

# Introduction to Autism: An Overview for Parents and Caregivers



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# Introduction to Autism

- A bit about me:
  - Clinical Social Worker,  
*UCSF STAR Center for ASD  
and NDDs*: <https://star.ucsf.edu/>
- What we will cover today

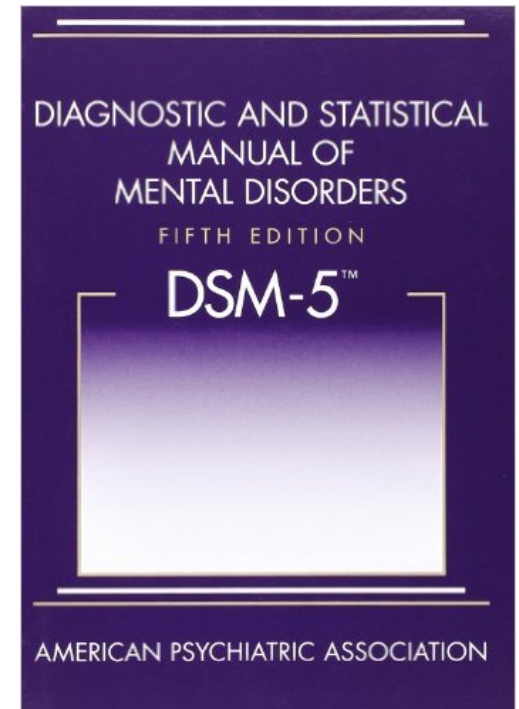
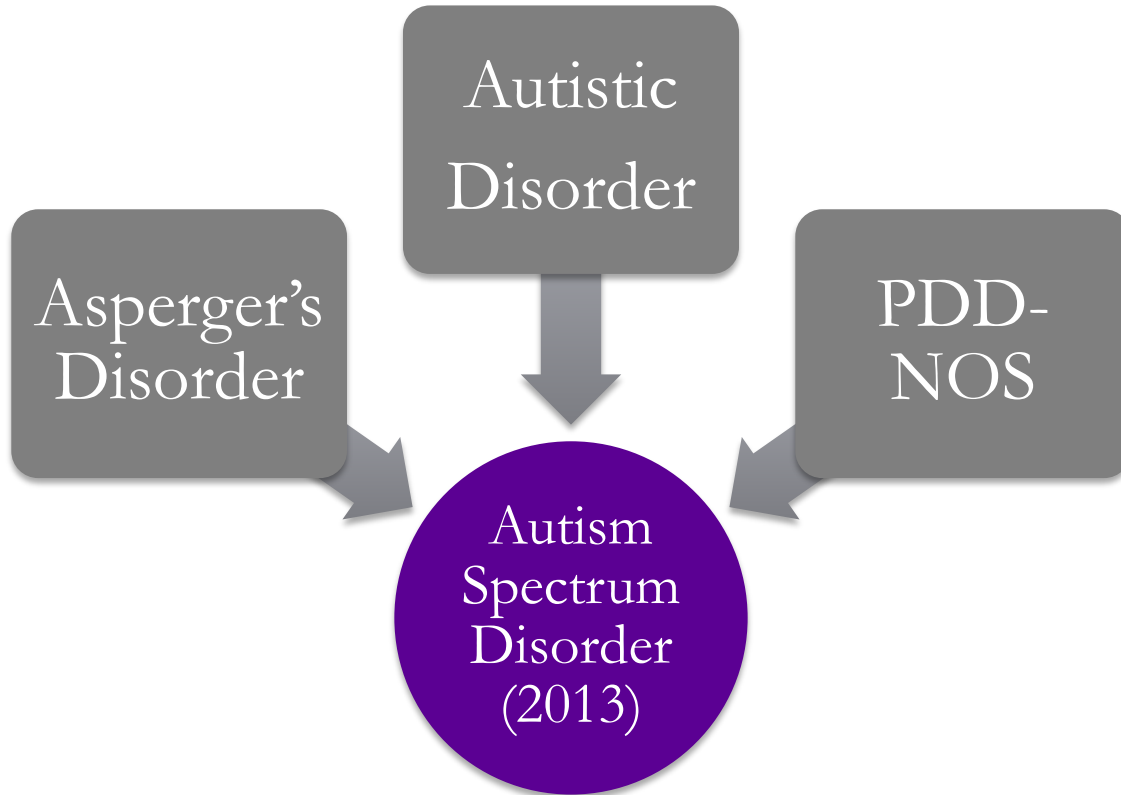


# What is Autism Spectrum Disorder (ASD)?

- A neurodevelopmental disorder
- Onset during early childhood (0-5 years)
- More common in boys than girls (4.5:1 ratio)
- Prevalence at 1 in 59 per CDC
- ASD occurs in all racial, ethnic, and socioeconomic groups



# Changes in Diagnostic Classification (APA's Diagnostic and Statistical Manual or "DSM")

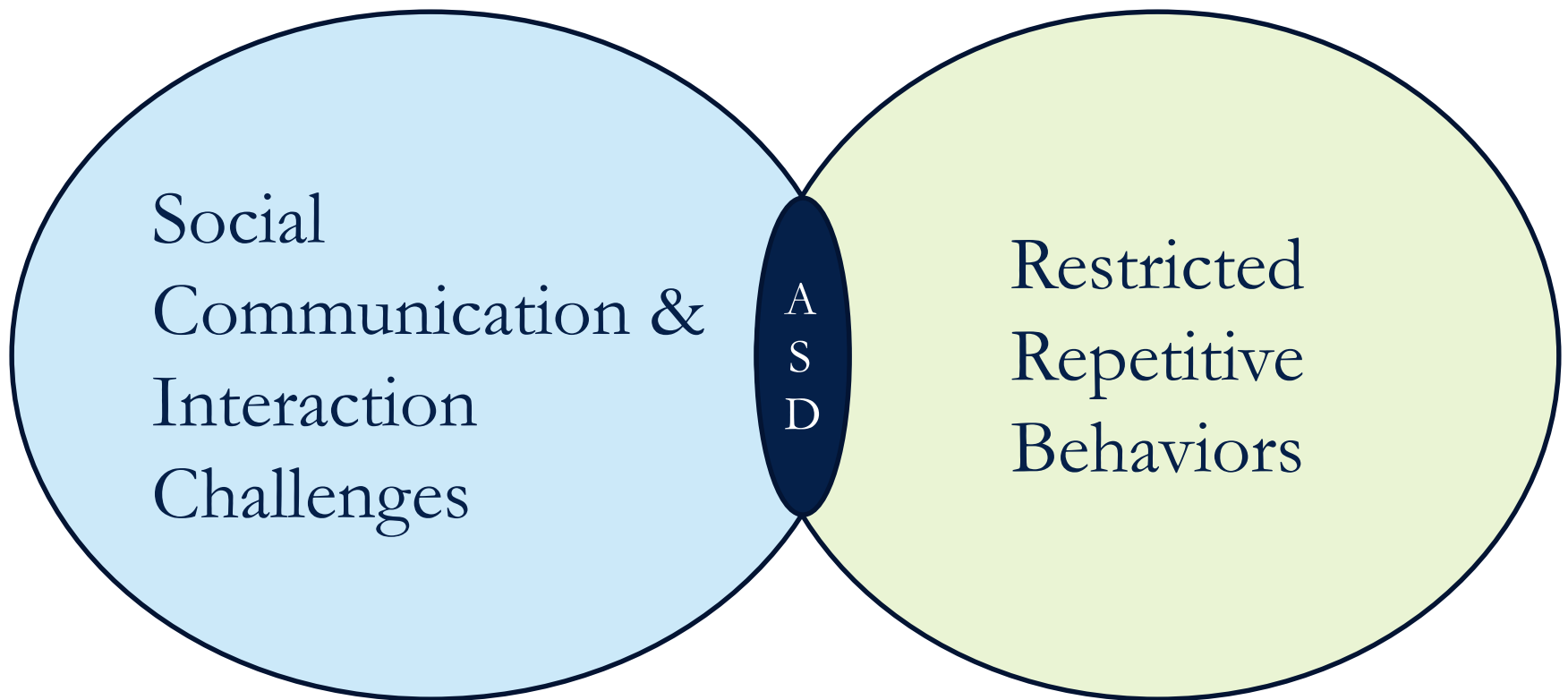


# How Do We Diagnose ASD?

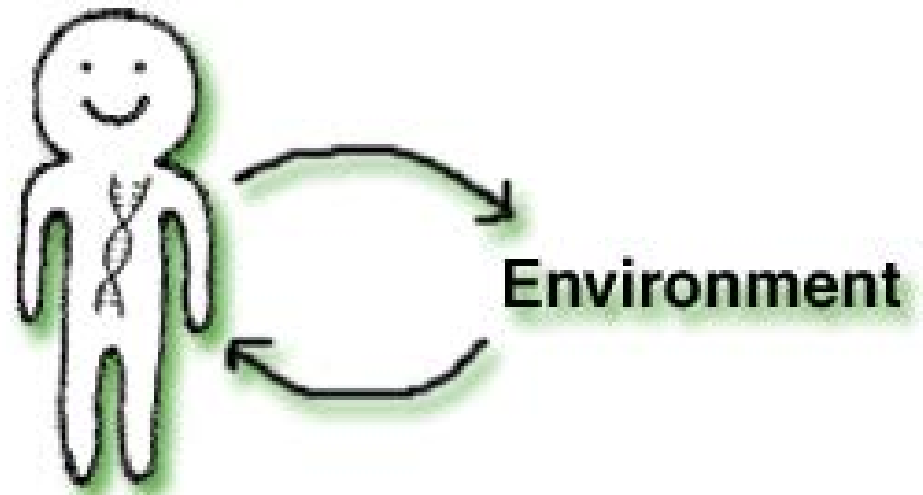
- No medical test can diagnose ASD (ex, blood test, MRI, etc.)
- Other medical conditions must be considered first before a diagnosis of ASD is given (ex. hearing problems, intellectual disability, etc)
- ASD is a **constellation of specific behaviors** that must be assessed by an ASD specialist, such as a clinical psychologist, child psychiatrist, pediatric neurologist, or developmental pediatrician.

# What Are the Core Symptoms of ASD?

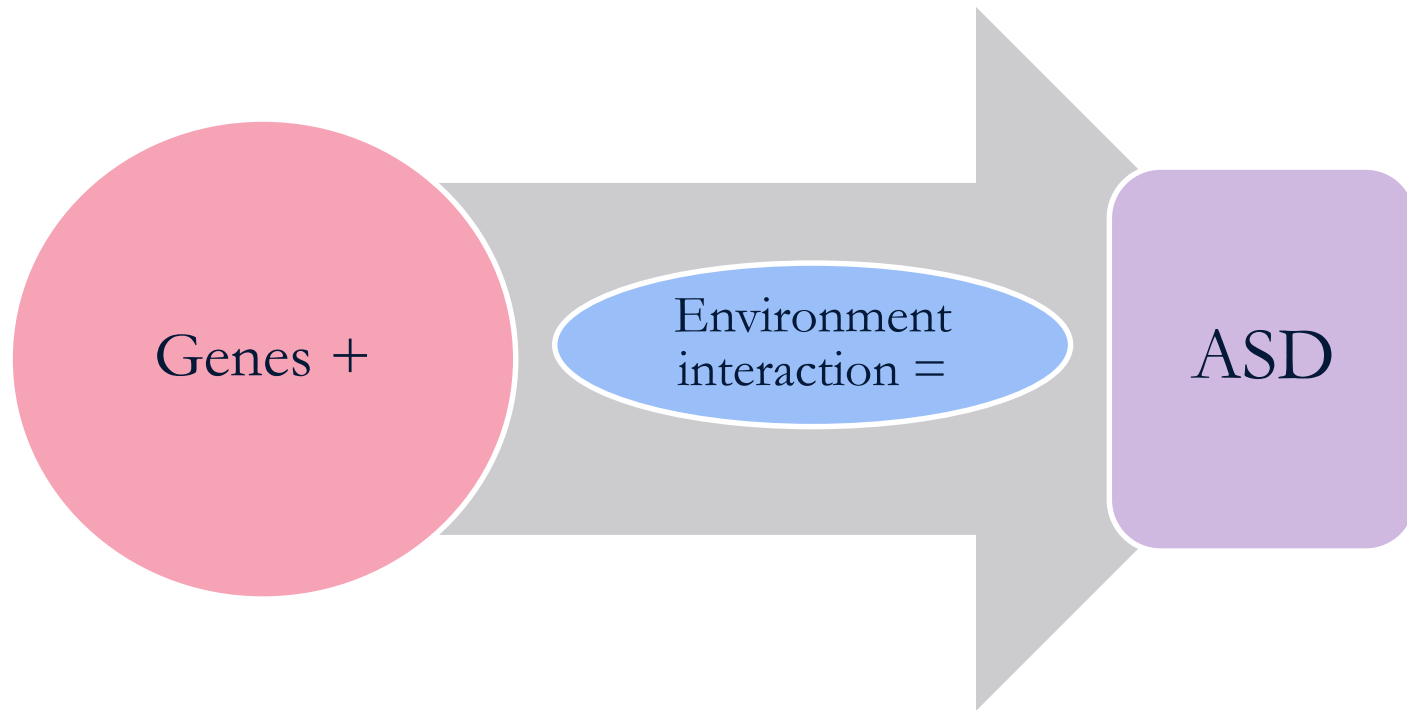
**A.** Problems in **social communication** and **social interaction** + **B.** **Restricted, repetitive patterns of behavior or interests**



# What Causes ASD?



# What Causes ASD?





# What Does *NOT* Cause ASD?

- “Bad parenting”

**Some doctors tried to say autism was caused by the lack of warmth from the moms of autistic children**

They call this the refrigerator mother theory



# What Does *NOT* Cause ASD?

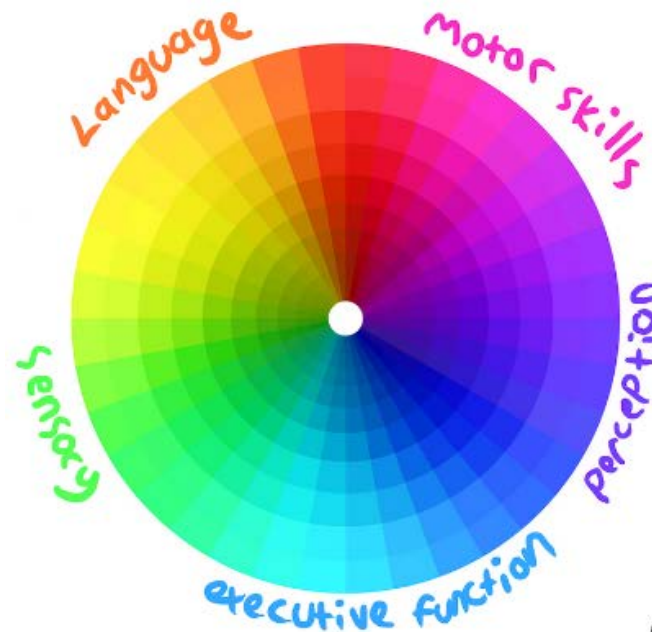


- Vaccines
  - Fraudulent research by Wakefield
  - Decrease in vaccinations due to media hysteria and rise in measles outbreak in U.S.
  - <http://autismsciencefoundation.org/what-is-autism/autism-and-vaccines/>

# Where is My Child on the Spectrum?

What does the autism spectrum look like?

- The fallacy of “high functioning” and “low functioning”
- Adjust thinking to strengths, challenges, and adaptive skills



Circular spectrum by  
Rebecca Burgess  
Montage @sciencebase

# Video Examples

- Differences between children with ASD and those who are typically developing

Toddlers:

[http://www.autisminternetmodules.org/mod\\_view.php?nav\\_id=1499](http://www.autisminternetmodules.org/mod_view.php?nav_id=1499)

# Evidence-Based Practice: Overview

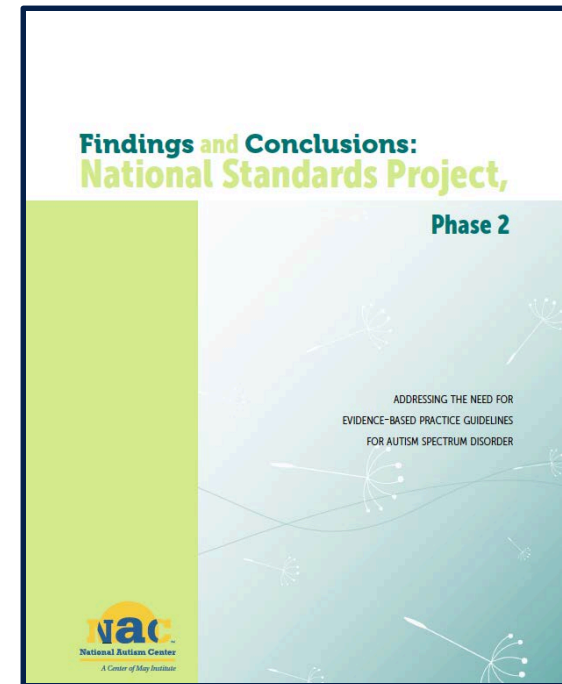


Missouri Autism Guidelines Initiative, 2012

# National Standards Project (NSP), Phase 2, National Autism Center, 2015

## 14 Established Evidence-Based Interventions

- Behavioral Interventions
- Cognitive Behavioral Therapy (CBT)
- Comprehensive Behavioral Training for Young Children
- Language Training (Production)
- Modeling (live or video)
- Natural Teaching Strategies
- Parent Training
- Peer Training Package
- Pivotal Response Training
- Schedules
- Scripting
- Self-management
- Social Skills Package
- Story-based Intervention



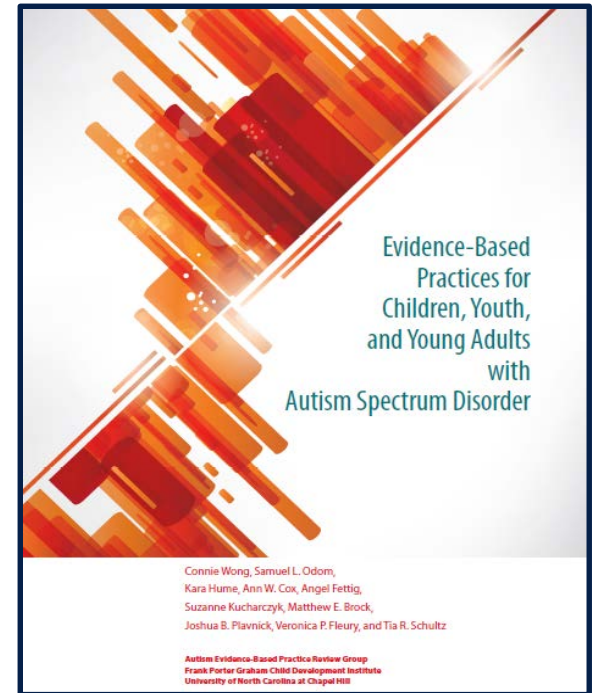
# National Professional Development Center on Autism Spectrum Disorder (NPDC), 2007-2014

## ▪ In 2010, 24 EBPs

- Included 10 years, 1997-2007

## ▪ In 2014, 27 EBPs

- Second review by NPDC
- Included 22 years, 1990-2011
  - 29,105 possible studies → 456 studies
  - RCT, quasi-experimental, single case design
- Strength of evidence for assessment
- Based on number, type of studies using each EBP



Connie Wong, Samuel L. Odom,  
Kara Hume, Ann W. Cox, Angel Fettig,  
Suzanne Kucharczyk, Matthew E. Brock,  
Joshua B. Plavnick, Veronica P. Fleury, and Tia R. Schultz

Autism Evidence-Based Practice Review Group  
Frank Porter Graham Child Development Institute  
University of North Carolina at Chapel Hill

# National Professional Development Center on Autism Spectrum Disorder (NPDC), 2007-2014: 27 EBPs.

## Antecedent-based Interventions

Cognitive Behavioral Intervention

Differential Reinforcement

Discrete Trial Teaching (DTT)

Exercise

Extinction

Functional Behavior Assessment (FBA)

Functional Communication Training

Modeling

Naturalistic Interventions

Parent-Implemented Intervention

Peer-Mediated Instruction and Intervention

Picture Exchange Communication System (PECS)<sup>TM</sup>

## Pivotal Response Training

Prompting

Reinforcement

Response Interruption/Redirection

Scripting

Self-Management

Social Narratives

Social Skills Training

Structured Play Group

Task analysis

Technology-Aided Intervention/Instruction\*

Time delay

Video modeling

Visual supports



## Comparison of NSP and NPDC Findings Showed Substantial Overlap

Overlap Between Evidence-Based Practices Identified by the National Professional Development Center (NPDC) on ASD and the National Standards Project (NSP)												
Evidence-Based Practices Identified by the National Professional Development Center (NPDC) on ASD	Established Treatments Identified by the National Standards Project (NSP)										Comprehensive Behavioral Treatment for Young Children	Joint Attention Intervention
	Antecedent Package	Behavioral Package	Story-based Intervention Package	Modeling	Naturalistic Teaching Strategies	Peer Training Package	Pivotal Response Treatment	Schedules	Self-Management			
Prompting	X			X						The NPDC on ASD did not review comprehensive treatment models. Components of The Comprehensive Behavioral Treatment of Young Children overlap with many NPDC-identified practices.	The NPDC on ASD considers joint attention to be an outcome rather than an intervention. Components of joint attention interventions overlap with many NPDC-identified practices.	
Antecedent-Based Intervention	X											
Time delay	X											
Reinforcement		X										
Task analysis		X										
Discrete Trial Training		X										
Functional Behavior Analysis		X										
Functional Communication Training		X										
Response Interruption/Redirection		X										
Differential Reinforcement		X										
Social Narratives			X									
Video Modeling				X								
Naturalistic Interventions					X							
Peer Mediated Intervention						X						
Pivotal Response Training							X					
Visual Supports								X				
Structured Work Systems								X				
Self-Management									X			
Parent Implemented Intervention	The NSP did not consider parent-implemented intervention as a category of evidence-based practice. However, 24 of the studies reviewed by the NSP under other intervention categories involve parents implementing the intervention.											
Social Skills Training Groups	Social Skills Training Groups (Social Skills Package) was identified as an emerging practice by the NSP.											
Speech Generating Devices	Speech Generating Devices (Augmentative and Alternative Communication Device) was identified as an emerging practice by the NSP.											
Computer Aided Instruction	Computer Aided Instruction (Technology-based Treatment) was identified as an emerging practice by the NSP.											
Picture Exchange Communication	Picture Exchange Communication System was identified as an emerging practice by the NSP.											
Extinction	Extinction (Reductive Package) was identified as an emerging practice by the NSP.											

## Before Starting Intervention...

- Do an assessment to determine your child's level of *cognitive, language, and adaptive functioning*

# Communication Challenges in *Nonverbal/Minimally Verbal* Children with ASD

- Possible structural oral-motor problems
- Self-directed
- Lack of motivation to communicate
- Different and/or inappropriate behaviors to communicate (e.g., hitting, crying, stomping feet)
- Difficulty with comprehension (receptive language)
- May not indicate when help is needed
- Parent as mind reader

# Communication Strategies for *Nonverbal/Minimally Verbal* Children with ASD

- Follow a *developmentally appropriate* communication hierarchy:
  1. Target *prelinguistic skills* as language building blocks (ex, joint attention, gestures, imitation, play)
  2. Word approximations
  3. Single words (at least 50-60)
  4. Initiations: Question-asking (e.g., *What is it, where is it*)
  5. Combining words into phrases

\*Goal: Combine these new verbal skills with eye contact and gestures to request, label, and comment.

# Communication Strategies for *Nonverbal/Minimally Verbal* Children with ASD

- Say (model) the word, wait, and reward attempts
  - Carrier phrases (“ready, set,...”)
  - Offer choices (verbally and visually)
  - In sight, out of reach
  - Time delay
  - Ask open-ended questions
  - Visual Supports, PECS (giving a picture card to communicate wants/needs)
  - AAC device
- \*\*When your child responds successfully, reinforce immediately!**

# Communication Strategies for *Nonverbal/Minimally Verbal* Children with ASD: Video Example

# Communication Strategies for *Nonverbal/Minimally Verbal* Children with ASD: Video Example

# Communication Strategies for *Nonverbal/Minimally Verbal* Children with ASD

## Visual supports: Schedule





# Communication Strategies for Young *Nonverbal/Minimally Verbal* Children with ASD

Visual supports: Work system



# Opportunities for Communication

## **Highly Preferred Activities**

- Your child is more likely to request items he/she desires. Be consistent with the words you use for each food, object or activity.
  - Snack or food times
  - Favorite toy play
  - Favorite songs
  - Sensory play: tickles, swings, spins

## **Everyday Routines**

- Routines that are repeated and predictable will help to teach and encourage language.
  - Opening doors
  - Dressing/Undressing
  - Getting up/down, climbing stairs

# Opportunities for Communication

## **Activities Needing Assistance**

- Presenting situations that require help is a great way to evoke words.
  - Tight lids on containers (Play-doh)
  - Small amounts of juice left in see-through cups encourage the child to ask for more
  - Small amounts of food in Tupperware

## **Play Time**

- Creating friendly challenges during play will also draw out language.
  - Puzzles with missing pieces
  - Toys with missing parts or that “stop working”
  - Boxes of markers or crayons with missing items

# Communication Strategy Summary for Young *Nonverbal/Minimally Verbal* Children with ASD

- Find opportunities for communication in daily routine: meals, play, outings
- Do less for your child in order to create communication openings
- Give items slower and in smaller amounts
- Add functional labels to actions and objects
- Be consistent with the words you use
- Add gestures to words
- Incorporate verbs/adjectives as your child progresses
- Respond quickly and celebrate all verbal communication attempts!

# Communication Challenges in *Verbal* Children with ASD

- Acquisition of language may be slow
- Echolalia (immediate and delayed)
- Pronoun confusion
- Unusual tone, pitch, volume
- Use of made-up words (neologisms)
- Difficulty with comprehension (receptive language)
- Literal use of language; lack of understanding of idioms
- Difficulty taking turns and listening in conversation
- “little professor”

# Communication Strategies/Services for *Verbal* Children with ASD

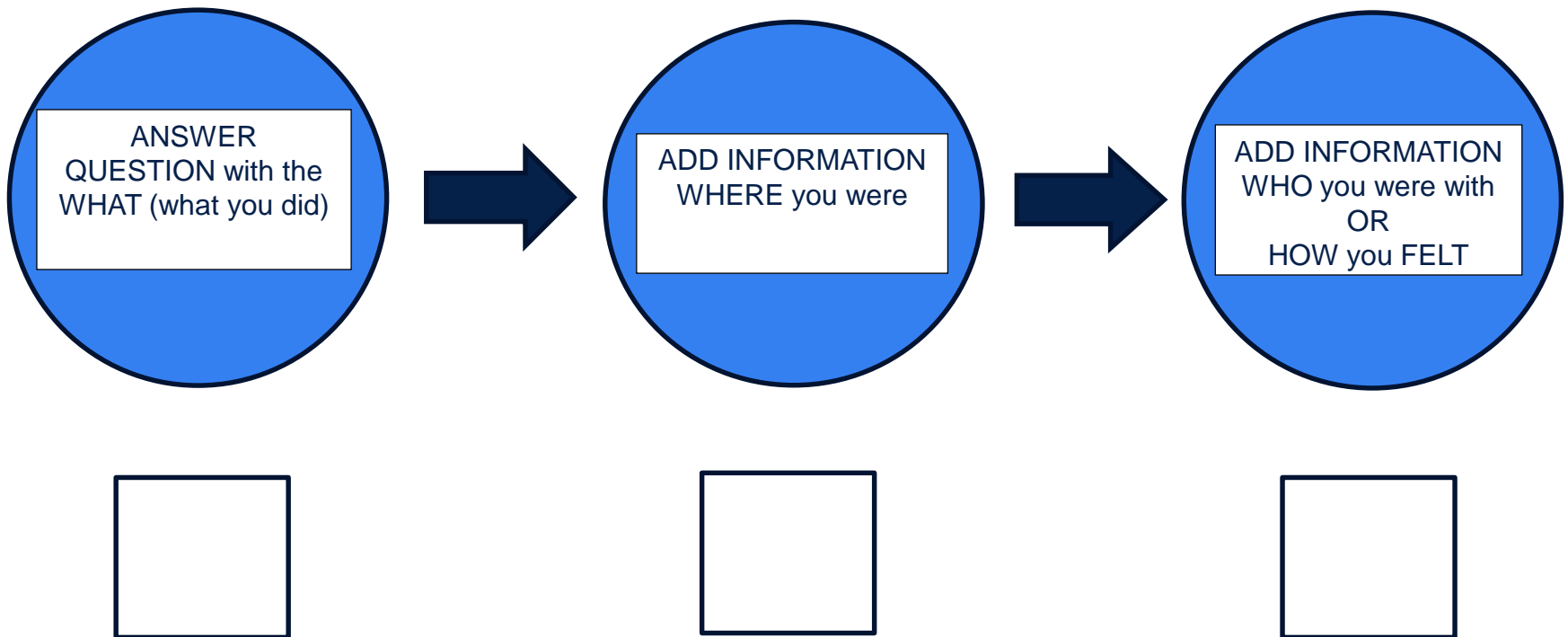
- Social skills training (ex, PEERS®)
- Speech therapy/behavior therapy focusing on *pragmatic language and nonverbal behaviors*
- Self-management
- Environmental arrangement (ex, hiding things)
- Time delay
- Open-ended questions
- Video modeling

# Communication Strategies for *Verbal* Children with ASD: Video Example

# Self-Management Form Example

Conversation with:

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# Social Challenges in Children with ASD

- Low rates of social initiation and response to others
- Fewer gestures
- Limited facial expressions
- Fewer acts of empathy or shared emotion
- Less imitation

# Social Strategies for Children with ASD

## ■ Interactive play

- Face-to-face social routines (ex, tag)
- Face-to-face + object (ex, reading a book)
- Sensory social routines (ex, tickling, peekaboo)



# Social Strategies for Children with ASD

- Interactive functional or pretend play (join the play)
- Facilitated play dates with another
- child (*at home*)
  - Time limited at first
  - Plan a structured activity
  - Targets: time spent engaged with peers, initiations and responses to play with peers, conversation, responding to peers' questions, small talk.



# Social Strategies for Children with ASD

- Social Facilitation Strategies
  - Facilitated play with another child (*during or after school with adult*)
  - Develop sharing exchanges
  - Seek assistance from peers
  - Buddy system
  - Cooperative arrangement
- Video examples:
  - Initiating and responding to peers
  - Facilitated play

# Social Strategies for Children with ASD: Video Example

# Social Strategies for Children with ASD: Video Example

# Social Strategies for Children with ASD

- What must happen *first* before these social activities can be successful?
  - Your child must be interested in/motivated by the activity
  - You must have your child's attention
  - Your child must be able to stay on task for the duration of the activity (keep activities short with clear start and end points)
  - Appropriate environment

# Social Strategies for Children with ASD

- During the social activity:

- Use simple, clear language appropriate to your child's current language level
- Use positive affect (engage, smile, have fun!)
- Praise your child immediately for desired actions, even if an approximation (use simple language that describes the action, ex. "good jumping")

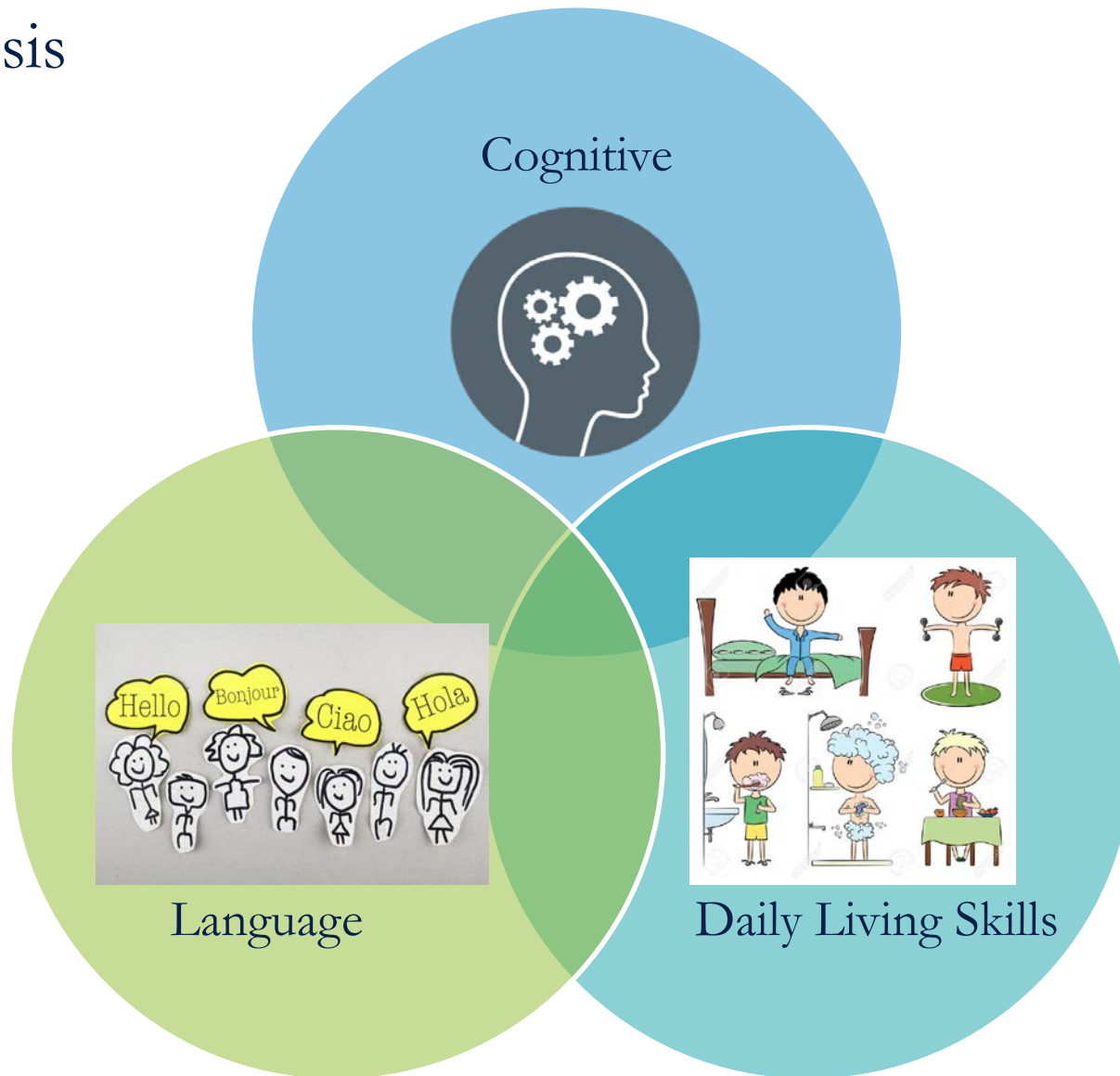


# Prognosis

- ASD is a lifelong condition ***but...*****evidence-based intervention, the earlier the better, can dramatically improve a child's abilities.**



# Prognosis



# Evidence Based Practice: Take Home Message

- Data-Driven
- Parent Involvement + Parent Training
  - **As a parent, YOU are in the session!**
- Focus on generalization of skills
  - In natural settings with multiple people
- Collaborate care across all disciplines
- Set reasonable expectations for yourself

# Community Resources

- **Regional Center** (over age 3, children must be eligible under Lanterman Act)
  - Regional Center advocacy: OCRA (Office of Clients' Rights Advocacy)
  
- **Public School + IEP supports**
  
- **Insurance-based services** (for ABA, speech therapy, cognitive-behavioral therapy, etc)
  - Insurance advocacy: *Mental Health & Autism Insurance Project*, <http://www.autismhealthinsurance.org/>

# Community Resources

- Government support for children with disabilities:
  - **SSI** (Supplemental Security Income)
  - **SSDI** (Social Security Disability Insurance)
  - **MediCal** Home and Community Based Services Waivers
  - **IHSS** (in home supportive services)
  
- **FMLA/CMLA** (Family Medical Leave)
  
- **ABLE Act** (Tax Free Savings Account): <https://www.treasurer.ca.gov/able/>
  
- Local Parent Support Agencies/Parent Support Groups (ex, **Care Parent Network**)

# What do I do now?

- **Focus on your child's strengths**

- Make a list and note today's date
- Use it as a baseline



# What do I do now?

- **Stay positive**

- The power of positive thinking is real
- No one knows the future



# What do I do now?

## ▪ Reach out and rely on others for support

- Avoid isolation
- Break the silence
- Respite care





# What do I do now?

- **Nurture your relationship with yourself and your spouse/partner**
  - Self care
  - Talk to each other
  - Schedule date night



What is the *most important* thing for a child with ASD?

YOU!



Questions?

# UCSF STAR Center Contact Information

**Website:** [www.star.ucsf.edu](http://www.star.ucsf.edu)

**Clinical Coordinator: Elise Evangelista at 415-502-3500 or [star@ucsf.edu](mailto:star@ucsf.edu)**

**Address:** UCSF Parnassus Campus

401 Parnassus Avenue

San Francisco, CA 94143

**My info:** Katy Ankenman, LCSW

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