CARING FOR THE AUTISTIC INDIVIDUAL THROUGHOUT THEIR LIFESPAN

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- Identify at least one characteristic of ASD
- 2. Identify at least one support need for individuals with autism.
- 3. Discuss one nonpharmacological and one pharmacological treatment option for ASD.
- 4. Identify at least one support group or system for individuals with ASD and/or their families.

LEARNING OBJECTIVES

- ► Neurological and developmental disorder characterized by 1)issues with social interaction 2) communication, and 3)repetitive/restricted behaviors or interests.
- Sensory abnormalities very often present (indifference to pain, unusual reactions to sound)
- Symptoms generally appear prior to age 2 years old and must be present in early childhood
- Symptoms must cause clinically significant impairment
- Varying degrees of symptoms and functions affected (spectrum)
- All genders, races, ethnicities, and economic backgrounds can be diagnosed with autism
- ► Males are 4 times more likely to have ASD than females
- ▶ 1 in 31 children are now diagnosed with Autism

AUTISM SPECTRUM DISORDER

CAUSE OF AUTISM

- Not one cause, complex and heterogenous
- Multiple reasons that a persons' brain either is not developing normally, or connections in the brain or communications between brain cells are not being done or made appropriately.
- Some genetic causes can be found other times genetic mutations may raise the risk of ASD
- Environmental factors: viral infections during pregnancy or after birth, medications, air pollutants, foods, or other environmental toxins
- ► Autoimmune?
- ► NOT A RESULT OF POOR PARENTING OR INTERACTIONS BETWEEN CHILD/PARENT

- ▶Level 1, Level 2, Level 3
- ▶ Genetic Disorders Rett Syndrome, fragile X syndrome, tuberous sclerosis complex, 22q11.2 deletion syndrome, Smith-Lemli-Opitz syndrome, Cornelia de Lange Syndrome genetic deletions often lead to symptoms of autism and developmental delay
- ► Autism- no known genetic disorder found or sometimes it can run in families
- ▶Brain Injury- can sometimes mimic s/s of ASD or have autism like traits

THE AUTISM UMBRELLA

Issues with eye contact- motor planning issue? Social issue? Communication issue?

Not responding to name or slow to respond to name

Problems with verbal communication (back/forth conversations, echolalia, nonverbal) or late to speak

Problems with nonverbal communication such as pointing, eye contact, reading social cuesbuilding the foundations for communication

Difficulties in showing and understanding emotions

Difficulties with adjusting to routine changes (rigid)

Trouble with imaginary play, restrictive interests, lines up toys or other objects

COMMON SYMPTOMS OF ASD-VERY COMPLEX/ CAN CHANGE OVERTIME



Repetitive movements or stimming- rocking, spinning, tapping, hand flapping, repeating words or phrases

Sensory processing issues including being more or less sensitive to sensory input in all sensory areas.

Developmental Delay

May or May not have cognitive or learning disabilities

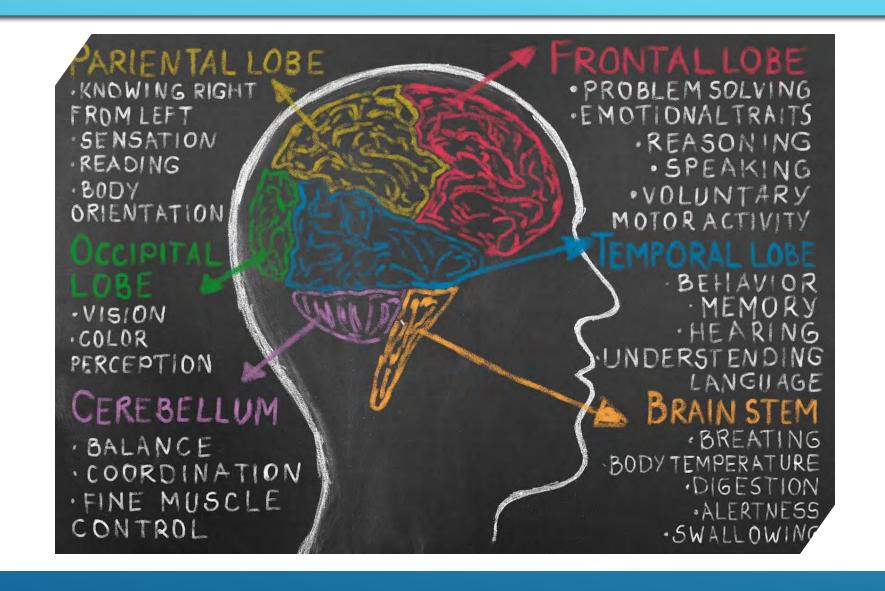
Co-Morbid conditions in some- Mental health, anxiety/depression, obsessive compulsive disorder, seizures, ADHD

SYMPTOMS CONTINUED

- A neurotypical or normal functioning brain is a complicated system of neuropathways, neurotransmitters, and connections that involves the bodies senses, cognition, and motor movements whether purposeful or non-intentional
- The brain is constantly changing and developing over time

THE BRAIN





- Almond-shaped region of the brain associated with emotional processes
- ► Impacts cognition, processes social input as well as helps understand social interactions
- ► Emotional processes-anxiety, aggression

AMYGDALA

CORTICAL BRAIN

- ► Controls conscious motor movement-(intention/purpose) "thinking brain"
- Helps deal with different sensations that the body is receiving
- ► Frontal lobe of the brain is still developing in children and young adults
- the motor cortex is in the frontal lobe, and is the part of the brain where voluntary motor movements are controlled, and higher executive functions occur

- In the brainstem, primary role is to **filter** bombardment of sensory stimuli and tell our "thinking brain" what is important or warrants attention
- Helps with wake-sleep transitions, mediate behavior, and important in attention



RETICULAR ACTIVATING SYSTEM



Wernicke's area is responsible for comprehension as well as understanding written language (forming thoughts or language)



Broca's area is **connected** to Wernicke's and located in the cerebral cortex, primarily responsible for language production (speech)

WERNICKE'S AND BROCA'S AREAS

APRAXIA

- ▶ Not being able to complete all the steps of intentional motor planning, even if they understand what they are being asked or what they are wanting to do
- Responsible for the disconnection between comprehension and motor planning to produce physical movements (like eye contact or speech) which both involve lots of motor and neuro pathways to complete
- Coordination of things as easy as taking a drink of water for example or asking someone to point to an object, blowing nose

REGULATION AND DYSREGULATION

- Regulation means managing yourself (recognizes needs whether internal or external stimuli and respond to emotions in appropriate ways)
- ▶ Dysregulation is when a person is unable to control or regulate emotions or physical response to external stimuli- sometimes described as dramatic fluctuation in mood or emotions which could result in anger outbursts, or self injury behaviors, behaviors towards others or damaging property

- ▶ Research findings published in October 2024 in Molecular Psychiatry
- After doing PET scans on adults with Autism, researchers found fewer synapses or junctions between nerve cells that send signals to and from each other and other types of cells- how they communicate
- ▶ 17% lower synaptic density was found across the entire brain
- ► The lower the density the more severe the symptoms (socialcommunication differences, repetitive behaviors, understanding social cues)
- ▶ Deeper Sulci in the Brain may also play a role
- Understanding the biology of Autism can help us offer better supports and treatments

THE BIOLOGY OF AUTISM

- Aspergers Syndrome (Hans Asperger 1943)- now known as level 1- often can live independently, have careers, challenges with routine, adapting to changes, regulating emotions, etc- was called "autistic psychopathy" in the past
- Kanner Syndrome (Leo Kanner 1944)- "early infantile autism" "classic autism" Symptoms more pronounced
- Schizophrenia (Prior to 1940s)- autism was referred to as a symptom of schizophrenia described as "withdrawal into one's inner world"
- "Sante De Sanctis" (1906)- very premature dementia

AUTISM HISTORY

DIAGNOSTIC MANUAL (DSM) CHANGES

- ▶ DSM-I (1952): did not include autism
- ▶ DSM-II (1968): autism defined as form of schizophrenia
- ▶ DSM-III (1980): first time autism defined as developmental disorder separate from schizophrenia
- ▶ DSM-IV (1994): Autism categorized into Asperger's, Classic Autism, Childhood Disintegrative disorder, sensory processing disorder, and Rett syndrome as "types"
- ► DSM-V (2013): Merged all previously separate diagnoses into a single diagnosis of ASD

NEW STUDY JULY 2025 NATURE GENETICS

- ► Led by researchers at Princeton
- Attempts to "categorize" ASD into 4 different categories
 - ► Social & Behavioral Challenges (37%)
 - Mixed ASD with Developmental Delay (19%)
 - Moderate Challenges Group (34%)
 - ► Broadly Affected Group (10%)

- According to the American Academy of Pediatrics, screening for Autism at 18 and 24 month well visits regardless of risk factors as well as routinely monitoring development at every visit
- ► Erase stigma from diagnosis
- Screening with the CHAT tool (18 months) and M-CHAT tool (older toddlers)
- ► Refer to Soonerstart for children under 3 for developmental delays
- Refer to child psychology for strong concern for diagnosis
- ▶ SoonerStart Referral Form (Page 1 of 3)
- Adults- refer to psychology when appropriate
- Severe delays or diagnosis should see genetics, do referral

ASD DIAGNOSIS

- ► Level 1 requires support
- ► Level 2 requires substantial support
- ► Level 3 requires very substantial support

How much support will be needed for the individual to be able to communicate, manage comorbid conditions, cope with sensory seeking issues to live independently, with family, or in residential facility.

AUTISM SPECTRUM DISORDER (DSM-V)

SEVERE AND PROFOUND AUTISM

- New term rapidly gaining recognition in the autism community
- ► First formally recognized in 2022 in *The*Lancet commission on the future of care
 and clinical research in autism and then
 the CDC definition in 2023
- ▶ 27% of autism
- At least 8 years old, requires lifelong 24hour care, can have significant intellectual disability with an IQ <50, and/OR be nonverbal or non speaking.
- ► Important distinctions- someone with profound autism may be intellectually disabled or they may not be, however they will be minimally verbal or nonverbal
- "nonverbal Autism"

Three Functional Levels of Autism

written from an autistic perspective







Level 1

Requiring Support

I need help navigating a non-autistic world.

Average traits

People may see me as awkward, not disabled.

I can be riend or date non-disabled people, but it's hard and I'm often lonely.

I can handle change, but I prefer routine.

My fidgeting is seen as quirky or "annoying."

People may think my developmental delays are signs of laziness or insecurity.

Please know that

Social interactions are challenging. Please be understanding and offer help.

I struggle more than I let on.

Meeting others' expectations is exhausting. Please be patient.

I deserve respect and support.

Level 2

Requiring Substantial Support

I need help handling everyday challenges.

Average traits

People can usually tell that I have a disability.

My social life is very limited or nonexistent.

Coping with change is very challenging.

My repetitive behaviors are noticeably unusual.

I have significant developmental delays and will meet milestones late.

Please know that

I may seem inattentive, but I hear and understand you.

Routines and repetitive behavior help me feel safe.

I need a lot of help coping with stress.

I deserve respect and support.

Level 3

Requiring Very Substantial Support

I often need one-on-one support.

Average traits

My disability is very obvious.

I usually only communicate to express needs or answer questions.

Change and transitions can be unbearably difficult.

My intense repetitive behavior is calming and important to me.

I have large developmental delays and may not meet every milestone.

Please know that

I may seem unresponsive, but I hear and understand you.

Routines and repetitive behaviors help me feel safe.

I need help with communication skills.

I deserve respect and support.

These levels aren't clear-cut or permanent. Someone's skills may change. Stress, environment, and support will impact someone's ability to function.

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LEVEL 3 AND SEVERE/PROFOUND ASD

- Highest support needs
- ▶ The most life changing diagnosis for the person and their families
- Obvious disability
- ► Life-Long supports, 24/7 at times
- ► The lives of these individuals are getting easier, though challenging, supports are helping with communication, learning, and behaviors.
- ► Non-verbal, issues with toileting, PICA, dangerous sensory seeking behaviors, movements are often misunderstood by others, eloping or wandering, sleep disorders, reasoning may be off, their senses are off, they cannot communicate the same way
- Some May need residential support
- Early Intervention is key

LEVEL 3 ASD SEVERE/PROFOUND

- May have a great memory
- May learn differently but able to learn especially with early intervention and supports- access to language
- Introspective, see the world differently at times
- ► Fun personalities when given the chance to show it
- Special interests
- Some will need "life skills" classes and some can graduate college with higher education degrees

- ▶ "The most beautiful sound I ever heard is the empty way the air flows between the trees. The sound goes unnoticed by most, but to me, it sings. It creates melodies that resemble my own silence... The wind is my muse. It inspires me to beam in my own way. Silent. NOT US. We are the sound of hidden beauty. Winds of Autism"
- "I often feel like that snake. Small, unseen, unnoticed & sometimes feared. I live silently in a world of talkers, the snake lives discretely in a world of walkers"

MAKAYLA'S VOICE ON NETFLIX

LEVEL 1

- May seem "able" but still need support to complete certain tasks
- ▶ Job coaches or life coaches
- Need behavioral health support (greater risk of suicide)
- May need accommodations for sensory issues or language or speech processing disorders
- May have certain abilities that are stronger than others in certain areas- hyperlexic, or "savants"

TREATMENT

- Seek to reduce bothersome symptoms
- Behavioral, Developmental, Educational, Social-relational, pharmacological, Psychological, complementary and alternative approaches
- Applied Behavior Analysis (ABA), Speech and language Therapy, feeding therapy, OT and sensory integration therapy, physical therapy for fine/gross motor skills, ocular therapy
- Educational accommodations, social stories, visual schedules, token boards
- Medications for managing high energy levels, inability to focus, or selfharming behaviors, treat anxiety/depression/OCD/mania, seizures, sleep, or GI issues
- ► Fecal transplants
- ▶ Special diets like dairy free, herbal supplements, or functional medicine

- ► ABA therapy uses principles of learning and human behavior to incorporate positive reinforcement to reduce challenging behaviors.
- ▶ Improve communication, social interaction, school readiness, and self-care as well reduce unwanted or dangerous behaviors.
- ▶ BCBA (masters or doctorial degree) will conduct assessments of behaviors and develop personalized plans to help reach goals.
- ▶ RBTs- help conduct therapy and monitor the goals in the plan made by the BCBA. Collect data to understand why a behavior is occurring.
- ► They will decide how much time and support is needed to reach goals. Submit insurance paperwork etc

APPLIED-BEHAVIORAL ANALYSIS (ABA)





△ Home

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ALTERNATIVE COMMUNICATION

LABORATORY TESTING

- ► Lead screening at normal ages
- Vitamin d and b12 levels, ferritin
- ▶ Omega
- (or of course support gaps in nutrition)
- MTHFR (methylation)
- FRAT test (folate metabolism)
- pharmacogenetics testing (Genesight)
- Functional medicine- GI mapping

- Research by Dr. Richard Frye, Behavioral Child Neurologist, published in 2020 in the US
- ▶ Folate Receptor Alpha Autoantibodies test
- ▶ Abnormalities in folate, a B vitamin that is essential for normal neurodevelopment, including partial blockage in the ability of folate to be transported into the brain utilizing the primary transport mechanism, the folate receptor alpha
- ▶ Autoantibodies that interfere with the function of the folate receptor alpha have been identified in 58-75% of children with ASD and corelate with decrease levels of folate levels in the CSF
- RX Medication: Leucovorin can bypass the blockage at the receptor alpha
- ► FRATNOW Order Test Kit For Adults & Kids

FRAT TEST

SENSORY PROFILES

- ► Kinesthetic-seeking
- ► Proprioceptive-seeking
- ► Impulsive
- ▶ Sensory avoiding

- Recognize s/s for early intervention (screen everyone) listen to concerns by parents or caregivers
- Recognize sensory profiles and needs in office
- ► Help support an individual and their family with Autism throughout their lifespan, especially after diagnosis
- Recognize the levels of support a person with ASD may need
- ► Have ready and give resources to families in need
- ► Encourage real expectations of a diagnosis however erase derogatory terms from your conversations (high or low functioning or saying a child or person will NEVER do something) and tell a family that you are there to support their child's needs to increase their abilities and functions

HOW CAN WE HELP AS NURSE PRACTITIONERS OR PROVIDERS?

PRESUME COMPETENCY

Assuming that everyone, including individuals with disabilities or communication challenges has the ability to learn, think, & understand, even if they do not demonstrate their understanding in a way that is immediately obvious

Listen Up: Autistic Youth Need to Be Heard (page 4)

PEDIATRICS JANUARY OF 2025 OFFICIAL JOURNAL OF THE AAP

DDS WAIVER SERVICES/TEFRA

- ► Tefra (for qualifying autism diagnosis)- Medicaid regardless of parents' income. Primary insurance of parents and then child has Medicaid secondary to pay for therapies especially things like ABA
- ▶ DDS Waiver waitlist- use to be over 10 year waitlist and is down to 1-2 year wait from when your application is received. A home/community based waiver program that gives financial support for things not covered under insurance including adaptive equipment and HTS (habilitation training specialist)
- ▶ Parents can get paid (as of 2025) as the HTS which is up to 24,000 a year to be used on services that include residential housing and programs to keep them at home. Includes Medicaid as well

► <u>Home and Community-Based Services Waivers</u>

LINK FOR SERVICES

- We Rock the Spectrum- Kids Gym and support groups in person and on social media
- Beyond The Spectrum OK
- Autism Oklahoma
- Autism Foundation of Oklahoma (AFO)
- Oklahoma Swim Academy- swim lessons
- Savannah Station- Therapeutic riding
- Dance lessons for those with disabilities
- Social Groups and activities for all ages (WRTS, speech pathways)
- The Spellers Collective in Edmond
- Spelling lessons in Tulsa
- > Tulsa also has a special needs theater group that performs

SUPPORT

► AFO Sensory Kit

- ▶\$65.00
- ► AFO's sensory kits include thoughtful tools for easing anxiety and increasing communication in high-stress situations for individuals with autism and other disabilities.
- ▶ Each kit includes:
- ▶ Durable Tote Bag with Zipper
- ► Noise-Cancelling Headphones
- ► Weighted Lap Pad
- ▶ 2 Sets of Laminated Communication Cards in English and Spanish
- ▶Notepad & Pen
- ► Activity/ Puzzle Book
- ▶Sunglasses for Dimming Bright Lights
- ► Assorted sensory/ fidget items (for all ages)
- ► Sanitizing Wipes

<u>Sensory Kit — Autism Foundation of</u> <u>Oklahoma</u>



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