Autism Spectrum Disorder: Current Thinking and Approaches

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Marist CLS

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Autism Spectrum Disorder (ASD)

Bio Neurological developmental disorder that generally appears before the age of 3 and is characterized by:

- social impairments
- cognitive impairments
- communication difficulties
- repetitive behaviors

understanding the spectrum

Wide-range of skills with ASD/Neurodiversity

Some have excellent vocabulary & high IQ,
but limited conversational/social skills.
Others may be nonverbal with a very low IQ.

Not all people with delayed language
or behavior issues have autism; every case is unique

Primary Symptoms of ASD

- **Communication Deficits**
  - 25%– use some words at 12-18 months and then lose them
  - 40% are nonverbal; may have apraxia

    Echolalia   Perseveration   Jargon speech   Monotone Voice

  31% have an **intellectual disability** [IQ] <70) with significant challenges in daily function, 25% are in the borderline range (IQ 71–85).

  - Some may only have delayed speech development
    - **If not talking by 5 years, outlook is less favorable**

- **Social interaction:**   Abnormal Relationships   Difficulty relating to self, others, environment, play
- **Stereotyped Behaviors**   Rituals & Routines, Insistence on sameness
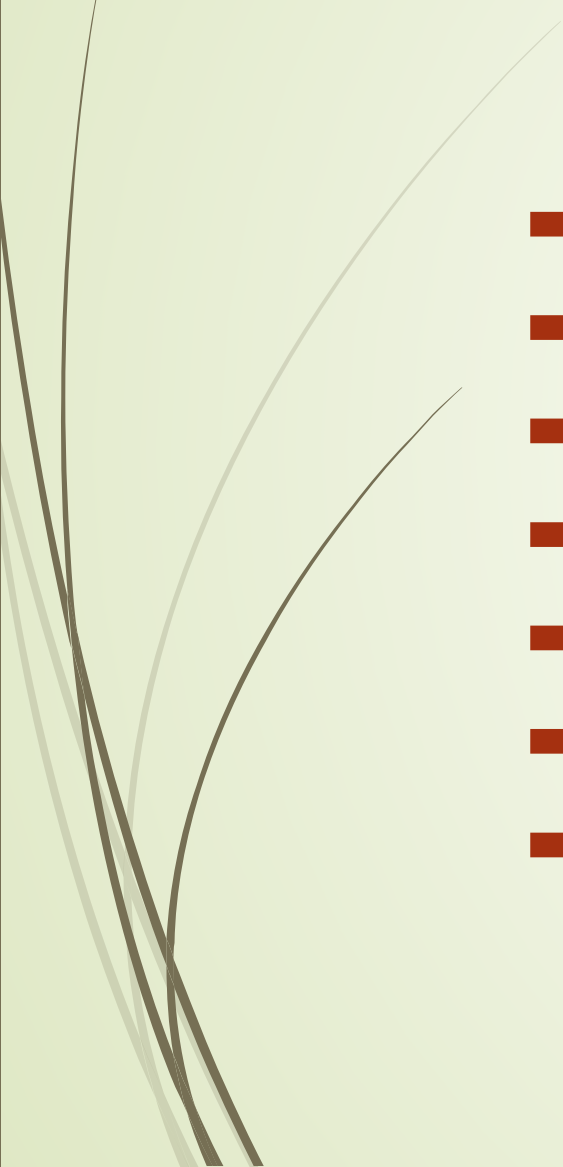- **Abnormal Sensory Response**

    Hypersensitive   Hyposensitive
- **Symptoms generally present in early development**

Other Possible Characteristics

- Have unusual interests/behaviors
- Have extreme or unusual anxiety/phobias
- Lines up toys or other objects
- Plays with toys the same way every time
- Likes parts of objects (e.g., wheels)
- Becomes upset by minor changes
- Has obsessive interests

Other Possible Symptoms: Con't.

- Hyperactivity
- Impulsivity
- Short attention span
- Aggression
- Causes self injury
- Meltdowns
- Unusual eating and/or sleeping habits
- Unusual mood or emotional reactions
- Lack of fear or more fear than expected

Watch clip and notice behaviors characteristic of ASD

https://www.youtube.com/watch?v=5oyZJDBUzWc

Rainman movie clip- look for symptoms

Famous people with mild autism:
https://www.youtube.com/watch?v=W505SFJXvvQ

https://www.autism.org/autism-movies/
List of 37 movies with characters with ASD

Yale Child Center- 5 year old – 1 year
https://www.youtube.com/watch?v=pSGVb60-BSw

Co-morbid medical conditions

- **54-70% of individuals with ASD have one or more including:**
- allergies, asthma, epilepsy, feeding disorders, sensory integration dysfunction, sleeping disorders, Fragile X, bowel disease, GI/digestive disorders, anxiety disorder, bipolar disorder, ADHD, Tourette Syndrome, OCD, immune disorders, autoimmune disorders, and neuroinflammation.
- naa@nationalautism.org

Current US Status of ASD
(CDC; National Autism Association, 2018)

Prevalence: 1/68 children (CDC)

1/58 (NAA)

Different states: 1/93 CO 1/41 NJ   (varying awareness/services)

Gender Ratio: Higher Incidence in Males (5:1)

Males: 1 in 42

Females: 1 in 189

Siblings: Increased prevalence (19%)

Increased risk in twins

- ➤ **Occurs in every community, race, ethnicity and SES**
- ➤ **Fastest growing developmental disorder**
- ➤ **Currently no cure but with early intervention/treatment symptoms can improve**

Brain and Gene Research

- ASD primarily genetic condition; Many genes contribute
  - Many language disorders- male predominance pattern
  - **Genetic transmission Male XY vs Female XX**
  - **Males: single X chromosome; girls-two – carrier or cancel**
- We have a Gene code for many kinds of brain connections
  - when abnormal additions/deletions occur in these genes, the brain cells don't connect as they should
- MRI studies show enlarged brain volumes in amygdala (emotion centers; fight-flight response)
- May lack early brain cells that **prune** connections between neurons in babies' **brains** (Scientific American, May 11, 2017)

Increased ASD Risk Factors

- **Paternal Age**
  - Men aged 40/older – significant increased risk than under 30 (6X greater)
  - Older age in mothers not associated with ASD
- **Maternal use of Antidepressants during pregnancy**
  - Serotonin involved in numerous pre/postnatal developmental processes, including creating links between brain cells
  - Selective serotonin reuptake inhibitors (SSRIs)associated w/ASD diagnosis
  - Users of SSRIs during 2nd/3rd trimester may have 87% increased risk of ASD child
- **More premature babies surviving**

JAMA Pediatrics, 2015

Why So Many Identified in last 20 years?

- changes in diagnostic practices and referral patterns
- availability of services (urban vs rural)
- younger age at diagnosis
- public awareness
- historical misdiagnosis of only intellectual disability
- more access to specialized services and special education makes clinicians and parents desire diagnosis

https://www.scientificamerican.com/article/the-real-reasons-autism-rates-are-up-in-the-u-s/

"No two autistic children are alike… The goal is to observe and find the specific pattern of response each child exhibits…"

**Temple Grandin
Emergence:
Labeled Autistic**

Timeline

1943/1944:
- Kanner & Asperger

1980:
- DSM III
- Infantile Autism
- Childhood Onset Pervasive Developmental Disorder

1981
- Translation of Asperger's Work

1987:
- DSM III-R
- Autistic Disorder
- Pervasive Developmental Disorder Not Otherwise Specified

1994:
- DSM IV
- Pervasive Developmental Disorders
- Autistic Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- Asperger's Disorder
- Pervasive Developmental Disorder Not Otherwise Specified

2013
- DSM 5 Autism Spectrum Disorder

DSM-V (2013) 3 major changes in diagnosis

Older DSM-IV- had **3** categories of symptoms: social difficulties, communication impairments & repetitive/restricted behaviors

DSM-V- now reduced to **2 categories** – social-communication impairment and repetitive/restricted behaviors

Older DSM-IV subtypes: autistic disorder, Asperger's syndrome & Pervasive Developmental Disorder-NOS)

DSM-V folded all subtypes into **1 broad category of ASD**

Children with social-communication impairments without 2 or more types of repetitive/restricted behavior receive the new diagnosis of **social communication disorder (SCD)**

ASD Symptoms for Diagnosis on DSM-V

- **Social Communication Deficits (Must have all)**
  - Social emotional Reciprocity
  - Nonverbal communication
  - Relationships- developing, maintaining and understanding

- **Repetitive Behaviors /Restricted Interests**

  (2 out of 4)
  - Repetitive behaviors with speech, body movements or with objects
  - Insistence on sameness or rigidity
  - Fixated or Intense interests
  - Sensory Sensitivities

Deficits in social communication across contexts Cont.

- **Deficits in social-emotional reciprocity**
  - abnormal social /conversations; reduced shared interests, emotions, or affect; failure to initiate/respond to social interactions
- **Deficits in nonverbal communicative behaviors in social interaction**
  - abnormalities in eye contact, body language, deficits in understanding/use of gestures; facial expressions and nonverbal communication
- **Deficits in developing, maintaining, and understanding relationships**
  - Difficulties adjusting behavior to suit various social contexts; in sharing imaginative play or in making friends; may lack interest in peers.

- **Must specify severity:**
  - **requiring support (Level 1)**
  - **requiring substantial support" (Level 2)**
  - **requiring very substantial support (Level 3).**

(DSM-V)

BARRIERS FOR WOMEN & GIRLS ON THE SPECTRUM

Girls are:
- ❖**Underdiagnosed**
- ❖**Tend to fly under radar**
- ❖**Are more shy**
- ❖**Seem to have fewer communication deficits (less aggressive/intrusive)**
- ❖**Symptoms are internalized**
  (Girls Growing up on Autism Spectrum, Shana Nichols, PhD)

Gender stereotype
- "You can't be autistic you're a girl"
- "Going under the radar"

misdiagnosis
- Coping strategies mask autism
- lack of knowledge as to how autism presents in women

Late diagnosis
- Increased mental health problems
- Lack of quality mental health support
- Chronic anxiety, lack of confidence

Julia- new character on Sesame Street (2017)

https://www.youtube.com/watch?v=dKCdV20zLMs

NYS-Best Practice for Early ASD Assessment

- **WHO?**
  - Primary MD may refer child to specialist for assessment or diagnosis
  - Developmental Pediatricians   Child Neurologists
  - Child Psychologists/Psychiatrists
  - Looks for Diagnosis vs. Eligibility   Interdisciplinary approach best
- **WHAT?**
  - Developmental history, observations, direct interaction, parent interview, talks/plays with child to see how she learns, speaks, behaves, and moves.
- **WHERE?**
  - Ideal in Multiple settings
    http://www.cdc.gov/ncbddd/autism/screening.html

Additional Early Signs of ASD

- Not respond to their name (child may appear deaf)
- Not point to objects or things of interest, or demonstrate interest
- Not play "pretend" games
- Avoid eye contact
- Want to be alone
- Have difficulty understanding/ showing understanding of others' feelings
- Have no/delayed speech
- Repeats words or phrases over and over (echolalia)

- Give unrelated answers to ?s
- Get upset by minor changes
- Have obsessive interests
- Flap hands, rock/spin in circles
- Over/under react to sounds, smells, tastes, looks, or touch
- Have low/no social skills
- Avoid or resist physical contact
- Demonstrate little safety or danger awareness
- Reverse pronouns ("you"for "I")

Earlier ASD Diagnosis at 12 months?

- **Research evidence of:**
  - **No big smiles or warm, joyful expressions by 6 mos.**
  - **No reciprocal sharing of sounds, facial expressions by 9 mos**
  - **No babbling by 12 mos**
  - **No reciprocal gestures (pointing, showing, reaching) by 12 mos**
  - **No words by 16 mos**
  - **No meaningful, 2-word phrases) by 24 mos**
  - **Any loss of speech, babbling or social skills at any age**

Best Diagnostic Tests/Scales for PRE-K

- ADOS [Autism Diagnostic Observation Scale]-
  - best for not missing children who have ASD
- CARS [Childhood Autism Rating Scale]
- ADI-R [Autism Diagnostic Interview - Revised]
- Current recommended practice for ASD diagnostic tools
  - used as part of a multi-disciplinary assessment, rather than as stand- alone diagnostic instruments

(Randall, M., Egberts, K. J., et al. (2018).

Possible Effects on Family Demands

Harder to get things done due to excess demands

Strains on marriage and personal relationships

Increased demands on family members

Minimal respite options; burnout and or depression can result

Strains and changes to employment of parent or caretaker

Increased financial burdens from issues relating to employment, therapies, medical bills, etc.

Anonymous quotes from family about kids with ASD

"My son has taken a stranger's food right off his plate. What could I possibly say… to apologize? "

" I don't know the last time I've actually seen the end of the movie because of the crowds, sounds, and lights. It just gets too difficult and we have to leave."

" When we go to the supermarket, so many people roll their eyes and start whispering. When we have to stand in a long line, she starts making noises and grabbing stuff. So now I just avoid taking her in public."

" Simple situations like haircuts, grocery shopping and community gatherings are not so simple at all."

" I don't want sympathy or pity like, 'Oh, I'm so sorry.' What I do need is for people to be patient, kind, and understanding."

focus on the family

Don't

- assume or presume
- pass judgment
- ask a family to participate separately

Families with autism are passionate about being accepted within their community

Social interactions need to be taught

- eating etiquette
- community social rules
- bathroom etiquette
- waiting in lines
- turn taking
- privacy
- personal boundaries
- social language
- dress code
- regard for authority (social hierarchies)

Social behavior must be taught directly. Many people with ASD do not learn social rules through observation

Community/societal impact

- Educational needs
- recreational
- residential options
- self advocacy
- family relationships
- healthcare /wellness
- day care/ after school care
- employment /vocations
- life planning /management

Inclusion strategies in Schools

- Recognize each person's challenges and abilities

- Provide appropriate modifications

- "Special" programs are appropriate but should not replace inclusive approaches

"With appropriate resources, sensitivity, and support,
community organizations can include individuals with disabilities
as regular and active participants without the need
to create separate and specialized programs."
Coalition for Inclusive Communities

Inclusion does not need to cost more money

Often requires only basic adaptations/accommodations

- slower pace
- adjusted rules
- altered lighting, sounds, movement
- simplified, direct instruction, activities, handouts
- use of photographs and other learning tools
- understanding and flexibility
- being open and prepared for the need to "escape" and/or return as needed

Plan for Inclusion in School

Develop Social Stories to increase both understanding and comfort level

- provides information about a place, activity or situation

- specifies appropriate social cues and expectations

- explains the order of events or layout of a location

- helps give appropriate responses to situations

Sometimes I can buy a snack at the theater.
There can be popcorn and drinks.
I should only buy one or two snacks. I can not buy all of them.
When watching the movie, I can eat snacks while sitting in my seat.
I shouldn't take any food or drinks from other people.
I should eat the snacks that belong to me.

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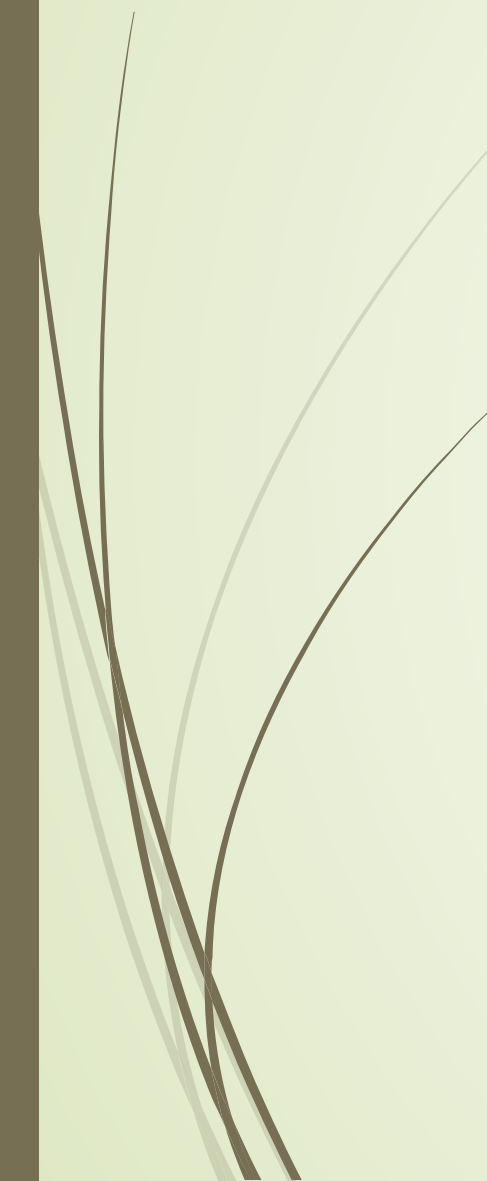
Therapy Interventions

- **Almost all have Educational & Behavior Modification Intervention**
  - Early intervention- key in treating ASD
  - Behavior modification techniques- crucial in a child's early years
  - Several types of behavior modification techniques, including:
    - Applied Behavioral Analysis (ABA)
    - Verbal Behavior (VB)
    - DIR Floortime
    - TEACCH
    - Son-Rise
    - Relationship Development Intervention
    - SCERTS
    - Pivotal Response Intervention

Lovaas Institute: Applied Behavior Analysis (ABA)

- Identifies goals in terms of specific behaviors
- Record target behaviors
- Identifies effective forms of reinforcement
- Use of extinction, shaping, and intermittent reinforcement
- Development of operant stimulus control
- Stimulus prompting, and the fading of prompts
- Development of chaining, generalization, rules, imitation, modeling, and other behavioral procedures.

Applied Behavioral Analysis (ABA)

- Systematic method for teaching skills & increasing adaptive behaviors
- Works to decrease behaviors interfering w/ development/use of critical skills (social, academic or life skills)
- Interventions emphasize motivation/reinforcement for desirable behavior
- **Some of the Skills Taught Using ABA Therapy:**
- **Communication including vocal, PECS, AAC**
- **Responding to verbal communication of others**
- **Academic skills   Toilet training   Play skills**
- **Self-care   Social skills   Vocational skills**
- **Some Behaviors Targeted Through ABA Therapy:**
- Aggression   Refusal   Tantrums
- Self-injurious behavior   Off-task behavior, etc.

ABA

· Analyzes behavior through a 3 term contingency model

· Antecedent

⬇

· Behavior

⬇

· Consequences

Operant Conditioning: ABC data

· **A**ntecedent causes **B**ehavior to occur

· Whether the behavior occurs again in the future will depend on the **C**onsequence that follows the action

ABC Data Sheet

Date 4/25 - 4/27   Time of Observation 10:00 - 10:15

Antecedent	Behavior	Consequence	Possible Function
Circle time - Students sing "Days of the Week"	Kicks other student	Time Out	Escape
Circle time - Singing "Day of the Week"	Kicks 2 students	Time Out	Escape

Applied Behavioral Analysis (ABA) Cont.

- **Example- Teach hand washing in steps:**

walk to sink   turn on water   wet hands

put soap on hands   rub hands together

rinse soap from hands   turn water off, dry hands

- ☐ ABA services provided in home, school, community or clinic setting
- ☐ Most insurance providers cover ABA services
- ☐ Schools pay when IEP team determines ABA is necessary to meet goals
- ☐ https://www.youtube.com/watch?v=V9YDDpo9LWg

TEACCH

- Treatment and Education of Autistic and Communication related handicapped Children
- Framework, NOT curriculum to support achievement of educational and therapeutic goals
  - Physical organization
  - Scheduling: Individualized schedules & Work (Activity) systems
  - Visual structure of materials in tasks and activities

Organization

- Develop areas based on curriculum
- Workspaces: teaching & independent
- Minimize distractions and stimulation: placement/barriers
- Establish a routine: associate activities with specific areas or places

Activity Schedules
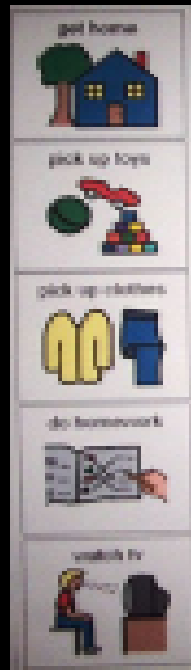
Activity schedules teach skills by using a set of images and/or written words. Community schedules can be used to help a person understand the order of activities. Some community schedules can include:
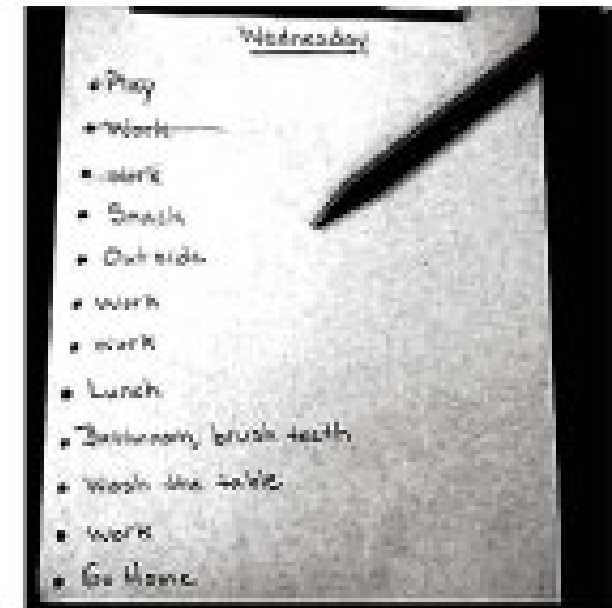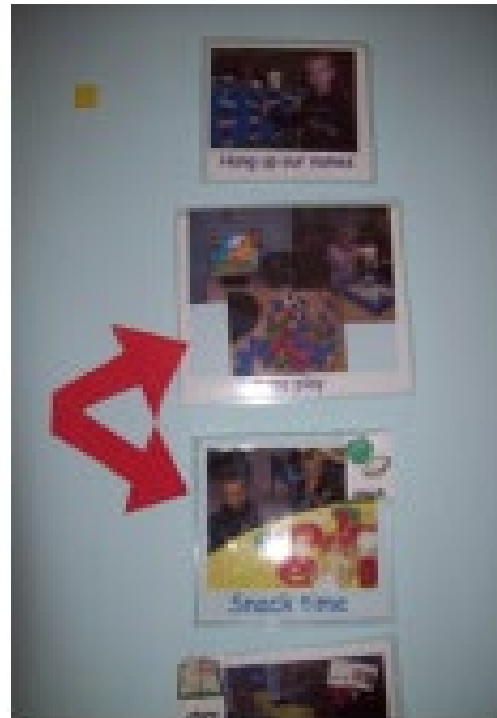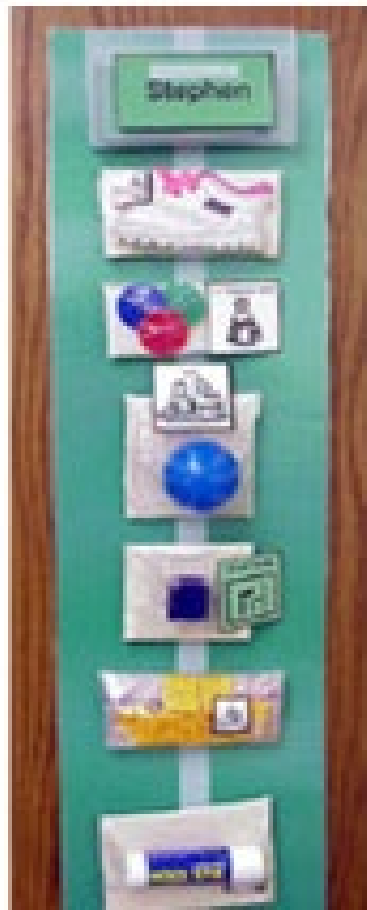
- going to the mall
- going to a restaurant
- going to the supermarket
- going to the movies

- getting a haircut
- wearing a seat belt
- playing a game
- using a public bathroom

"If I can't picture it, I can't understand it."
Albert Einstein

Schedules

- Visual cues to indicate what will occur and in what sequence
- Objects   photos   symbols   words

DIR/Floortime Principles

- Developmental: understanding the child's developmental level in order to plan appropriate treatment model
- Individual Differences: refers to sensory, motor, communication, visual spatial, & cognitive differences
- Relationship Based: relationships with teachers, parents, & clinicians that foster learning

Dr. Stanley Greenspan's DIR Floortime

- DIR- Development of Individual Differences Relationship Model

- **Aim**: help child reach **6 key milestones** contributing to emotional and intellectual growth:

➢ Self-regulation and interest in the world

➢ Intimacy, or engagement in relationships

➢ Two-way communication

➢ Complex communication

➢ Emotional ideas

➢ Emotional thinking

➢ Therapists teach parents how to direct their children into more complex interactions,"opening/closing circles of communication," is central to the Floortime approach

➢ https://www.bing.com/videos/search?q=Dir+Model&&view=detail&mid=A4C415F9B900D9904860A4C415F9B900D9904860&&FORM=VRDGAR&ru=%2Fvideos%2Fsearch%3Fq%3DDir%2BModel%26FORM%3DVDMHRS

Picture Exchange Communication System (PECS)

- Based on Skinner's book, *Verbal Behavior* (1985)
- Does not require complex or expensive materials
- Teaches requesting as first skill
- Doesn't require eye contact, imitation, or labeling as pre-req
- Verbal prompts are not used
- Some learners using PECS also develop speech; others may transition to a voice output system
- Taught in 6 structured phases

VISUAL SCHEDULE CARDS
ROUTINE, CHORES, AFTER SCHOOL & MORE
©HEIDI DICKEY, 2017

fluidity

light box

drums

bubbles

instruments

pond

I want

balloons

story time

songs & music time

church

errands

nap time

playdate

cozy corner

go to sleep

story time

put on pajamas

brush teeth

eat dinner

clean up toys

outside

take a shower

activity time

➢ Barry Prizant, PhD – clinical scholar, consultant, researcher, consultant
➢ Published over 120 articles/chapters on ASD; 700 seminars/workshops
➢ *Autism spectrum disorders: A developmental, transactional perspective* (2000)
➢ Developed assessment instruments, *The Communication and Symbolic Behavior (CSBS) Scales (1993) and The CSBS-Developmental Profile (2002*)
➢ Mainstream audience book: *Uniquely Human: A Different Way of Seeing Autism*, **(2015)**
➢ **Co-developed SCERTS Program**
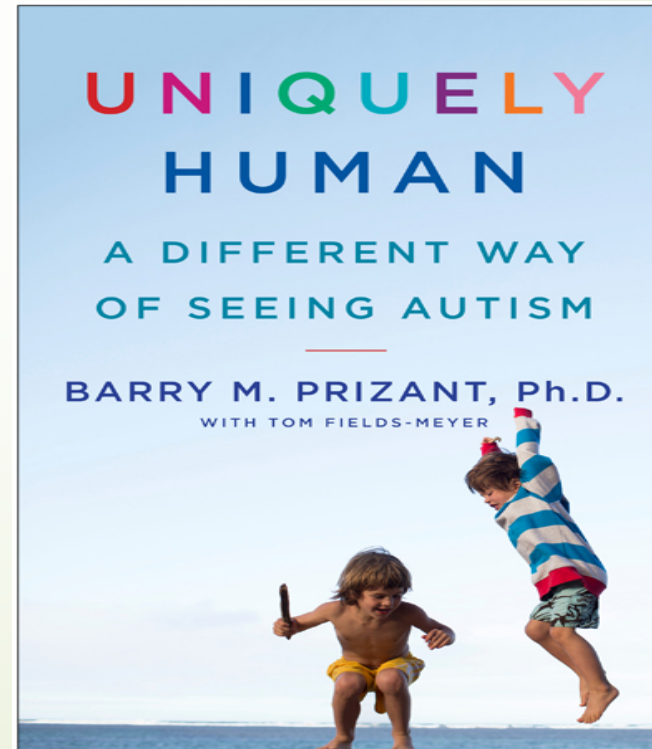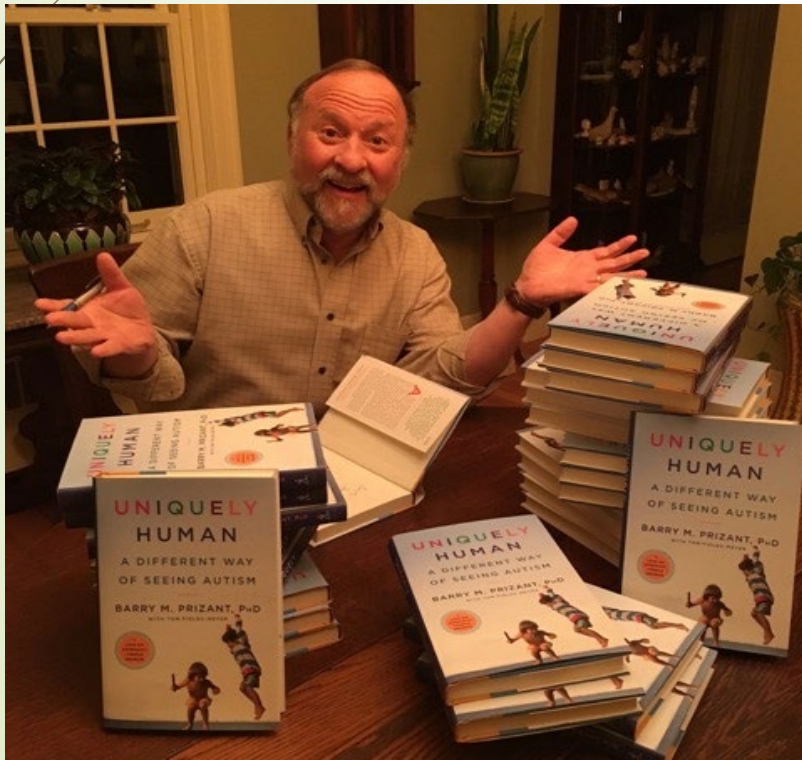
Therapy Intervention

- "SCERTS" refers to the focus on:

- "SC" - Social Communication – development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults.

- "ER" - Emotional Regulation – development of ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting.

- "TS" – Transactional Support – development and implementation of supports to help partners respond to the person's needs and interests, modify the environment, and provide tools to enhance learning. Specific plans are developed to provide educational and emotional support to families, and to foster teamwork among professionals.

- https://www.bing.com/videos/search?q=scerts&&view=detail&mid=BEB7939A05A3A36B35DEBEB7939A05A3A36B35DE&rvsmid=83018031EBF7F57F234783018031EBF7F57F2347&FORM=VDRVRV

alternative communication

Some people with autism use
alternate forms of communication

Here are some examples:
- gestures
- sign language
- sounds
- objects
- photographs / pictures / symbols
- voice output devices
- computerized and technological devices
- writing
- physical contact

Types: Alternative Augmentative Communication (AAC): High-Tech

- Speech Generating Electronic devices permit storage/retrieval of messages
- Multi functional
- Candidates

Types of AAC: Mid-Tech

- Battery operated- has more vocabulary than low-tech systems
- Variety of "levels"
- Teach independence if possible

Remember…

- iPad communication applications aren't right for everyone!
- There's other options
- iPad may not be the best place to start
- Consider low tech or no tech

AAC Considerations

- AAC - We want to know what the student wants to say, NOT what you want to tell them

Maximize Appeal:

- Use bright colors
- Motivating items
- Popular characters – familiar artists,
- Photographs of friends and family.
- Integrate social activities, play, routines & mealtime.

AAC Device Considerations

- Make sure AAC systems are available at all times
- Can be sent to/from school everyday
- AAC is a student's voice
- Users can only learn new words if provided access to vocabulary!
- AAC systems can increase children's independence
- AAC can support inclusion in activities with other children as well as with family members
- AAC does not inhibit oral language
- AAC promotes oral language!

Music...
CAN NAME THE UNNAMEABLE
AND COMMUNICATE
THE UNKNOWABLE
Leonard Bernstein
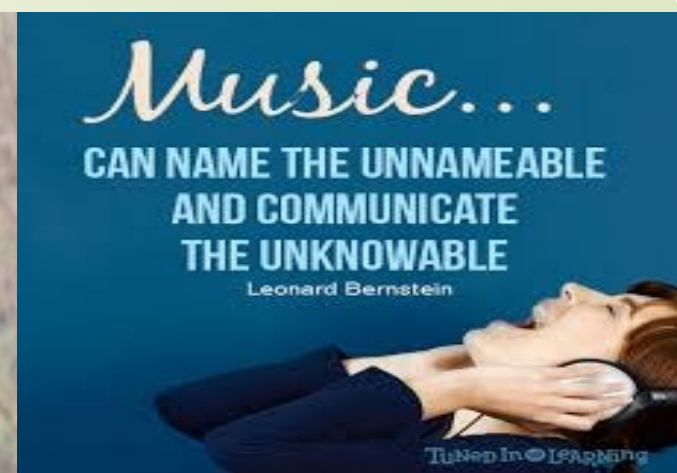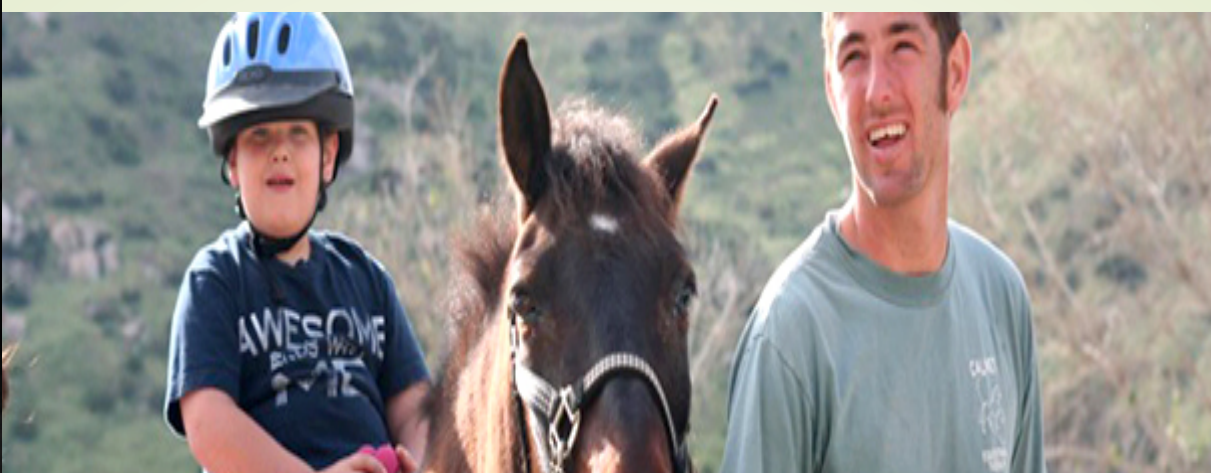
Music therapist

Equine therapy- Therapeutic Horsemanship helps riders walk, talk, connect, focus, behave and learn.
Riders learn to care for horses so students see the world from a the horse's perspective!

Occupational and Physical therapy

"The word autism still conveys a fixed and dreadful meaning to most people.
They visualize a child mute, rocking, screaming, inaccessible, cut off from human contact. And we almost always speak of autistic children, never of autistic adults, as if such children never grew up, or were somehow mysteriously spirited off the planet, out of society."

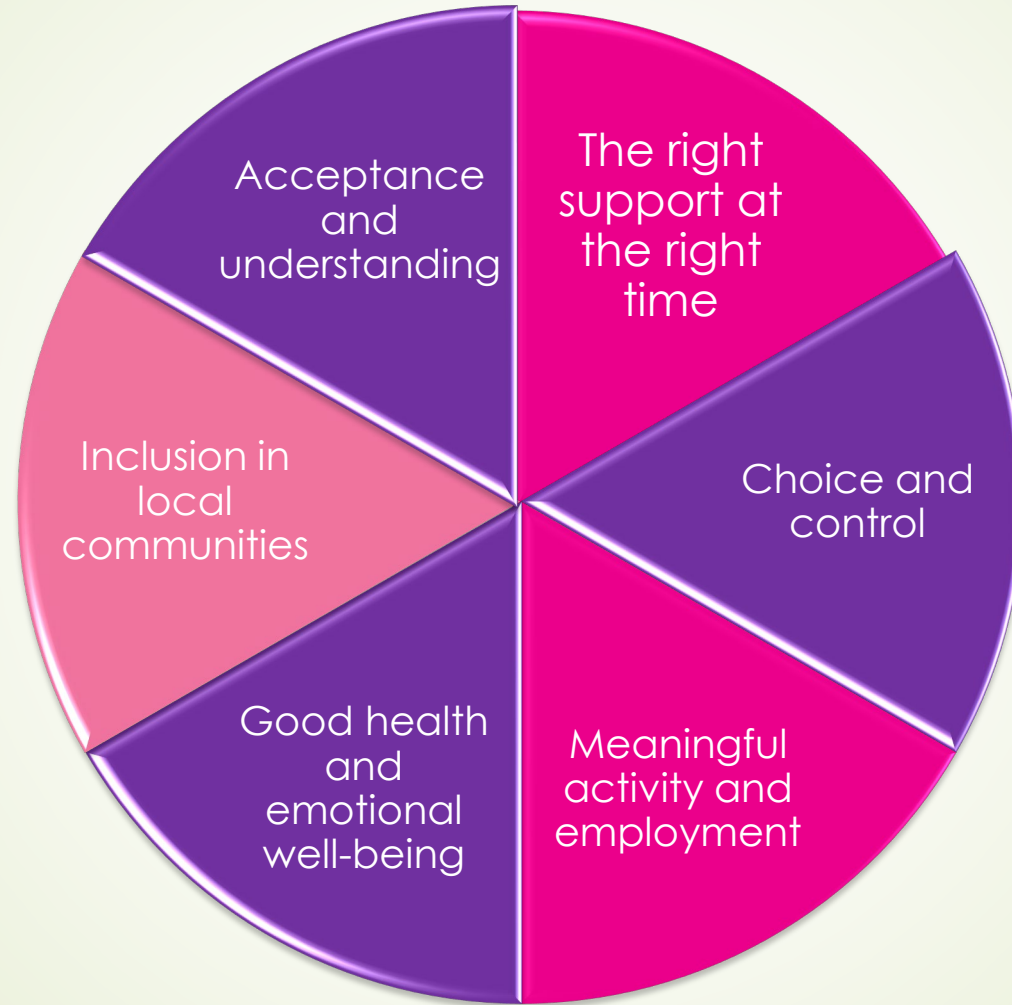Temple Grandin PhD

The Autism Cliff: Transition into Adulthood

- Gap between services provided to child and adults
  - after age 21 services/supports decline
- Job skills, dating, living arrangements- may present challenges
- AutonomyWorks helps adults w/ ASD navigate hiring processes
  - More companies seeing benefits of neurodiversity and inclusion programs at the workplace
  - start by advocating for programs at our own workplaces
  - 60Minutes segment on hiring autism with Anderson Cooper
- https://youtu.be/YnAUy4BM0w8

What do autistic people want?

Pie chart with six segments:
- The right support at the right time
- Choice and control
- Meaningful activity and employment
- Good health and emotional well-being
- Inclusion in local communities
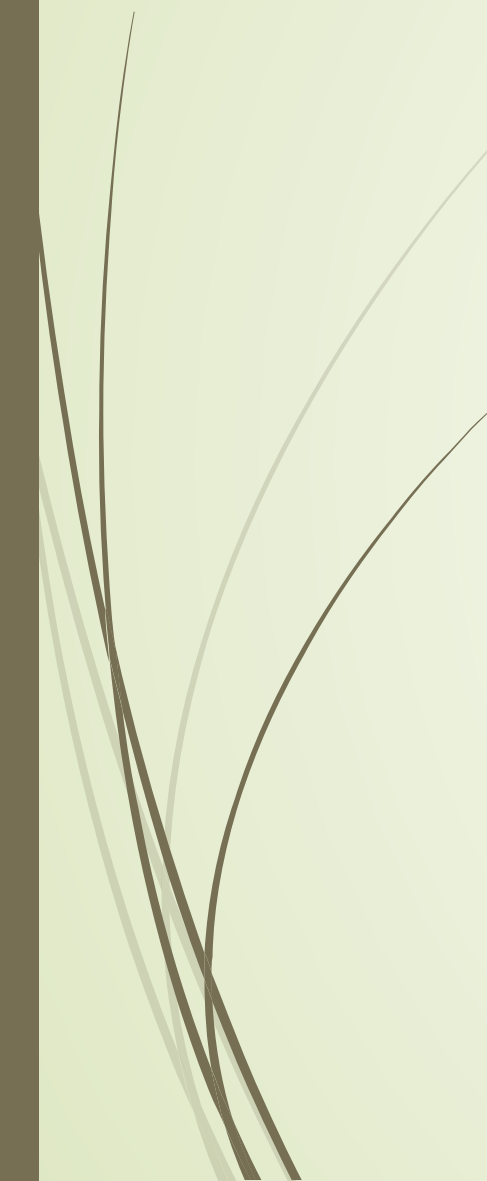- Acceptance and understanding

Issues in the workplace

All can affect being able to obtain/maintain employment :

➡ Sensory issues (the work environment)

➡ Communication issues – interacting with others

➡ Literal use of language, insensitive to feelings

➡ Misunderstandings

➡ Can seem odd eccentric

➡ Subject of bullying

➡ Social issues – socializing

Employment Support strategies:

- Support to self monitor anxiety levels in order to ensure emotional well-being

- Be aware of learning styles. Individuals may not be able to multitask or think abstractly

- Practical demonstrations are useful

- Coaching and mentoring

- Acceptance and understanding are key

functional skill sets

- categorizing
- collating
- copying
- data entry
- folding
- following a sample
- handicrafts
- handling
- horticulture activities
- laundering
- machine operation
- making lists
- manipulation of objects

- matching
- money exchange
- number application
- packaging
- preparation
- printing
- quality control
- sequencing
- sewing
- simple assembly
- sorting
- stuffing
- weighing

Success in Employment

Reasonable adjustments:

- Raise awareness of ASD among staff
- Accommodate sensory needs
- Written feedback helpful
- Try to express expectations as literally as possible
- Own desk rather than "hot desking"
- Tap into special interests – some are excellent researchers and advocates
- Hiring: Autonomy Works, Ford, Microsoft, AMC, Walgreens, Ernst & Young, Spectrum Enterprises, Stop & Shop, etc

Future for ASD

- Better diagnostic and intervention strategies
- Further understanding of brain development and causes of ASD
- Increased acceptance of Neurodiversity and diversity in general
- Thank you!!

https://nationalautismassociation.org/guide-for-grandparents/
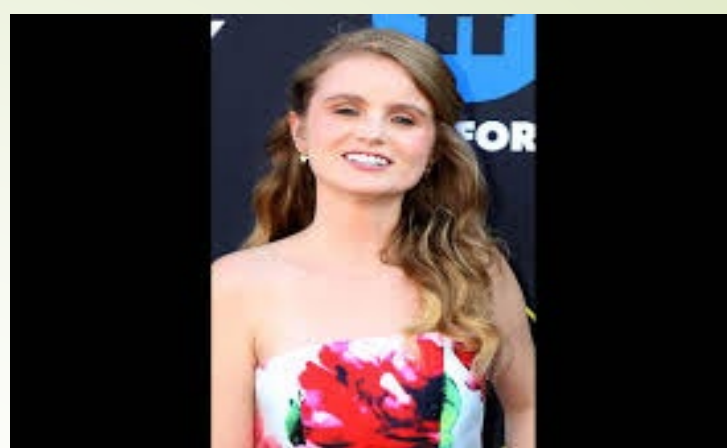
A Guide for Grandparents:
Answers to Common Questions &
Concerns Relating to Autism
Spectrum Disorders

A Resource Provided by the National Autism Association

NATIONAL
AUTISM
ASSOCIATION