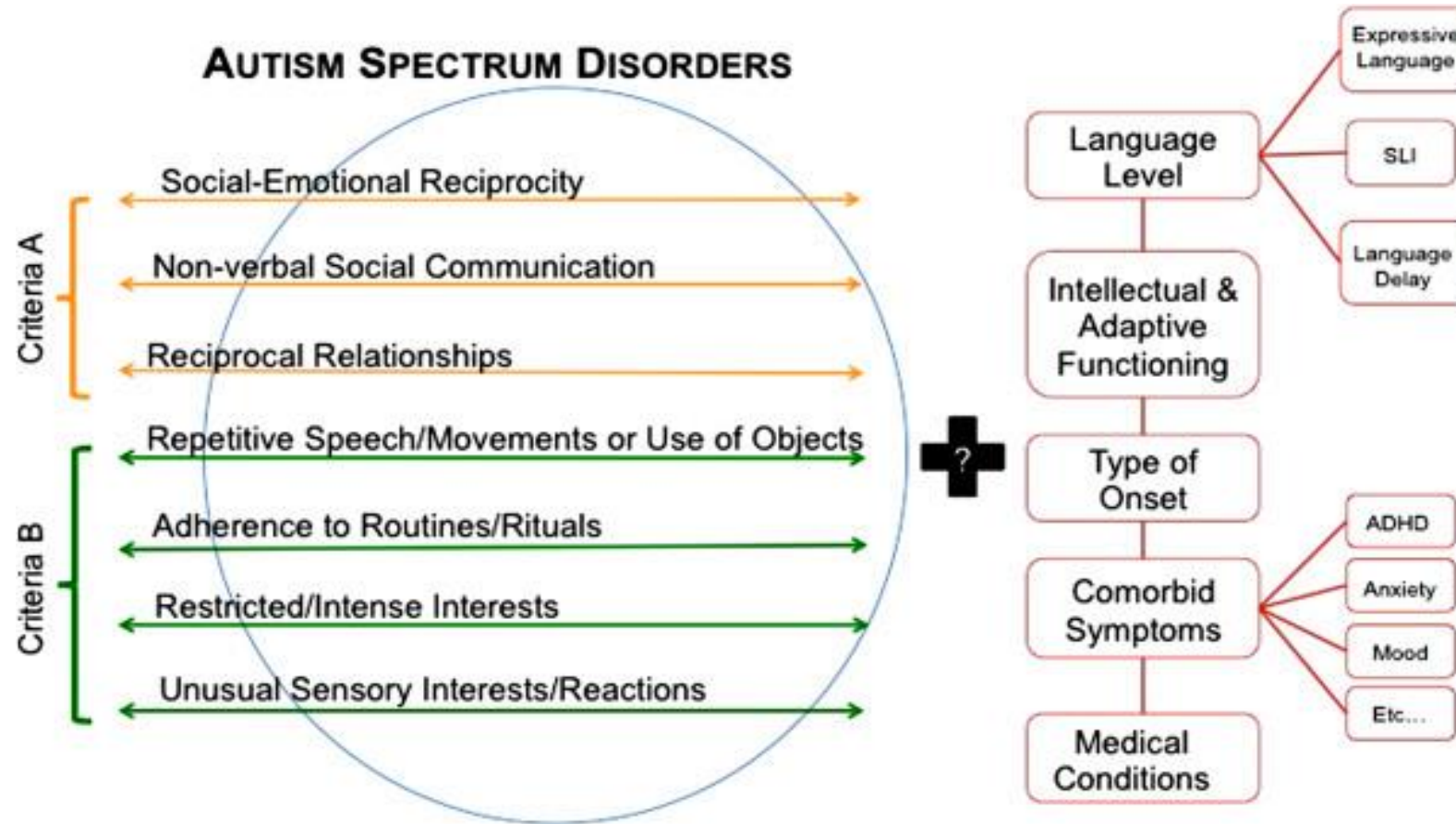
The disability is part of YOU, and the solution to the disability is to fix YOU

## **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

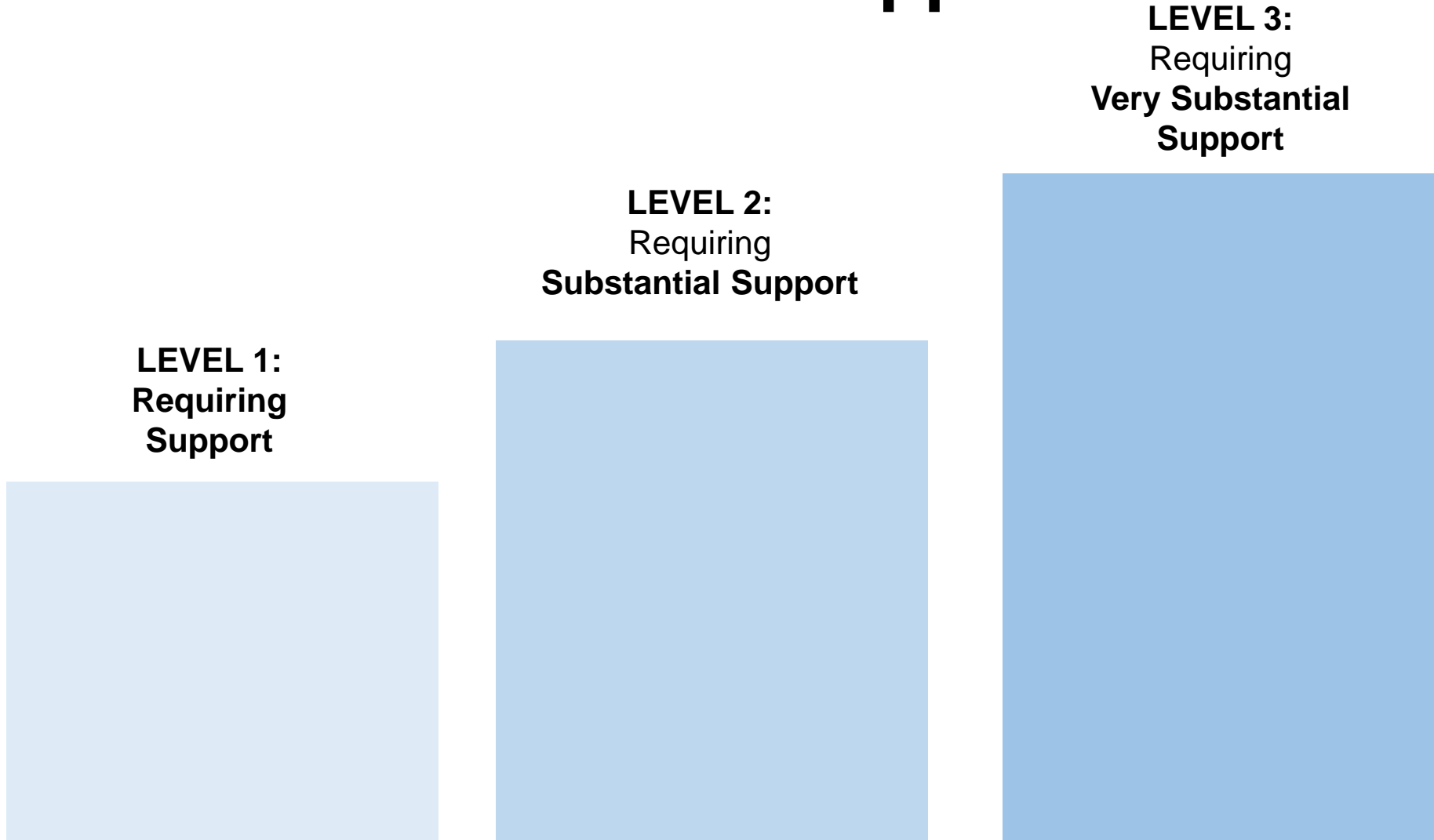
**Restricted, repetitive patterns of behavior, interests or activities**

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



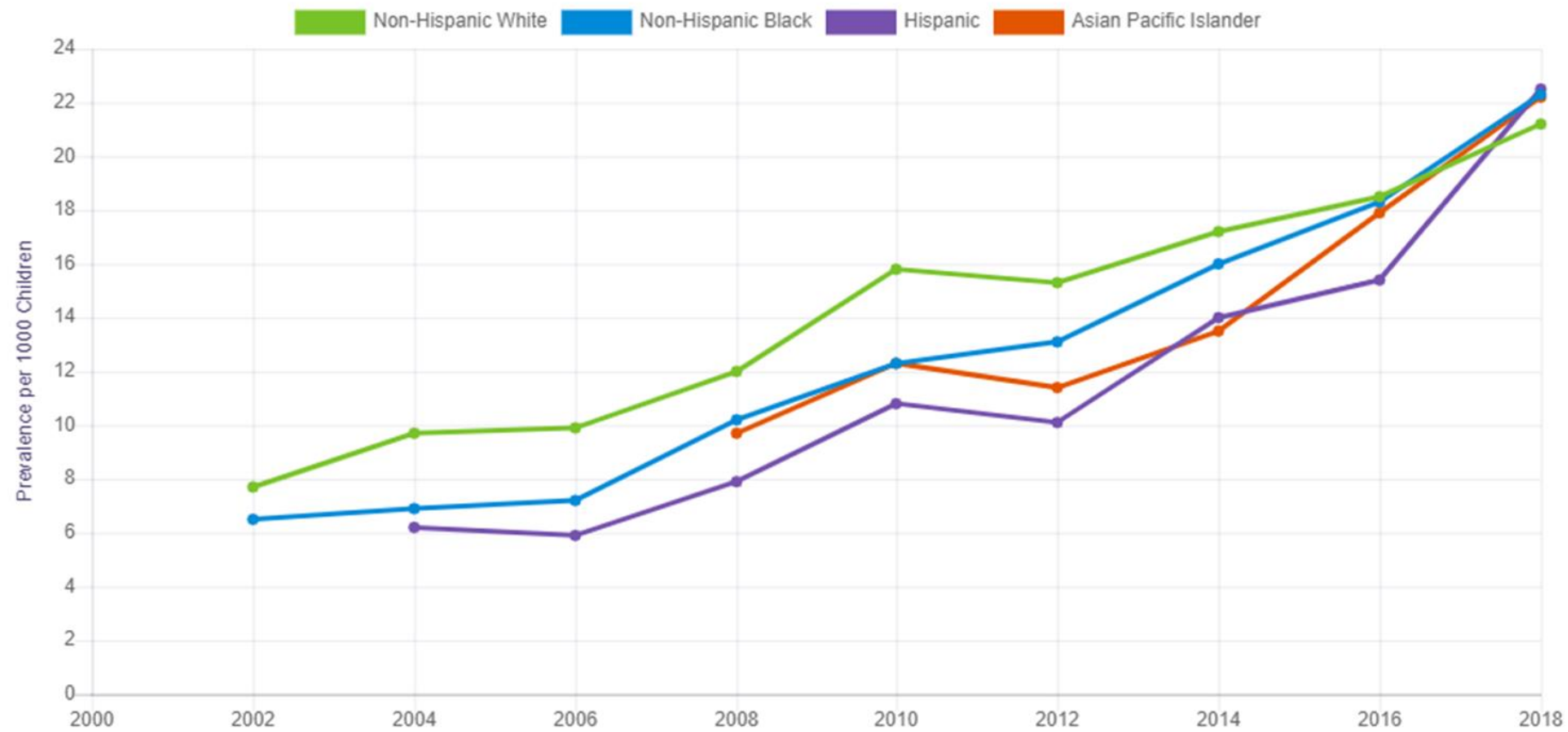
# ASD prevalence data and trends

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



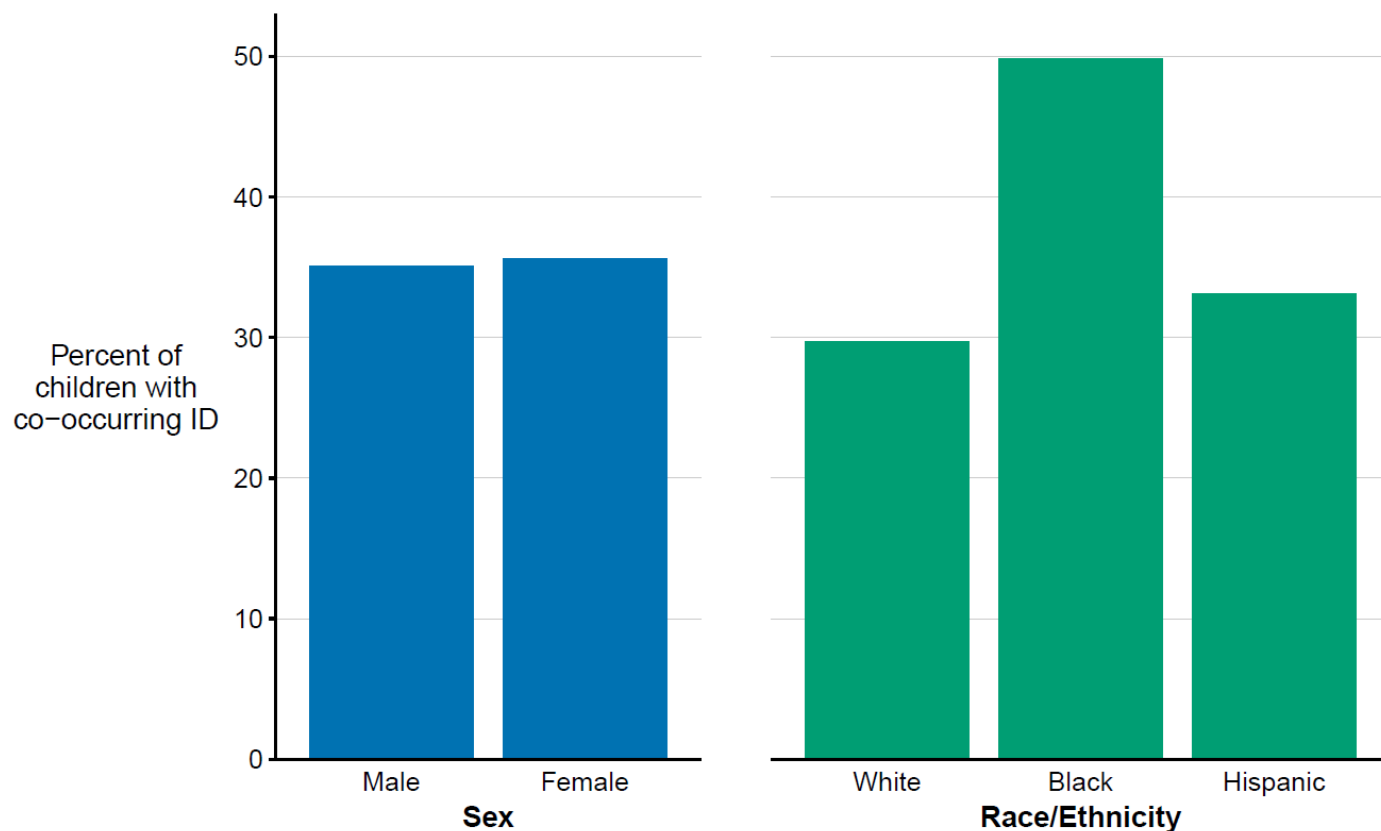
# ASD prevalence and trends



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



# 2018 ASD and Intellectual Disability : Racial Discrepancies

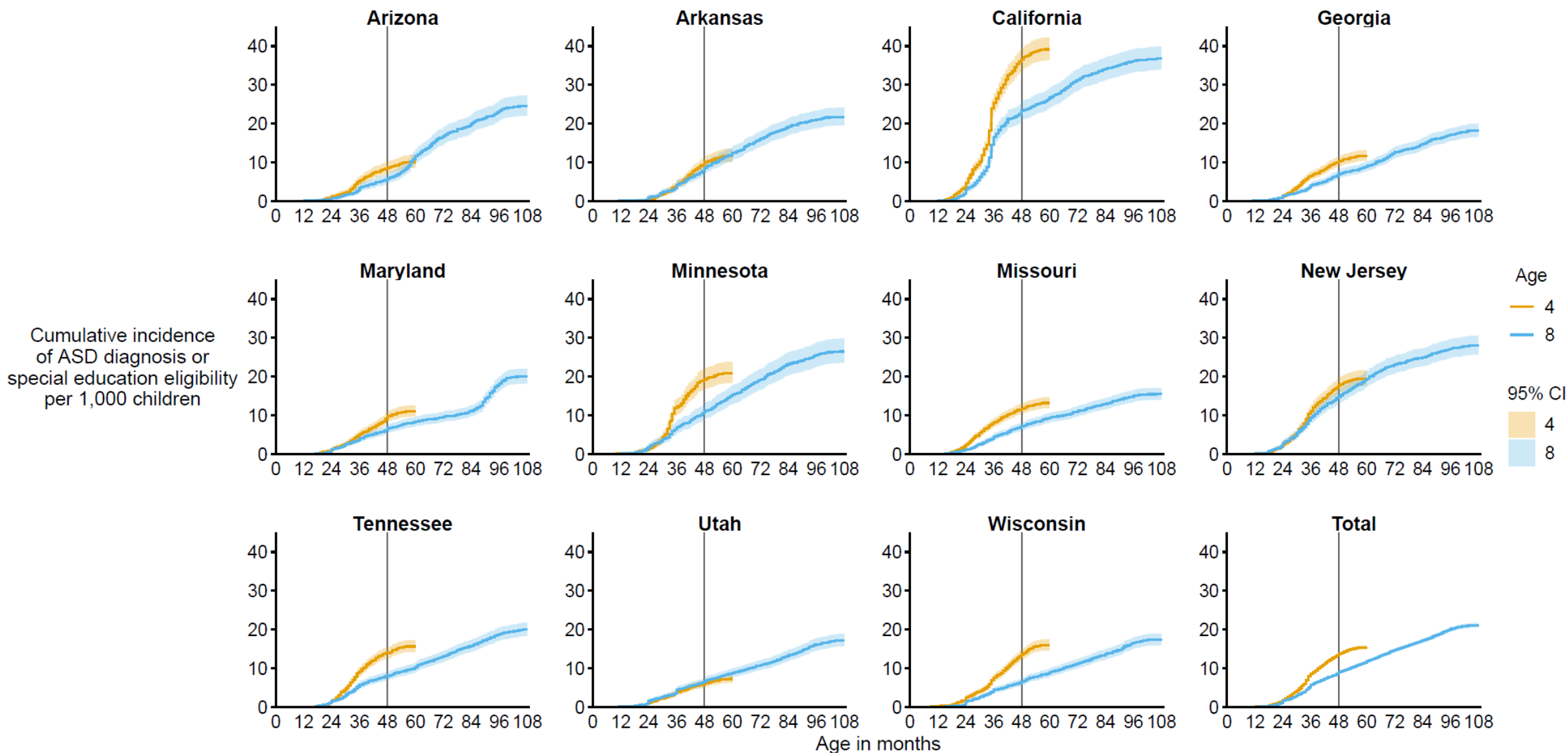


\* IQ score  $\leq 70$  or examiner statement of intellectual disability in a comprehensive evaluation

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
<b>M-CHAT R/F</b> Modified Checklist for Autism in Toddlers Revised-Follow-up	16-30 months	20	5-10	No
<b>SCQ</b> Social Communication Questionnaire	≥ 4 years (mental age >2 years)	40	10	Yes
<b>POSI-SWYC</b> 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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“Early signs of Autism Video Tutorial” Rebecca Landa, PhD, CCC-SLP, Kennedy Krieger Institute. June 11, 2013

# 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



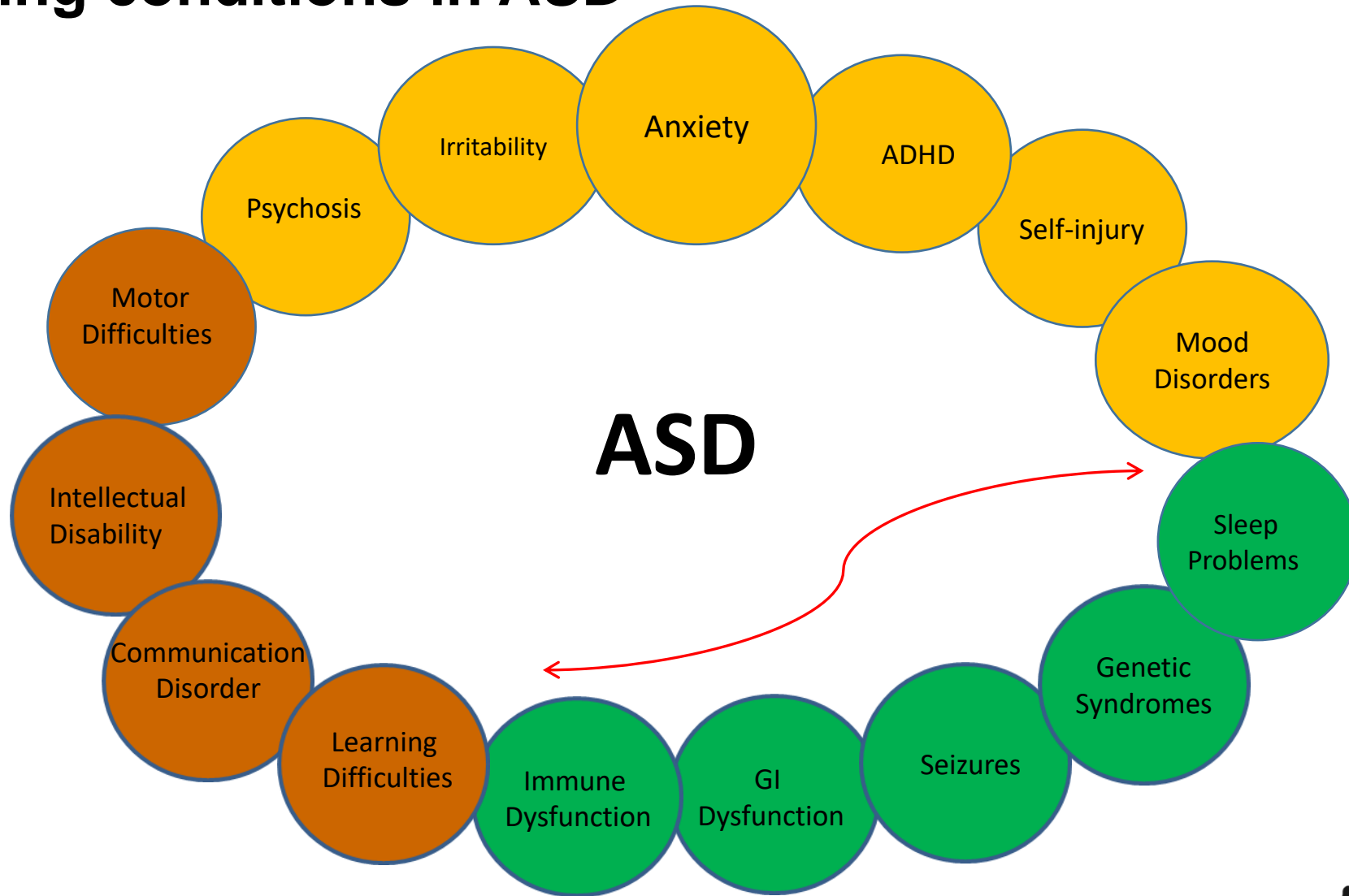
# ASD in primary care (after ASD diagnosis)

## 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"><li>• Rule out Iron deficiency and underlying neurological concerns.</li><li>• Behavioral Psychology</li></ul>	<ul style="list-style-type: none"><li>• Begin Behavioral Psychology</li><li>• Attend parent education session</li><li>• Consult with outpatient OT and school staff.</li></ul>	<ul style="list-style-type: none"><li>• Will call Pathfinders to find new Behavior Psych provider</li><li>• Contact Jane Doe OT and School team for tips.</li></ul>	<ul style="list-style-type: none"><li>• Pathfinders call completed</li><li>• Phone conference w/school and outpatient OT scheduled 12/01/14</li></ul>

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



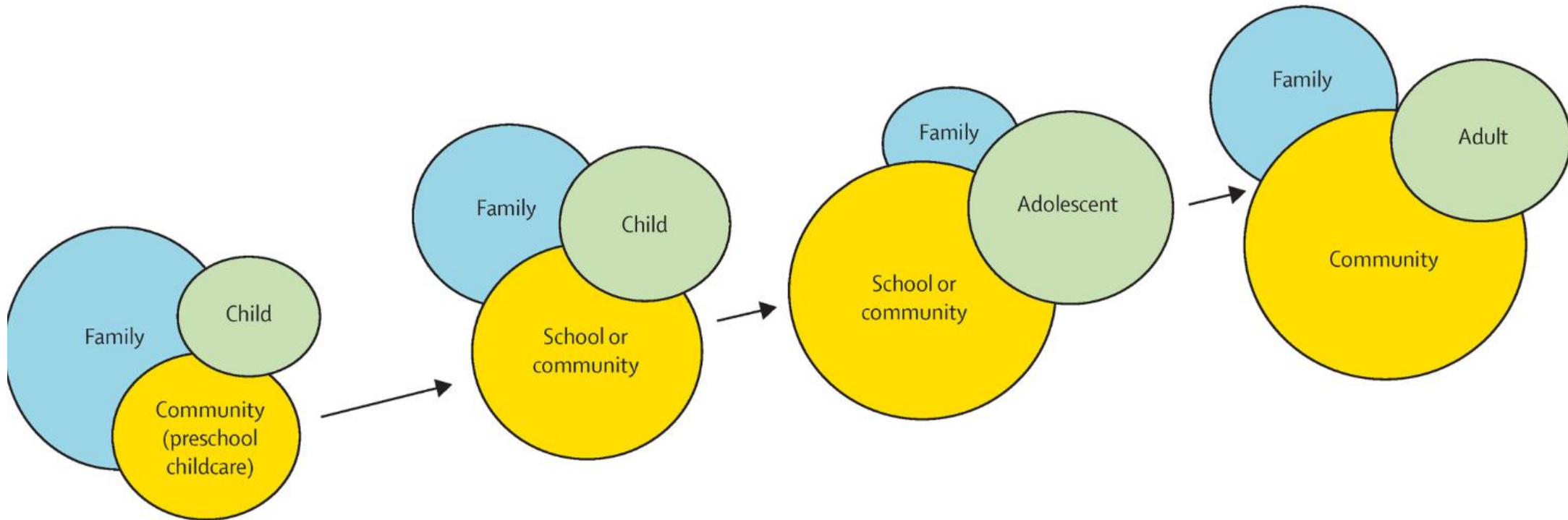
# Life course ASD

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)

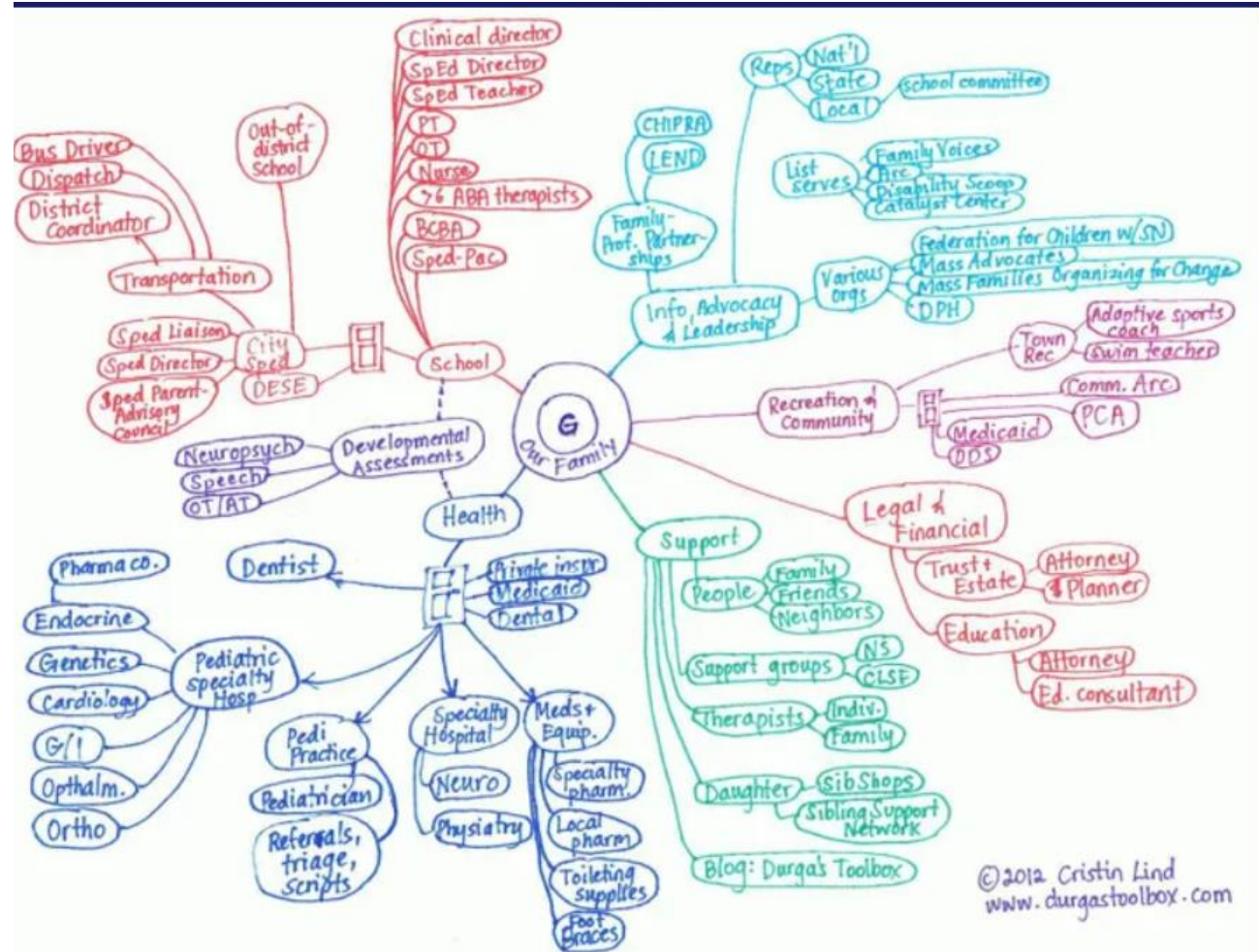
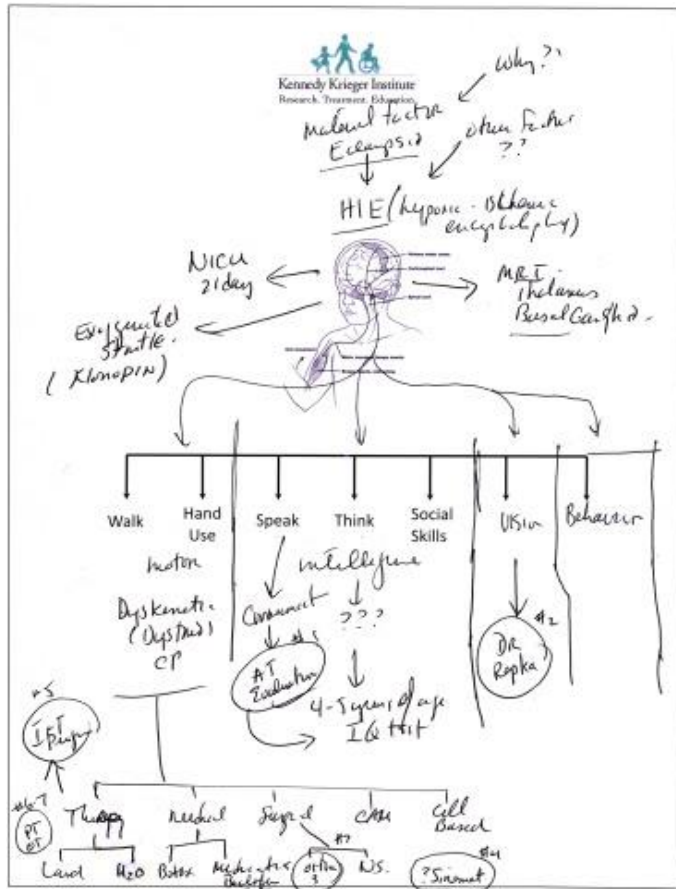


Adapted from Lord , 2022





# The drawing she kept: road map





# 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.*

441  
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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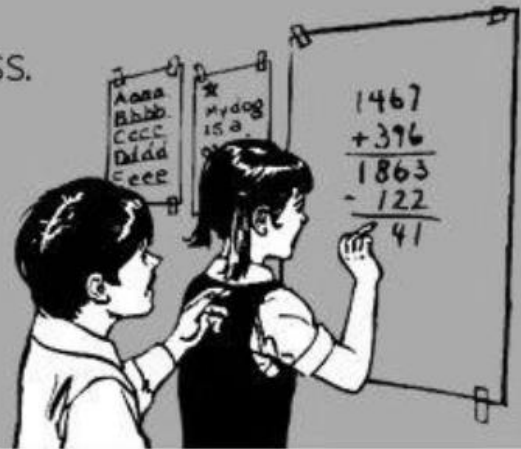
# Questions, comments, feedback



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

Happiness.

Billy has happiness.

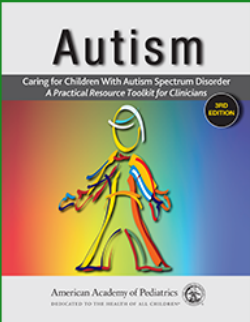


someecards  
user card



# 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  
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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](http://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](http://vroom.org).



Centers for Disease  
Control and Prevention  
[www.cdc.gov/ActEarly](http://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](http://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*:

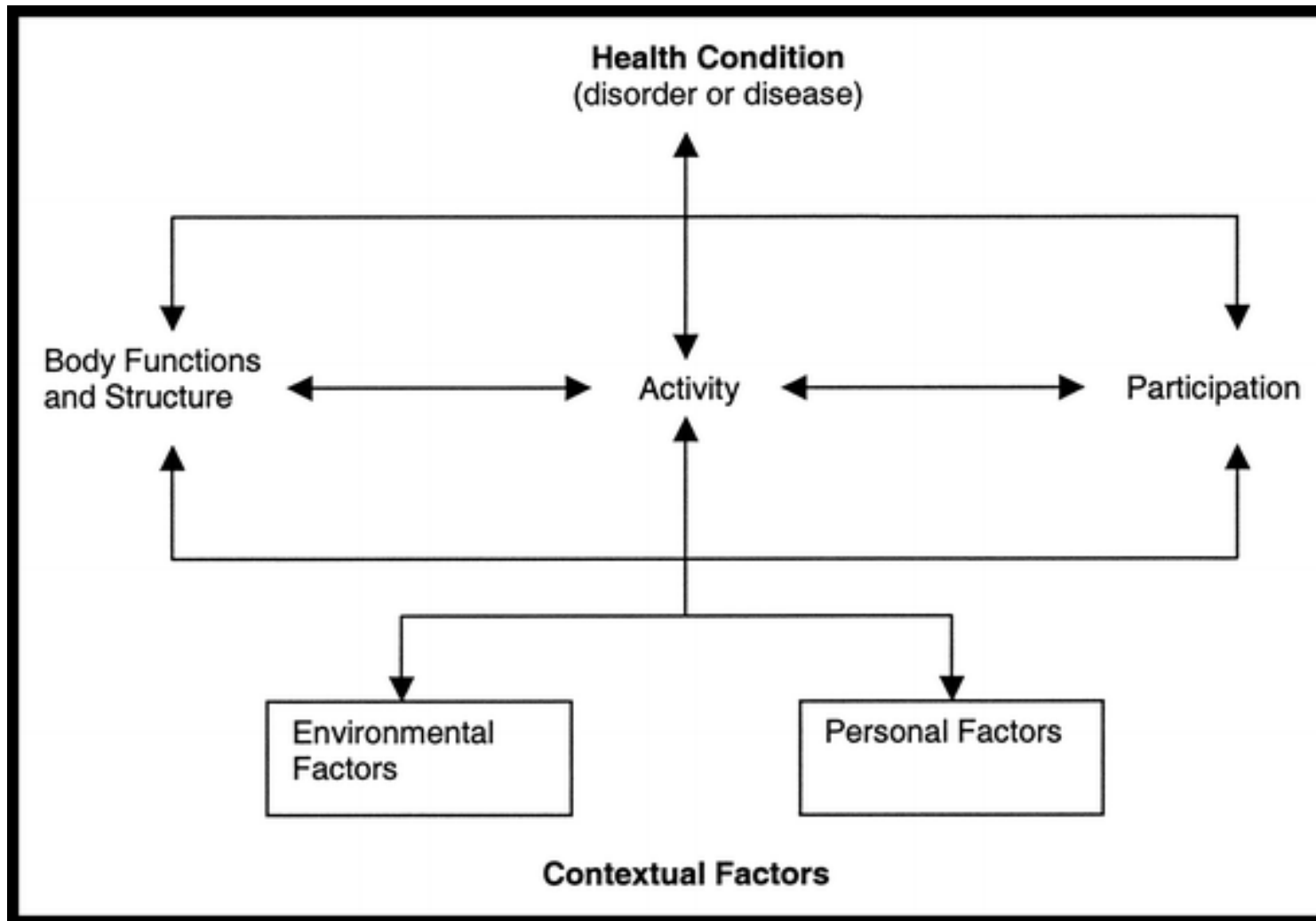
A Course for Pediatric Clinicians. Find the course at [Identifying and Caring for Children with Autism Spectrum Disorder: A Course for Pediatric Clinicians - AAP](#). It is available until **Sunday, April 19, 2023**.



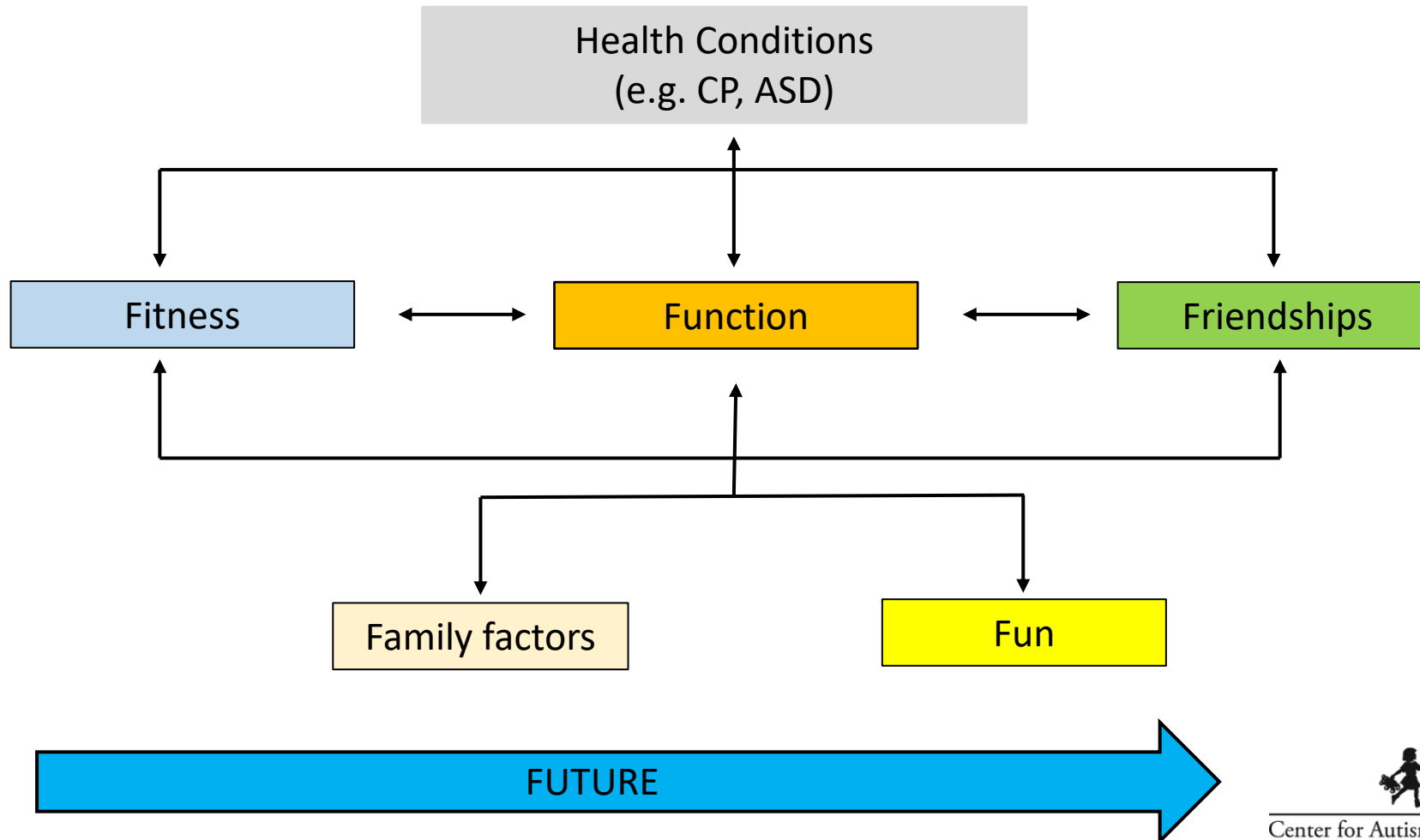
# Extra slides on the WHO model



# 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

