
AUTISM

Introduction to the Native American SmartCare Program

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Shawn Singh Sidhu ian Associate Professor of Psychiatry at the University of California San Diego (UCSD) and Rady Children's Hospital of San Diego where he serves as Training Director for the Child and Adolescent Psychiatry Fellowship Program. Along with supporting asylum-seeking migrant youth and families at the border, Dr. Sidhu's greatest honor has been to serve American Indian and Alaska Native families over the past 10 years. Dr. Sidhu served rural tribal health centers in three different states in his role as Associate Medical Director for the Indian Health Services - University of New Mexico Telebehavioral Health Center of Excellence Program. He now serves as Co-Medical Director for the Vista Hill Native American SmartCare Program, a collaboration between California Area Indian Health Services and Vista Hill Foundation. He also serves AI/AN families directly at the Southern Indian Health Council.

Shirley Fett, FNP-BC PMHS

- Shirley Fett is a Family Nurse Practitioner and a Pediatric Mental Health Specialist.
- She is a graduate of the University of Iowa, San Diego State University and UCSD. She has been an NP for 27 years working in family practice, internal medicine and for Vista Hill for the past 8 years, including extensive experience as a behavioral health consultant at Vista Hill.
- She is an expert in developmental disabilities, particularly in autism, including assessments, therapeutic services, and systems of care.
- She is a consultant at Rady's Children's Hospital in the Autism Discovery Institute.
- She is an executive board member of the Autism Society San Diego. She provides many professional trainings on autism spectrum disorder throughout the county and state.
- Shirley and her husband live in San Diego with their two adult autistic sons.

The Native American SmartCare Team

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NASC: California Indian Health Services Funded Program

What We Offer:

- Live Telehealth Treatment Team Consultation (we join your treatment teams!)
- Scheduled Patient Consultations
- Behavioral Health Education and Training for Staff
- Behavioral Health Newsletters
- Linkage to resources

Contact Information:

General Questions **760-427-6427**

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MY **MOST** IMPORTANT JOB….

BROCK Age 33

DEREK Age 31

Autism is a complex, developmental, disability that typically appears during the first three years of life. It is the result of a *neurological disorder* that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills.

Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

With appropriate interventions, all children and adults with autism will show improvement in their symptoms.

WHAT WE KNOW…..

- Developmental disability – develops before age three and causes delays or differences in social and communication throughout the person's life span.
- The cause or causes of autism are unknown.
- Likely genetic origin with probable environmental influences; tends to run in families
- 4 males for every 1 female
- CDC: Affects 1 in 36 children in the US
- No cure for autism

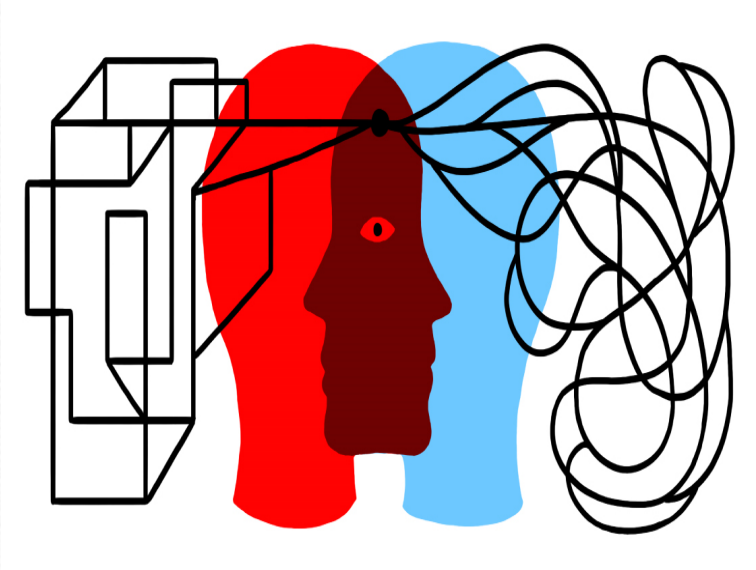
Behaviors of Concern Include:

- regression (loss of) of previously achieved language milestones, including babbling
- lack of pretend play, or even imitative play, such as babbling on a toy telephone
- lack of response to one's name, or decreasing response to name
- lack of pointing, to indicate needs and lack of response to pointing behaviors of others

CORE CHARACTERISTICS OF AUTISM

Challenges in:

- Social Skills
- Communication
- Behavior



SOCIAL CHALLENGES

- Hard to recognize other's feelings
- Difficulty understanding social situations
- Difficulty communicating, reciprocal communication
- Easily overwhelmed in social situations
- Repetitive or obsessive behaviors and insistence on an adherence to fixed routine

COMMUNICATION CHALLENGES

- Nonverbal communication: 40% with ASD do not speak
- Verbal communication

  Speech that is unintentional, repetitive, echolalia, stuttering

- Tone of voice –cannot easily modulate their voice

  Monotone, singsong, flat, husky, or unusual sounding

  Poor volume control or intonation

- Facial expressions

  Little to no control over facial expression (may lead others to believe that individual cannot ‘feel’)

BEHAVIORAL CHALLENGES

-Walking with an uneven gait

-Motor awkwardness

-Odd or bouncy gait or posture, poor handwriting

-Engaging in excessive or repetitive movements (rocking, hand flapping, pacing, hand clapping, self talk, finger flicking, arm flapping)

-Struggle to transition from room to room *or* situation to situation

BEHAVIORAL CHALLENGES (continued)

- Crying, screaming
- Inappropriate laughter
- Self-injurious behavior-hitting, biting self/pulling own hair
- Sleep Dysregulation

BEHAVIORAL CHALLENGES (continued)

- ***Passions, Interest, and Rituals***

  Fascinations (trains, vehicles, machines, weather, numbers etc.). Some remain interested in one area their entire lives, others change and evolve.

  Rituals/Rigidity

  Time and Space

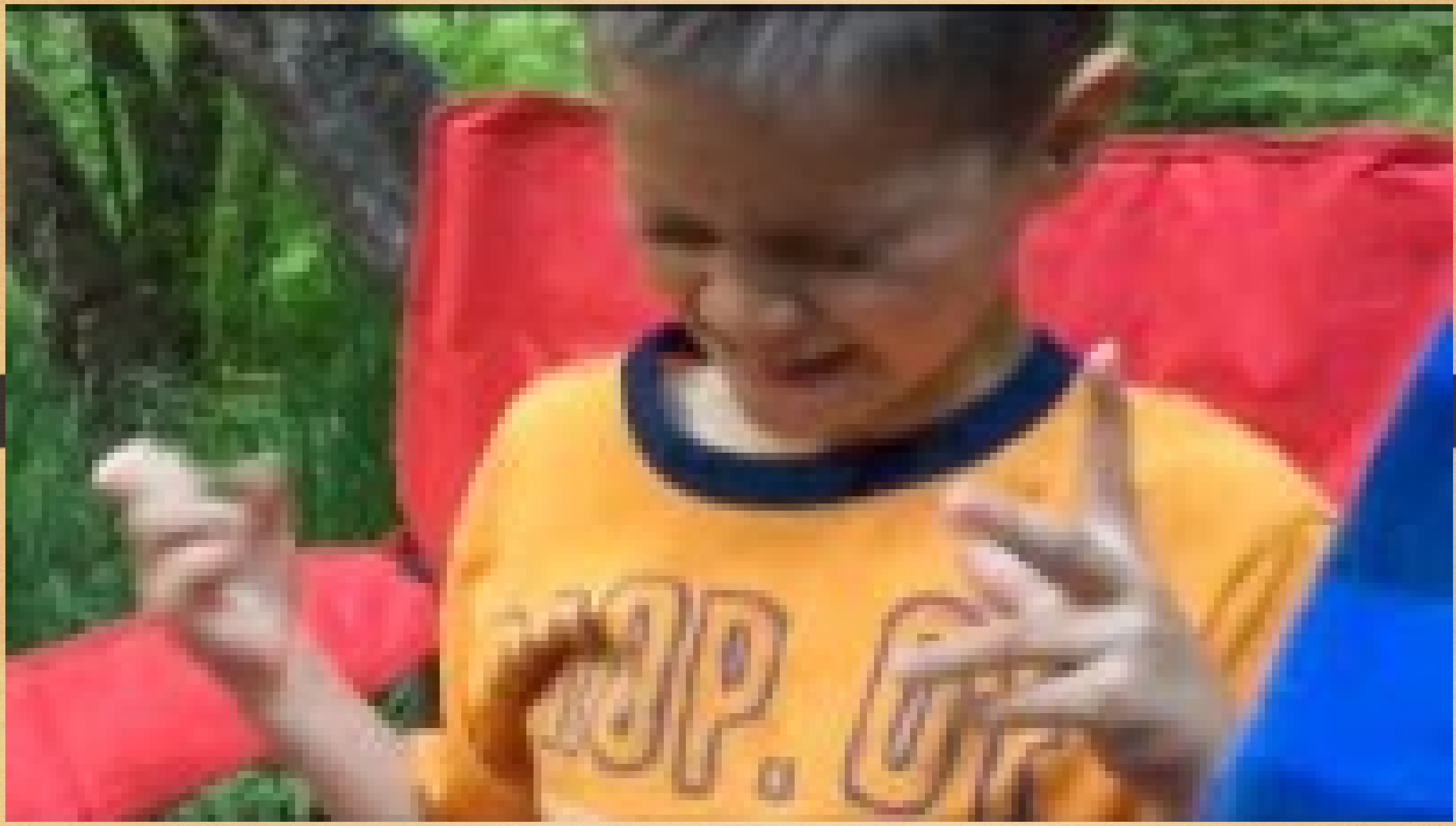
  How and When they engage in certain behaviors

  Activities in their lives (eating, leaving the house, going to bed, shopping, interacting with others, route they travel to and from places)

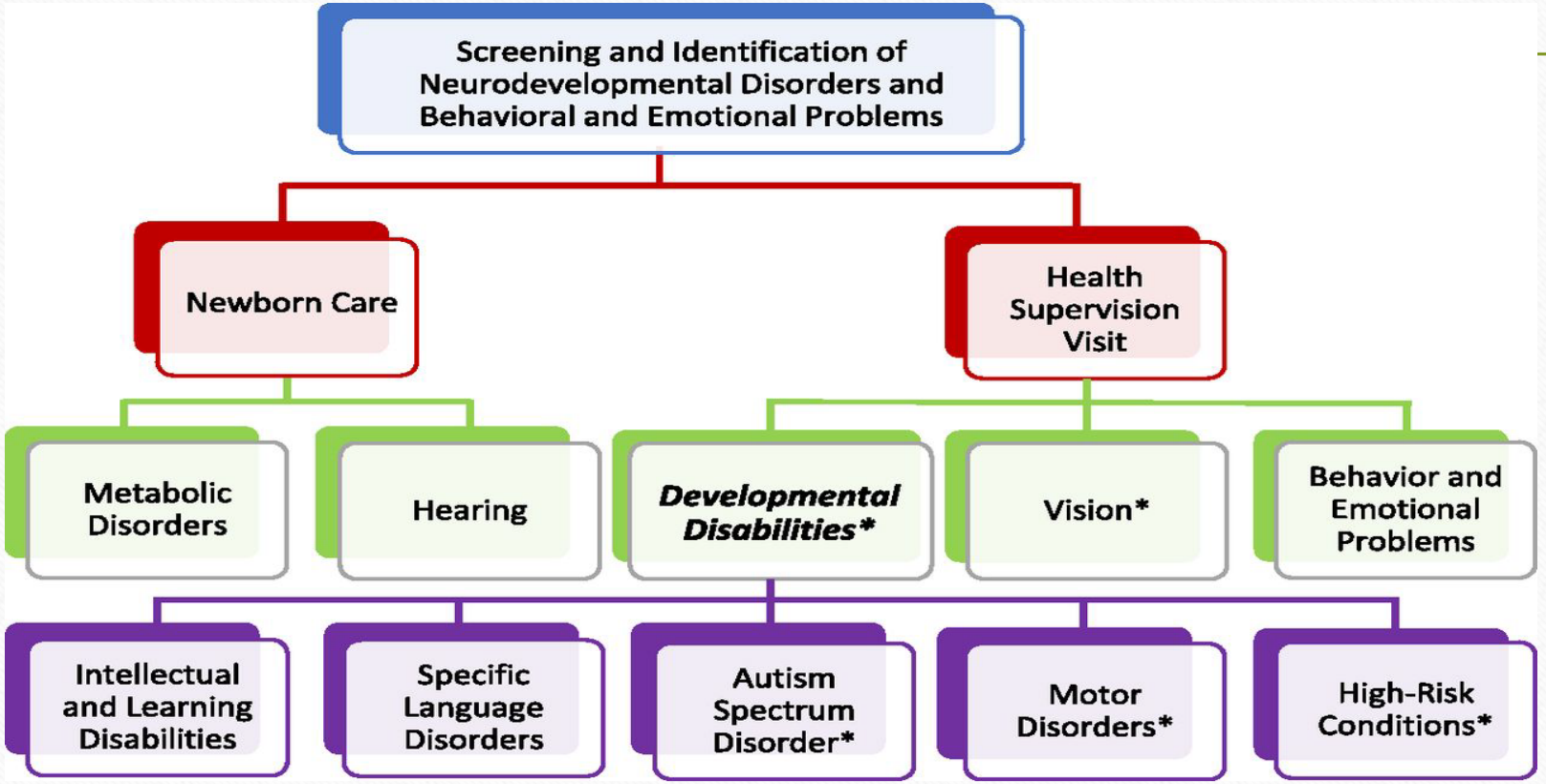
SENSORY DIFFERENCES

- **Tactile** – over or under reactive to touch, clothing, textures
- **Taste**- avoid or prefer very specific food
- **Temperature**-often unaware of extremes in temperature
- **Noises and sounds**-heightened sensitivity to sound, often seen covering their ears, yelling, can take longer to process information
- **Vision**-direct eye contact often difficult
- **Smell**-often heightened sense of smell
- **Pain-**threshold may be different, higher or lower

Examples of Stereotypic, Repetitive Behaviors, Language Delay



The AAP recommends screening for ASD at the 18 month and 24 month WCC



Diagnostic Instruments

Diagnosis is based on observation and description of behaviors, no labs or imaging tests currently available.

- The Childhood Autism Rating Scale (CARS)
- The Gilliam Autism Rating Scale (GARS)
- A combination of the Autism Diagnostic Interview- Revised (ADI-R) and the Autism Diagnostic Observation Schedule **(ADOS).**
- M-CHAT Modified Checklist for Autism in Toddlers

What to expect during an autism evaluation

The **physician's exam** should focus on possible medical and/or genetic issues associated with your child's symptoms

The **psychologist administers** developmental and cognitive tests

The **speech-language pathologist evaluates** communication and social skills

The **occupational therapist** can further evaluate sensory and motor issues

Following the diagnostic evaluation, the team should provide the family with comprehensive feedback, including a written report that fully explains all test results. This feedback session and report should be presented in understandable language.

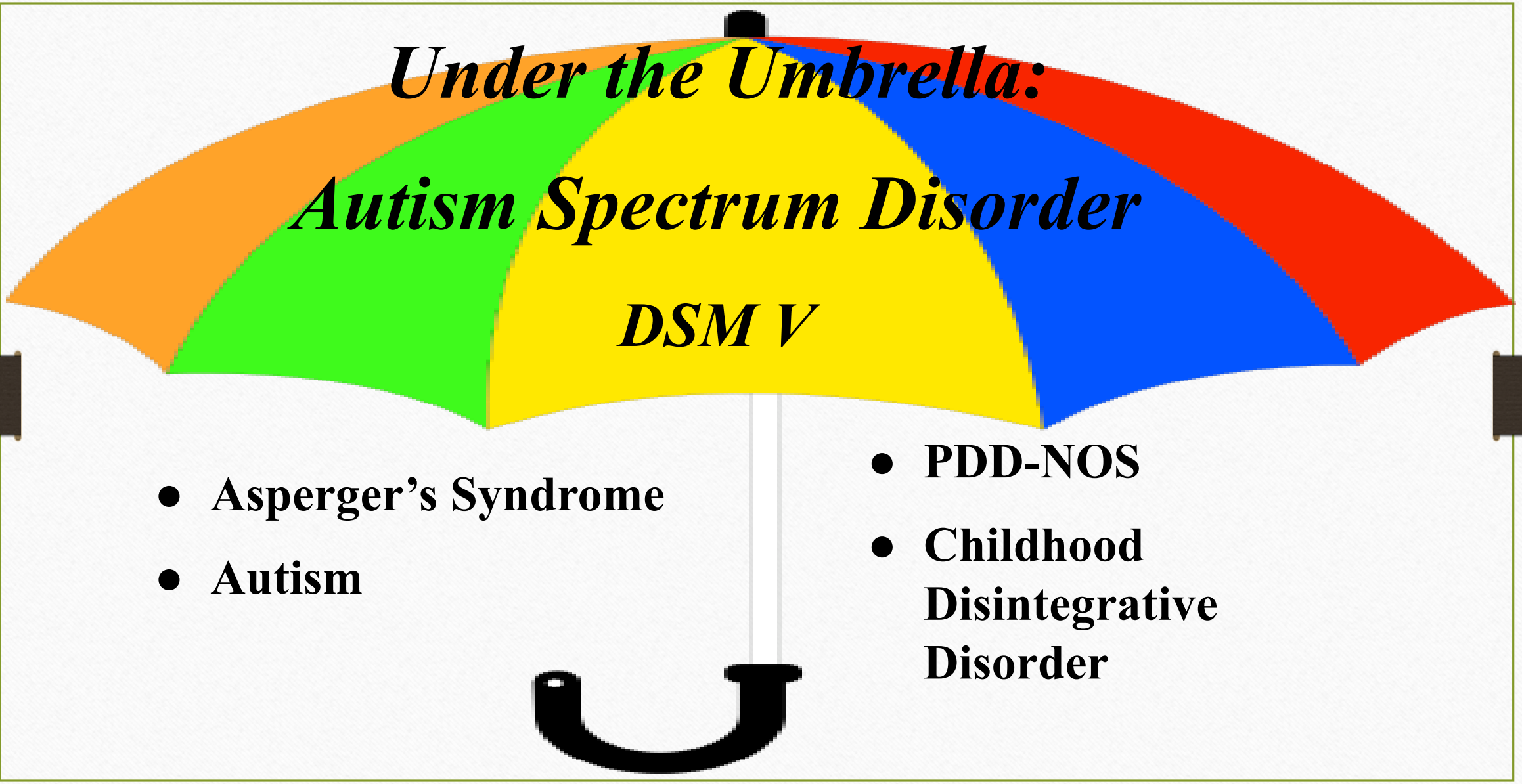
DSM IV to DSM V: What were the changes?

- In the DSM-IV, autistic disorder, Asperger's disorder, childhood disintegrative disorder and pervasive developmental disorder-not otherwise specified (PDD-NOS) were all distinct conditions.
- The DSM-5, released in 2013, absorbed these into a singular diagnostic category: autism spectrum disorder.

Under the Umbrella:

Autism Spectrum Disorder

DSM V



- **Asperger's Syndrome**
- **Autism**
- **PDD-NOS**
- **Childhood Disintegrative Disorder**

All 5 Criterion Must Be Met to Diagnose ASD (DSM-V)

- **Criterion A**: Persistent deficits in social communication and social interaction across multiple contexts
- **Criterion B:** Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two
- **Criterion C**: symptoms existing in early childhood
- **Criterion D:** symptoms cause significant clinical impairment in social, occupational or other areas of functioning
- **Criterion E:** impairments are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay (APA, 2011; CDC, 2014). ASD and ID are often co-morbid.

DSM 5 Includes Description of Presence and Severity of Symptoms

Severity is based upon levels in two areas: social communication and restrictive, repetitive behaviors

Level 1 Requiring support

Level 2 Requiring substantial support

Level 3 Requiring very substantial support

Level 1 Autism REQUIRING SUPPORT

- Without supports in place, deficits in social communication cause noticeable impairments

- Difficulty initiating social interactions
- Atypical or unsuccessful response to social overtures of others
- May appear to have decreased interest in social interactions

- Inflexibility of behavior causes significant interference with functioning
- Difficulty switching between activities
- Problems of organization and planning hamper independence

Level 2 Autism REQUIRING SUBSTANTIAL SUPPORT

- Deficits in verbal and nonverbal social communication skills
- Social impairments apparent even with supports in place

- Limited initiation of social interactions
- Reduced or abnormal responses to social overtures from others

- Inflexibility of behavior
- Difficulty coping with change
- Restricted/repetitive behaviors appear frequently and interfere with functioning
- Distress and/or difficulty changing focus or action

Level 3 Autism REQUIRING VERY SUBSTANTIAL SUPPORT

- Severe deficits in verbal and nonverbal social communication skills

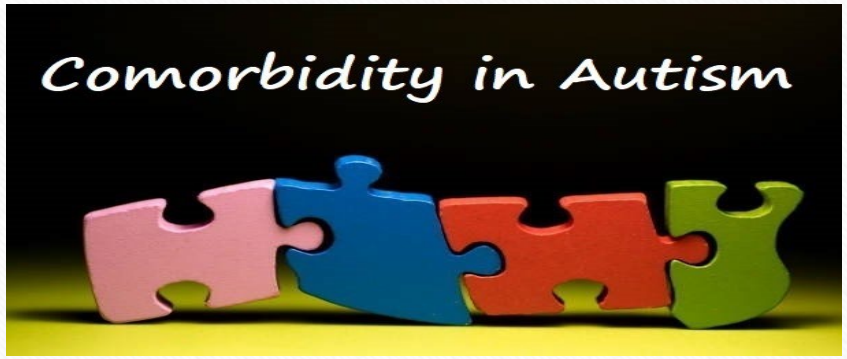
- Very limited initiation of social interactions
- Minimal response to social overtures from others

- Inflexibility of behavior
- Extreme difficulty coping with change
- Restricted/repetitive behaviors markedly interfere with functioning
- Great distress/difficulty changing focus or action

Specifications

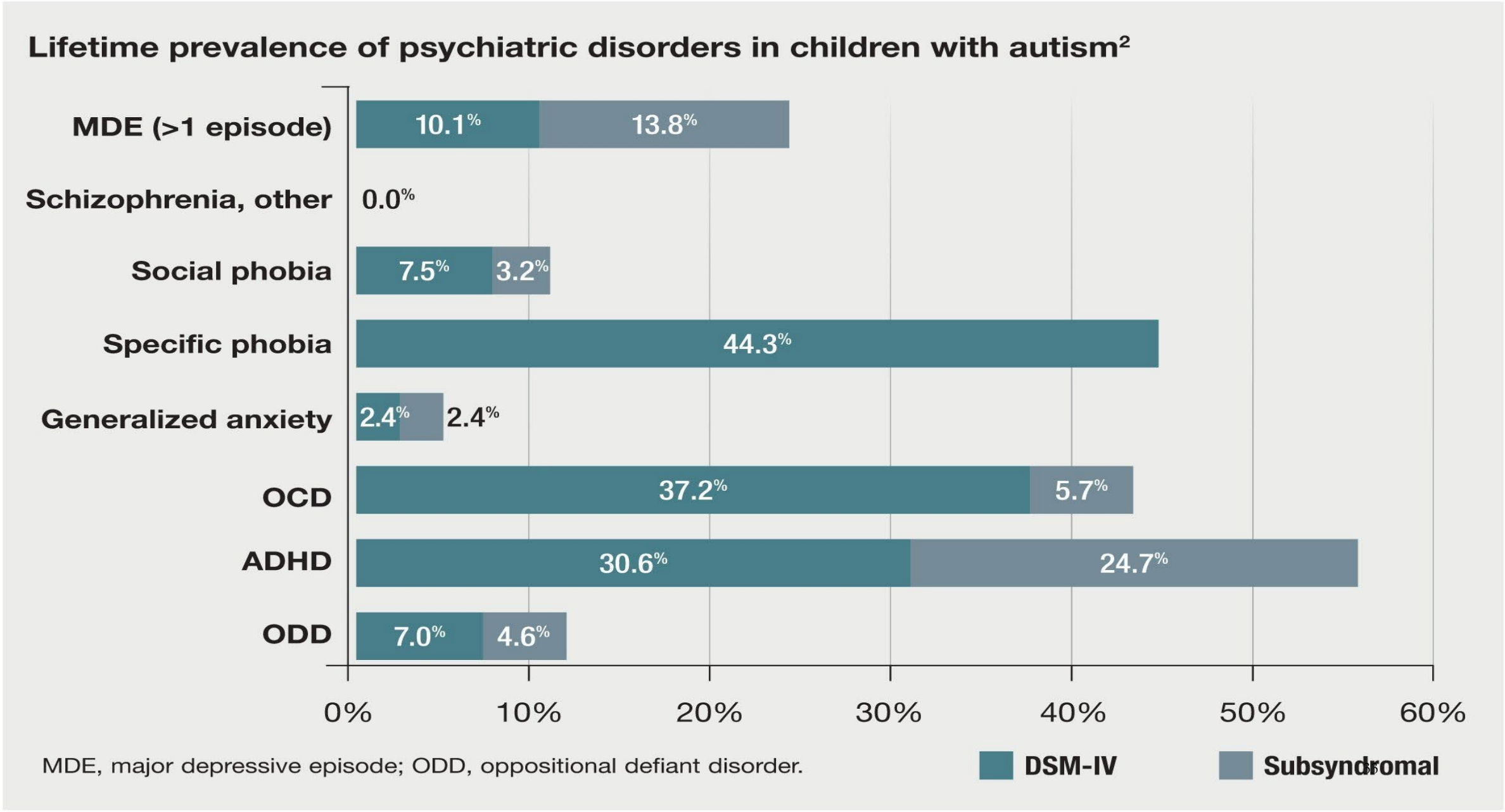
- **With or without accompanying intellectual impairment**
- **With or without accompanying language impairment**
  - (Coding note: Use additional code to identify the associated medical or genetic condition.)
- **Associated with another neurodevelopmental, mental, or behavioral disorder**
  - (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)
- **With catatonia**
- **Associated with a known medical or genetic condition or environmental factor**

General Guidelines for Assessing Psychiatric Co-Morbidity



Consider co-morbid condition(s) when symptoms are:

- Beyond what is expected in ASD,
- A noticeable change from baseline occurs or
- Patient is not responding to traditional therapies as expected.


Lifetime prevalence of psychiatric disorders in children with autism²
MDE (>1 episode)
10.1%
13.8%
Schizophrenia, other
0.0%
Social phobia
7.5%
3.2%
Specific phobia
44.3%
Generalized anxiety
2.4%
2.4%
OCD
37.2%
5.7%
ADHD
30.6%
24.7%
ODD
7.0%
4.6%
0%
10%
20%
30%
40%
50%
60%
MDE, major depressive episode; ODD, oppositional defiant disorder.
DSM-IV
Subsyndromal

TREATMENT OPTIONS & CONSIDERATIONS

What is the chief complaint?

Consider co-morbid targets

MUST rule out the basics –language delay is very common and makes assessment more difficult

MEDICAL problems are common cause of behavioral concerns

Differential assessment for behavioral challenges-we have to be detectives!

- Medical problem?
- Inability to communicate wants and needs?
- Cognitive demands too high or too low?
- Sensory dysregulation: Too much? Too little?
- Reinforcement of behavior happening?
- Mental Health-Could there be a co-occurring diagnosis?
- Family/School/Day Program Dynamics?

Evidence Based Treatment

There are limited evidenced-based mental health treatments for patients who have autism.

- *Cognitive Behavioral Therapy* for anxiety, depression, social skills; requires the individual to be able to talk and minimal intellectual delay
- *Applied Behavior Analysis* (ABA) to improve social, communication & learning through positive reinforcement. Is considered an evidence based practice by the US Surgeon General and Am. Psychological Association.

MEDICATION OPTIONS:
Irritability, Impulsivity, Aggression

Once medical issues have been ruled out:

If **mild – moderate** can start with alpha 2 agonists:

- **guanfacine**
- **clonidine**

Some research support for these meds.

If ***severe or failed*** other trials

Risperdal or aripiprazole (Abilify): Atypical antipsychotic medications for aggression: Only 2 FDA approved for irritability in ASD.

RUPP Study (Research Units on Pediatric Psychopharmacology) focused on tx of children with aggression/ASD

Significant metabolic concerns: wt. gain, hyperlipidemia, hyperglycemia

MEDICATION OPTIONS:

Co-morbid diagnoses

Melatonin, trazodone can be helpful for *sleep*

SSRI's may be helpful for *repetitive behaviors*, but limited research to support this

SSRI's for *anxiety and depression*

Autism in Adults

Signs and symptoms of autism in adults:

- Feeling awkward in social situations
- Preferring to be alone
- Responding to conversations in a blunt way
- Taking things literally
- Same daily routine
- Noticing small details or patterns
- Intense and specific interests

Adults with autism may have difficulty:

- Understanding what others are thinking or feeling
- Making friends
- Understanding social rules
- Making eye contact

ASD Adults

Co-Occurring Health Issues in ASD Adults

- Epilepsy: 25-30%
- Sleep Disturbance: 12%
- GI Issues: 34.7%-constipation, reflux, diarrhea
- Anxiety: 20%
- Depression: 70% with at least one episode of MDD
- Bipolar: 6%
- Schizophrenia/Psychotic Illness: 6.4%
- Eating Disorders/ARFID: 8%
- ADHD: 30%
- Intellectual Disability: 32%-50%

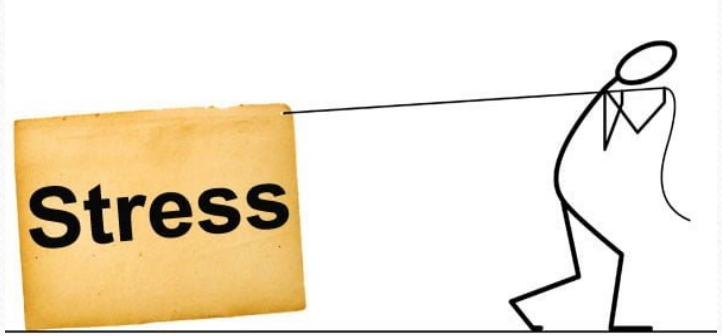
Suicide Risk in ASD Adults

- There is a **3-fold higher** rate of suicide attempt and suicide compared with all other persons after adjusting for sex, age, and time period.
- Lack of social integration, unemployment, and psychiatric disorders have been found to be associated with ASD in adults; the same factors are associated with suicidal behavior,
- The highest rates of suicide attempt were found for people with ASD who were unemployed
- https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2774853

FAMILY: Challenges and Needs

- "As a challenge to the family, autism must rank among the most stressful of childhood developmental disabilities," according to one Australian study.
- Fully 72% of parents reported that difficult child behaviors had a moderate to great negative impact on their lives.

Common Family Stressors



Difficult Behaviors

Wandering/Elopement

Sleep Disruption

Financial Burdens- Estimated lifetime cost *$3 million dollars!*

Difficulty at School

Difficulty Obtaining Treatments

Sibling Issues

Worry About the Future

Marriage Issues

HELPFUL THINGS TO SAY AND DO…..

"All children with autism improve and make progress."

Say something complimentary about the child, i.e. he has beautiful hair, he/she is very athletic, he/she has a great smile, etc…

Providing time for the parent/caregiver to tell you their concerns/issues

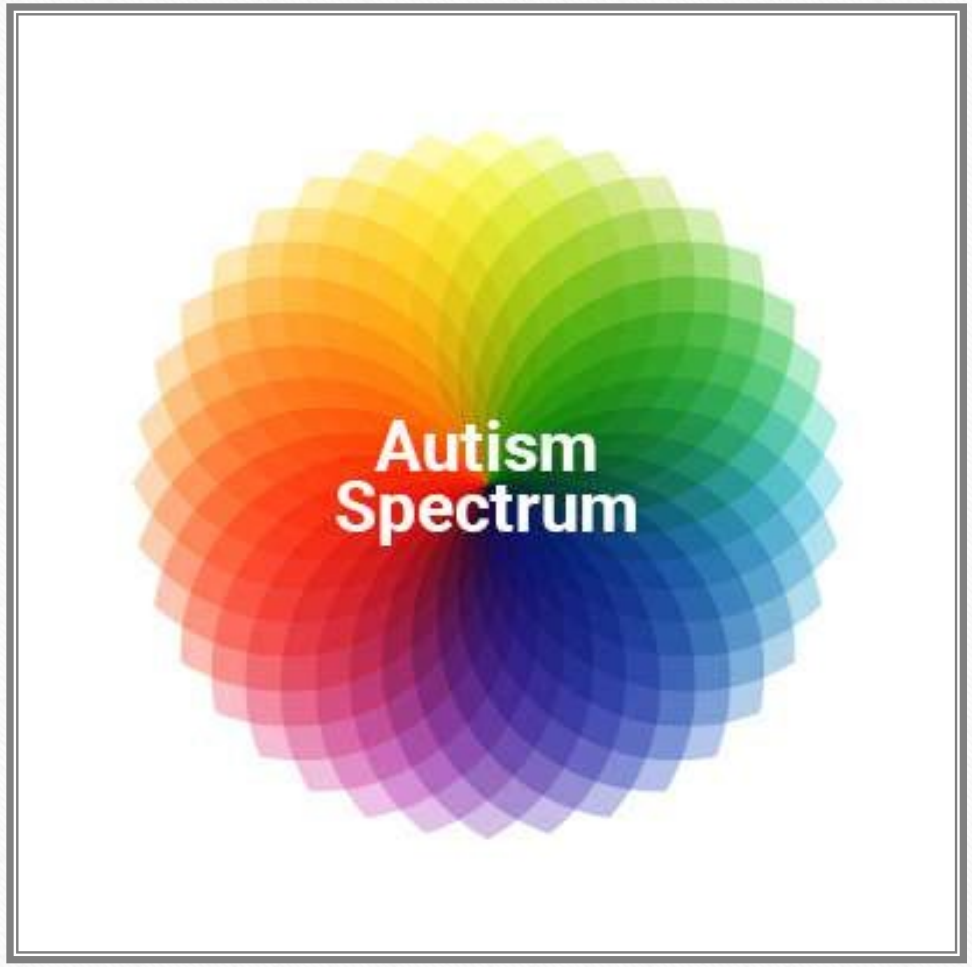
Listening to the parent; trying to understand where they are emotionally on this journey

Providing parents with choices and options.

"What can we do to help you get …….going?"

Encouraging parents to get help for their own emotional well being.

Have things written down in a report with recommendations; parents need to be able to go home, think about it, and then go back and process that again."



The Future of Autism Care

- Personalized, evidence-based assessments and interventions that are accessible and affordable to all
- Increased appreciation of neurodiversity
- Prioritization of research that can improve the lives of people with autism and their families.

Thank you for your interest and attention!

Native American SmartCare:

- **Provider Line 888-987-0960**
- **Parent/Family Line 888-660-6616**

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Website:

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