

Working with Children and Adolescents on the Autism Spectrum

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Plan for today

- 15 minute break at approximately 10:00 am
- Lunch break at approximately 12:00-1:00 pm
- 15 minute break at approximately 2:30 pm



Our Approach

- Understand ASD very well in order to adapt and adjust with individual circumstances and development
- Plan interventions with independence and self-advocacy in mind

DSM-V Criteria: A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

- Deficits in social-emotional reciprocity
 - Abnormal social approach; failure of back and forth interactions; reduced sharing of interests, emotions, or affect; failure to initiate or respond to social interactions.

• APA, 2013

2. Deficits in **nonverbal communicative behaviors** used for social interaction

- Poorly integrated verbal and non-verbal communication
- Abnormalities in EC and body language
- Deficits in understanding use of gestures, nonverbal
- Lack of nonverbals or expressions



• 3. Deficits in **developing, maintaining, and understanding relationships**

- Difficulty adjusting behavior to social context
- Difficulty in sharing imagination
- Difficulty making and keeping friends
- An absence of interest in peers

Social Communication Misunderstood

- He's so *"SOCIAL!"*
- She makes *eye contact*
- He plays *pretend*
- She wants friends...she even *has friends!*
- He has *conversations* with us

DSM-V Criteria: B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least 2 of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech

- Simple motor stereotypies
- Lining up toys
- Echolalia (immediate or delayed)
- Idiosyncratic phrases



APA, 2013

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior

- Extreme distress with changes
- Difficulty with transitions
- Rigid thinking



- 3. Highly **restricted, fixated interests** that are abnormal in intensity or focus

- Strong attachment to or preoccupation with unusual objects

- Excessively circumscribed or perseverative interests



- 4. Hyper- or hypo-reactivity to **sensory input or unusual interest** in sensory aspects of the environment

- Indifference to pain/temperature
- Adverse response to sounds/textures
- Excessive touching or smelling of objects
- Visual fascination with lights or movement



- C. Symptoms must be present in the early developmental period (**but may not become fully manifest until social demands exceed limited capacities**, or may be masked by learned strategies later in life)

- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning
- E. Disturbances are not better explained by intellectual disability or global developmental delay

APA, 2013

It's All Autism Spectrum Disorder

- Asperger's Disorder and PDD are now classified under ASD
- Verbal language deficits are de-emphasized
- Focus is on the brain
- Level of support needed across each domain
- AND MAYBE MORE...Now you can also have ADHD
- Related – should you use person first or “autistic?”

What You *Don't* See

- Hand flapping and monologues about ceiling fans are obvious
- Does it matter that *you* are in the room?
- Does it matter *how* you respond? And why does it matter?
- Are you being used? How?
- Going through the motions vs. depth and novelty

Differences We See: Information Processing

Differences in Information Processing

- Weak Central Coherence Theory
 - Missing the forest for the trees
 - Difficulties putting information together to form context (i.e., missing the big picture)
 - Inability to see the relationship between components (i.e., detail oriented bias)
 - Inability to holistically integrate the components of a social situation to comprehend greater meaning
 - Trouble distinguishing emotions, responding appropriately, adjusting behavior to context, comprehend the relevance of emotions in social situations
- OR.... Not deficits in getting the big picture, but a superior ability to process features

Complex Information Processing

- Minshew et al. (1998); Bertone et al. (2005) highlight the importance of the complexity of the task
 - "Superior when autonomous, inferior when synchronized" explains the difference in performance of more complex vs. less complex visuospatial processing in ASD
 - A processing pathway that is efficient and superior for an isolated task (less complex tasks)
 - As components are added to increase the complexity of the task, visual areas are required to work in sync and that's when the person with ASD's processing becomes less efficient
- Kumar, 2013

Differences in Information Processing

- Theory of functional underconnectivity (a neural model of ASD)
 - Individuals with ASD rely on posterior regions of the brain to work in autonomy rather than in collaboration with frontal regions to perform visuospatial and cognitive tasks
- There is no I in TEAM!
 - As tasks increase in complexity, NTs are able to employ all players on the team
 - Social cognitive, cognitive, problem solving, high level language comprehension, inhibition – all require teamwork!
- Kumar, 2013

Eye Tracking and Face Scanning

- Yi et al., 2013
- Children with ASD fixated less on faces than age and IQ matched NT children
- ASD group spent less time looking at the right eye than NT control groups
- AND, when looking at the left eye, ASD group actually looked at area slightly below the eye whereas NT controls tended to look at the pupils

What's wrong with the right?

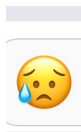
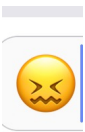
- Right side of the face typically more emotionally expressive
- Supports greater difficulty in ASD in understanding facial expressions and emotions
- Could explain deficits in joint attention, helps us understand weaknesses in understanding intentions

The Mouth

- Repeated studies show gaze focuses on the mouth and less at eyes
- But many people with ASD *can* recognize faces and expressions
- More difficulty when complexity of social understanding increases
- What is it about the mouth?
 - Avoiding eyes/more emotional information?
 - Mouths move and emit noise?
 - Compensatory strategy?



But He *Can* identify expressions



Most of the Time

Research Lab vs. Real Life

- Clear demonstration that we sometimes see differences and we sometimes do not
- General agreement that the more complex a task and the more integration of skills required, more trouble individuals with ASD have

Processing of Emotional Responses

- Cassidy et al., 2014 and 2015
- Participants presented with video clips or static pictures while eye movements recorded
- Told they would see videos or pictures of people receiving either a box of chocolates, fake money, or a tacky glitter card
- Asked to judge which gift the person was given and state the person's emotion
- Emotion response was coded as positive, negative, pretend, or confused

Processing of Emotional Responses

- Individuals with ASD were more accurate overall when presented with pictures rather than video
- When they have more time to process (pictures), tend to be more accurate
- But for mixed messages, individuals with ASD tended to rely on speech content rather than other nonverbal cues to help them determine emotions
- When speech content isn't there (as in when presented with pictures), they show difficulty interpreting mixed emotional responses (i.e., smiling in confusion)

Boiling it down

- Individuals with ASD *can* process information but
 - They tend to focus on 1 piece of information at a time and have trouble integrating
 - They tend to need more time to make sense of everything all together
 - Mixed messages, subtle cues, and very complex situations make it much harder
 - We see this in people with ASDs brains, behavior, and everyday functioning
 - We don't always see this in...

Where It Doesn't Always Show Up

- Standardized tests in a 1:1 test situation
- Routine, predictable situations
- Calm situations
- Situations where the messages are consistent

Why Is This Important?

- People with ASD aren't always identified in schools as having deficits
- But have difficulty managing the demands of social situations throughout the day
- Accuracy and ability to successfully navigate situations is inconsistent
- Just because they *can sometimes* doesn't mean they *always will*
- Fight or Flight or Freeze often misperceived as behavior problem

What Can We Do?

- Evaluate complexities
- Move to video and real life vs. static
- Calm things down and isolate
- Keep messages consistent
- Be clear with language, facial expressions
- Allow for processing time
- Teach about confusion and asking for clarification
- Provide ways to decrease sensory demands
- Routines, process, predictability

The Individual with Autism's Eye View

- First hand accounts
- Beyond ASD, understand that individual
- Avoid rubber stamping interventions, plans
- As individuals develop (and develop greater awareness of their strengths and weaknesses), involve in treatment planning

Don't Underestimate Anxiety

- Fight or Flight or Freeze
- Avoidance and escape behaviors can be difficult to manage, and don't forget the individual is suffering, too
- Recognize triggers, clues, signs that anxiety is escalating
- Teach anxiety management skills
- Learn crisis management skills

Or Sensory Experiences

- Sensory Simulations on You Tube
- Shopping at Walmart (among others)

Developing A Plan

| | |
|--|---|
| Strengths/Assets <ul style="list-style-type: none"> - What does the child do well? - What are the child's interests or passions? - What strengths can be found in teacher, school, parents, family, community? | Weaknesses/Deficits <ul style="list-style-type: none"> - What does the child struggle with? - What makes it hard to connect with the child? - What challenges can be found when you look at adults in child's life and environment? |
| Increase/Put in Place <ul style="list-style-type: none"> - What could be put into place to make life (for child, parent/family, teacher) easier? - What do you want to build on? | Decrease/Take Away <ul style="list-style-type: none"> - What could be taken away to make life (for child, parent/family, teacher) easier? - What would you like to eliminate? |

To label or not to label

Labeling

Family/Caregivers

Self/Individual

Publicly

"Officially"

Calling it ASD

Are we sure?

Stigma

Public Misconceptions

Heterogeneity of ASD

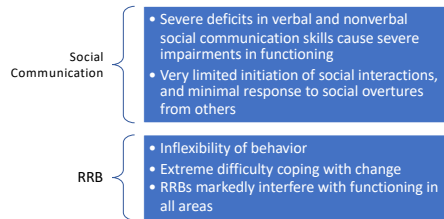
If you've met one person with Autism...



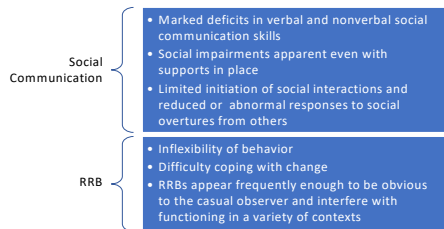
Communicating Level of Impairment

- Asperger's Disorder vs. "Autistic"
 - Outdated and inaccurate
- High-Functioning vs. _____
- Under DSM-V level of support needed in each domain (Social Communication and Restricted, Repetitive Behaviors)
 - Requiring very substantial support
 - Requiring substantial support
 - Requiring support

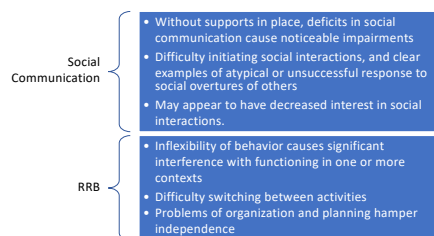
Very Substantial Support



Substantial Support



Support



ASD in the classroom

- Challenging behaviors
- Problems with peers
- Social behaviors that can be disruptive, odd, embarrassing, awkward...for everyone
- Problems with organization, attention
- A strong dislike for anything seen as boring or pointless

Often boils down to

- Misunderstandings
- Confusion
- Taking offenses personally
- Power struggles
- The demands exceed the individual's capacity, skills, or abilities

Behavioral principles

- Reinforcement
 - Increases the behavior
 - Can be positive (put something in place) or negative (take something away)
- Punishment
 - Decreases the behavior
 - Can be positive (put something in place) or negative (take something away)

Reinforcement

- Prefer reinforcement to punishment, particularly with skill acquisition (I don't speak Spanish)
- Punishment continues the negative cycle, particularly with grudge-holders

Applied Behavior Analysis

- ABCs (not just M&Ms)
 - Antecedent
 - Behavior
 - Consequences

Functional Behavior Analysis

- Identify ABCs (Social Behavior Maps can help with this; BCBAs are better!)
- What does the behavior do for a person in that setting? What is the individual getting from exhibiting the behavior?
 - Escape/avoidance
 - Attention
 - Sensory
 - Rewards

• Cipani et al., 2011

Common Areas of Focus

- Anxiety
- Attention
- Self-Regulation
- Impulsivity
- Social Skills

Anxiety

Specific phobias

- Dogs
- Planes

Generalized

- What ifs
- Excessive (Repetitive) worry thoughts

Because life with ASD can be hard

- Social communication deficits
- Sensory
- Perseverative thoughts

Aspie Trainer's Blog, ADW

- "In the past I've had therapy (a combination of CBT alongside other acronyms I've forgotten) to try and mitigate my mental health difficulties, and there appears to be two schools of thought in relation to this: one which says that CBT can be adapted for autistic individuals; and the second, which I fall into, that find it unnecessarily confusing/unhelpful, and hence a source of anxiety. Finding a therapist who has sufficient knowledge about autism is still quite tough. The fact that I had 8 months of therapy without being identified as an Aspie/autistic serves to illustrate this point."

But, wait...CBT is perfect

- CBT very linear
- Many strategies are basically self-talk social narratives (or can be turned into them)
- Can make strategies concrete and visual
- And, actually, here's what ADW goes on to suggest...

CBT for Anxiety

- Educate and Explain
- Teach tools for changing thoughts
 - Click on a new video
 - Index card stacks
- Teach tools to relax and calm body
- Teach alternative actions

When
you're
anxious
because
you're
unaware or
too aware

Ask for help

Teach phrases to "save face"/get
out of a tricky situation

Teach about confused feelings and
clarification

Acceptance and a healthy
perspective

Attention

- Understand distractions, teach a plan
 - Developmentally appropriate
 - Use special interests, if possible
 - Make it visual and concrete
 - Change the environment

Interventions for Attention

- Help from others
 - Physical proximity
 - Physical prompts, cues
 - Checklists
 - Timers
- Use of fidgets/OT interventions
 - Fidget vs. Distraction



Interventions for Organization

- Visual schedules
- First, then
- Visual cues – labeling, separating space with tape, color-coding
- Process and routines
- Planned (and routine) clean-outs
- Use calendars/agendas
- Prepare and build in wiggle room



Making homework less work

- Support from school, teachers
- Routine
- Chunk homework
- Build in breaks (if needed, effective) and a reward (i.e., preferred activity)
- Estimated time, actual time
- Make the complaining/whining/procrastinating time visual



Red=complaining/whining/procrastinating
 Green = homework
 Orange = dinner
 Yellow = free time

Using Breaks

- Can be used to address sensory needs, movement needs, self-regulation
- Think about how it makes sense and doesn't disrupt
- Keep behavioral principles in mind
- Consult as available

Social Thinking Skills

Basic Tenets

- Thinking About You, Thinking About Me – Michelle Garcia Winner
- Expected/Unexpected Behaviors
- Perspective Taking
- Body and Brain in the Group
- Social Behavior Maps

Teaching Perspective Taking

- I think about you; you think about me
- I think about your intentions; you think about my intentions
- I realize you are having thoughts about me and I think about what you might be thinking about me; you do the same
- I regulate my behavior to keep you thinking about me the way I want you to think about me; you do the same

Michelle Garcia Winner, 2007

Thoughts About You

- Uncomfortable thoughts/comfortable thoughts
- Memory Jars
- Memory Files



Michelle Garcia Winner, 2007

Expected/Unexpected Behaviors

- Social behavior mapping
 - Another form of a social narrative
 - Behavior
 - Others' thoughts and feelings
 - Consequences/what happens
 - How you feel

Michelle Garcia Winner, 2007

| Social Behavior Map | | | |
|---|--|---|--|
| Behaviors That Are EXPECTED For Learning as Part of a Group in the Classroom | | Behaviors That Are UNEXPECTED For Learning as Part of a Group in the Classroom | |
| Expected Behaviors | How They Make Others Feel | Unexpected Behaviors | How They Make Others Feel |
| <ul style="list-style-type: none"> Listening to others in a group Waiting for one's turn to speak Using appropriate voice level Following directions Respecting personal space Using appropriate touch Using appropriate body language Using appropriate facial expressions Using appropriate eye contact Using appropriate posture Using appropriate hand gestures Using appropriate head movements Using appropriate leg movements Using appropriate arm movements Using appropriate torso movements Using appropriate whole-body movements | <ul style="list-style-type: none"> Respected Valued Safe Happy Relaxed Comfortable Respected Valued Safe Happy Relaxed Comfortable Respected Valued Safe Happy Relaxed Comfortable | <ul style="list-style-type: none"> Disrupting others Not listening to others Not waiting for one's turn to speak Using inappropriate voice level Not following directions Not respecting personal space Using inappropriate touch Using inappropriate body language Using inappropriate facial expressions Using inappropriate eye contact Using inappropriate posture Using inappropriate hand gestures Using inappropriate head movements Using inappropriate leg movements Using inappropriate arm movements Using inappropriate torso movements Using inappropriate whole-body movements | <ul style="list-style-type: none"> Disrupted Not valued Not safe Not happy Not relaxed Not comfortable Not respected Not valued Not safe Not happy Not relaxed Not comfortable Not respected Not valued Not safe Not happy Not relaxed Not comfortable |

The Hidden Curriculum

Brenda Smith Myles, Ph.D.
Judy Endow MSW

It's Common Sense

- Social information that is not directly taught
- Social information we assume everybody knows
- Unstated rules or customs that
- Can cause confusion, anxiety, loneliness, and negativity for those with ASD who are not neurologically wired to automatically "get it"

About the Social Rules

- They change based on age
- They can be different based on gender
- They can change based on your environment
- They can change depending on who is around

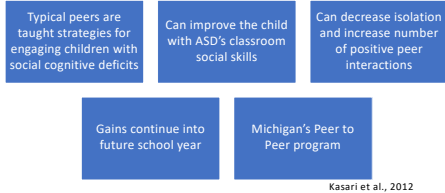
Teaching the Hidden Curriculum

- The ECLIPSE Model (Moyer, 2009)
 - includes sample IEP goals along with "pick up and use" lesson plans
- The Social Times (Burton, 2010)
 - Newsletter written directly to students in their "voice"
- One A Day hidden curriculum calendars (Trautman & Wragge, 2010)
 - Geared towards kids and older adolescents
- Teach about the hidden curriculum, clarification, and social repairs

Social Skills Programming

- Individuals with ASD want to establish meaningful social relationships
- Skills to be successful socially may need to be taught directly
- Successful social behaviors are not always "proper"
- Requires an ability to adapt to our environment
- Teaching social skills may not feel comfortable (to you)
- Bellini, 2006

Peer training



Using peers in other ways

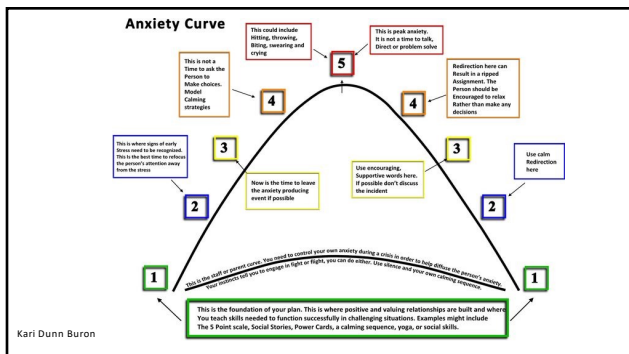
- Disclosure
- Make it a class-wide initiative
- Incorporate self-awareness, understanding, and self-advocacy

Academics and ASD Deficits

- Interpretation: "what is the most obvious answer?" Cognitive verbs: think, know, guess, decide, consider
- Writing: check to see if writing quality improves if they are able to pick the topic
- Teach idioms and common phrases

Self-Regulation – Anxiety, Behavior, Mood

| Individual | Others |
|--|---|
| <ul style="list-style-type: none"> Understanding Identify (5 point scale) Stop and Slow Down/Pause and Break Follow plan | <ul style="list-style-type: none"> Understanding Identify (5 point scale) Stop talking Make expected behavior clear and put supports in place to <i>shape</i> |



Name: David My Scared/Annoying Scale

| Rating | Looks/Sounds like | Feels like | Safe people can help I can try to |
|--------|--|--|---|
| 5 | I am going to scream and cry and throw things. | I am going to scream and cry and throw things. | I will need an adult to help me (mom, dad). |
| 4 | I am going to scream and cry and throw things. | People are taking about me. I feel embarrassed, mad. | Could my mom and dad help me? Could my teacher help me? |
| 3 | You can't tell I'm scared, you can't hear. | I should hide. | Write or draw about it. Could my mom help? |
| 2 | I don't want to go to school. | My stomach gets a little upset. | How do I feel? Tell my mom. Tell my dad. |
| 1 | I don't want to go to school. | I don't want to go to school. | Stop it! |

Registered with permission from Buron, K. & Curtis, M. (2003). The Incredible 5-Point Scale: Assisting students with Autism Spectrum Disorders in understanding social interactions and controlling their emotional responses (pp. 1-34, 42-43). Shawnee Mission, MO: Autism Support Publishing Company. www.autism.org

Ask for help

Take a break

Calm body by...

Go to a quiet space

Move my body

Feelings

Good
 Tired
 Embarrassed
 Confused
 Sad
 Anxious
 Angry

What is happening with me?

I'm frustrated because _____

I think I'm in trouble. I'm not sure why _____ is upset

I need help with _____

I don't understand _____

I am worried about _____

I can't get _____ out of my mind

What could help?

☐ Need a brain break
☐ Go for a walk or get a drink
☐ Take deep breaths/meditate
☐ Talk to someone about size of the problem
☐ YP or MP?
☐ Talk to someone about my feelings or draw them out
☐ Write it down and recycle it

☐ Give directions in small parts
☐ Repeat what the teacher said
☐ Use the standing desk
☐ Help me get started
☐ I need more time

| | How I feel right now | What I can do | What can teachers do |
|----------|-------------------------------|---|--|
| 5 | I need some help now! | <ul style="list-style-type: none"> Go to quiet room Go take a break | <ul style="list-style-type: none"> Give him a break |
| 4 | I'm really upset | <ul style="list-style-type: none"> Ask to take a break Talk to someone about why you are upset Deep breaths | <ul style="list-style-type: none"> Use other page to try to determine why he is upset |
| 3 | I've got a problem | <ul style="list-style-type: none"> Tell a teacher you need some help Ask a friend for help Take deep breaths | <ul style="list-style-type: none"> Clarify directions Help him get started YP or MP Size problem |
| 2 | Things are pretty good | <ul style="list-style-type: none"> Think good thoughts | <ul style="list-style-type: none"> Positive Encouragement |
| 1 | Feeling Great! | <ul style="list-style-type: none"> Keep up the good work! Have fun | <ul style="list-style-type: none"> Reward system Praise good work |

Ask for Help (with words, cards, or codes)

- Ask for a minute (pause)
- Ask to slow down
- Ask for a break
- Ask for clarification
- Ask for guidance

Self-Regulation, EF and Screens

- Is it possible?
- What helps? Hacks.
- Parents set limits and boundaries early, shift the managing to kids and adolescents little by little (engage in planning, working back)
- Online social world – benefits and risks, teach “scammers”
- Screens and sleep

Set Parameters

- Find the appropriate limits, make it very concrete
- As much as possible, build in cooperation and interaction
- Keep systems and devices out of bedrooms
 - Ideally with an adult nearby
- Fight fire with fire – utilize technology

Fighting Fire with Fire

- Apps for monitoring and controlling your child’s access and use of devices
- Wireless networks that can be turned on and off at specific times
- Parental Controls
- Camera blockers

Keep in Mind

- Parameters have to be palatable for the family
- Parameters can be individualized – not a one size fits all
- Probably don't have the luxury of much flexibility
- Think about the Displacement Hypothesis and use it to your advantage
- Likely impossible to limit all exposure

Electronic Fasts

- Find a period of time to remove screen exposure and rip the band aid off
- "Reset Your Child's Brain: A Four-Week Plan to End Meltdowns, Raise Grades, and Boost Social Skills by Reversing the Effects of Screen-Time."
- Track behavior and keep data!
- You're going to have to make changes, too

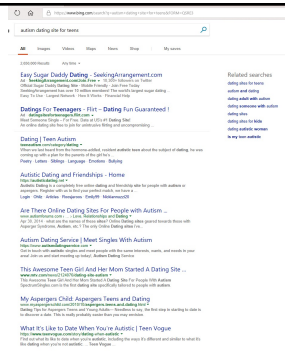


Social Skills

- Remember we use social skills anytime we share space (physical or *virtual*) with others – the internet, interactive gaming, social media, texting all require us to use social skills

Perspective Taking

- What others want to see online
- Other people's intentions
- How people might interpret your comments, posts, "likes"
- Why certain articles are written, if they are "fact" or not
- How people are reacting to your comments, posts, texts
- What's "safe;" what's not



Adjusting Behavior

- Once you make a guess about others' intentions/reactions, adjust your behavior
- Continue monitoring others
- Make social repairs
- Recognize when something doesn't seem right and be able to tell someone, block someone, stop interactions
- Set limits for self; regulate self



Explain the Risks

- You're the kind of kid who might get pretty stuck on...
- It can be hard to stop thinking about the game world and start thinking about the real world when you need to
- There can be fake, confusing, inaccurate, scary, and even illegal stuff online – and sometimes you find it by accident or sometimes it can find you
- There are strangers online and they might break rules or try to trick you; they might want something from you that they should not have

Explain the Risks

- People might do or type mean things to you – they might even be sneaky about it!
- You might do or type things that are mean to other people – and you might not even know you're doing it!
- There are no secrets online or in texts...and you can't ever erase it

A reminder: Do not forget to have this conversation, at different levels, time and time again....In an age when 18 month olds are given their parents' phones to occupy themselves with a game, we see they know how to use these devices and we don't necessarily realize how much they begin exploring without us. Kids end up with lots of online freedom and it can be because of a slippery slope into the online world.

How You Can Protect Yourself

- Remember your privacy
 - Know what private information you should never share
 - Set privacy limits on apps
 - Think of private screen names
 - Avoid posting photos of yourself, your room
- Tell an adult if you find something scary, confusing, or inappropriate online – we can help you understand it
- Learn what is against the law

How You Can Protect Yourself

- Follow your "never" list
- Check with an adult if you're unsure, confused, or uncomfortable
- You may want to block "friends" who...and you can check with a adult before or after

When You're Online or Texting

NEVER

- Give up your privacy
 - Name, address, school, birthdate
 - Pictures of yourself
 - passwords
- Agree or arrange to meet an online-only friend in real life
- Give someone credit card/debit card information

MAYBE – Check with _____

- Open attachments
- Download games, software, apps
- Private message with an online friend
- Post pictures, videos

When You're Online or Texting

ALWAYS

- Tell _____ if something you see, read, or do makes you feel uncomfortable, confused, or scared
- Tell _____ if someone asks for your personal information, to meet, or for money
- Remember "this might not be true" and check with _____

ALWAYS

- Take breaks from screens to keep yourself healthy
- Stick to the limits in our plan
- Follow the law

How We Will Help Protect You

- We will make a plan for when, where, and how long you can go online or be on your device
- We will put controls on your computer or device to try to limit inappropriate content, pop-ups
- We will have your passwords and will check in on what you're doing online

How We Will Help Protect You

- We will pay attention to the games you're playing, who you're playing with, and how you're playing
- We will check out games, apps before and let you know if they are appropriate and safe for your use
- We will help you figure out if/when someone is being mean to you online and what to do about it
- We will help you figure out if you are being mean online and what to do about it

Plant Real-Life Coaches

- Older cousins, siblings to be "friends"
- Can provide feedback to individual as well as to their parents
- Feedback should be direct and honest
- Offers to "pre-approve"
- Posting practice sessions

Autism Social Networking Sites

- WeAreAutism.org
- WrongPlanet.Net
- AutismSpeaks.Ning.org

Resources

- Autism Speaks Internet Safety, Social Networking, and Technology toolkit
- Internet safety role playing discussions
 - www.safesurfingkids.com/lesson_plans_grades_3_12.htm
- Social Safety: An Online Social Networking Guide
 - <https://socialsafety.wordpress.com/stranger-danger/educationalopportunities/>
- Autism at-a-Glance (CSESA)

Let's Talk About Sex

Typical Sex Talks

Hand a book, hope for the best

Vague references, information, "beating around the bush"

And then, the confused kid picks up information from friends, TV, internet

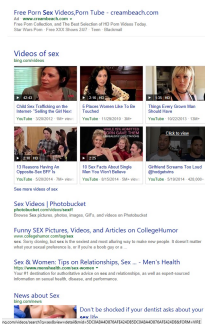
So People with ASD Will Understand

- Avoid euphemisms
- Avoid unfinished sentences
- Be clear, honest, and specific
- Be comfortable
- Check in for understanding, clarifications

Why Is This So Important

- Because people with ASD are human beings with sexuality and will most likely engage in sexual relationships in their lifetime and are entitled to accurate information
- Vulnerabilities
 - Increased risk for sexual abuse and assault
 - May go to internet for education and become very confused
 - May lack social skills to keep their behavior within the confines of the law and others' comfort level

When I typed
“sex” into search
bar...



Why Is This So Important

- May need instruction re: expression of sexual feelings
- Because sex is one component of adaptive functioning
- And sexual relationships, sexual behavior are components of social skills

Myths About ASD and Sexuality

- People with ASD are asexual
- People with ASD are oversexed
- People with ASD won't be able to handle sex education
- Talking about sex will "put ideas in their head"

Research About ASD and Sexuality

- Individuals with ASD display sexual needs similar to NT peers, along with a wide variety of sexual behaviors, wish to engage in intimate relationships, are neither hypersexual nor asexual
- Problematic sexual behaviors in individuals with ASD tend to be the result of deficits in social and communication skills
- There is a demonstrated need for sexuality and relationship education in the ASD community and a paucity of research

ASD At-Risk

- May not have knowledge about sex, reproduction, STDs
- May not understand what sex abuse is
- May be trained to comply with adults
- May be “rule followers”
- May have difficulty asking for help

ASD At-Risk

- May lack healthy social relationships
- May not know how to safely use social media, internet
- May have difficulty reading others’ intentions
- May not believe other people could lie, “use” them

Start Education Early

- Teach about body parts *and body functions*
 - Teach proper terms then decide about introducing slang and the concept of other terms
- Teach about privacy in developmentally appropriate ways with learning needs of individual taken into consideration
- Teach the difference between public and private (thoughts, too!)

Consider the Following

- All areas of development – teach what is necessary in a way that is tailored towards cognitive development and maturity level
- What information does the child already have/understand?
- What is the child exposed to or has the child been exposed to?

Specific Concerns

- Teasing
- Culture of peer group
- Exploitation/prompting
- Masturbation
- Physical appearance and awareness of personal space, privacy
- Suspicion of sex abuse

For Older Children, Adolescents, Adults

- Assess what they “know”
 - Conversation, open-ended questions, follow-up questions
 - The Sexual Attitudes and Knowledge Assessment
 - Sexual Abuse Risks Assessment
 - S-T-A-R-S Guidebook

Prepare

- Get comfortable
- Gain knowledge
- Practice – we make kids role play, you should do the same!
- Be open
- Be straightforward
- Be sensitive
- Be proactive

As a Provider

- Clarify with caregivers family values and attitudes
- Be clear about your plan and recommendations

Resources and Support

- *How to Talk with Your Child About Sex: Help Your Children Develop a Positive Healthy Attitude Toward Sex and Relationships – John Chirban, 2007*
- Organizations, chat rooms – parents of other kids with ASD
- Your child's team: teachers, therapists, physician
 - Sex education, puberty education, self-care for menstruation can and often should be a part of the education plan

Resources and Support

- Relationship Building and Sexual Awareness for Kids with Autism – STARS 2 (Heighway & Webster, 2015)
 - Understanding relationships
 - Social interaction
 - Sexual Awareness
 - Assertiveness

Resources and Support

- Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders (Hartman, 2014)
 - Broad teaching curriculum that includes concepts such as identity, safety, love, intimacy, and relationships (which may or may not have a sexual component)
 - Primary goal to support children in developing a healthy sexuality
 - Understanding, Preventing, Supporting, and Responding

Puberty

Puberty in ASD

- Individuals with ASD begin puberty around the same time as NT peers
 - Precocious puberty noted in some females with ASD
- Greater levels of emotional and social loneliness than NT peers (Bauminger et al., 2003)
- Mixed findings re: exacerbated or improved symptoms during this developmental stage of life

Growing and Changing

- Difficulty with change and transitions
- Increased responsibilities and tasks related to hygiene
- Physical discomfort
- Moodiness
- New sensory experiences

In General

- Prepare in advance for changes (by age 9, at least and more detailed and repeated as they grow)
- Normalize and be matter-of-fact
- Think concrete
- Then think abstract
- Teach about their sex
- Then about the opposite sex
- Teach about moods and how to feel better
- When using videos, online material – review first!

Bras

- Introduce bras slowly and naturally – draw their attention to bras
- Sensory issues
- Practice

Menstruation

- Teach about menstruation early (average girl starts at age 12 or 13, but range is 9-17)
- Concerns that come up: am I dying? Did I poop my pants? Will everyone know? Will I feel the blood coming out? Will it be one big gush?
- Explain what it may look like, what it may feel like
- Privacy around menstruation

Menstruation

- Make a plan
 - Who will she talk to when she first menstruates?
 - Who will help her if she is at school?
 - Where will she keep pads? How will she access?
 - Will she need a prompt or assistance changing the pad?
 - If someone will need to assist her in the bathroom, explain the boundaries and limits of that help

Menstruation

- Teach how to use/change a pad
 - Visuals
 - Model with underwear
 - Have her practice
 - Trusted adult nearby to offer assistance or check

Pre-Menstrual Tension and Other Info

- Teach about symptoms of PMT
- Teach what can help take away discomfort
- Explain clues that she should be prepared with pads, wear darker pants
- Teach how to track periods and how often they will probably come
- Teach slang terms
- Teach for unexpected situations

For Caregivers

- Be clear on the school's policies
- Consider alternate underwear for daughters
- Support group and others parents as resources

Erections

- Boys begin to get erections as early on as infancy; from 2-5 may begin to notice erections – explain matter-of fact, “yes, that happens to boys’ penises. That’s called an erection. It will go away after a minute or so and your penis will feel soft again.”

Erections

- Means your body is working the right way, but it is private
 - Don’t tell people when you have an erection
 - In fact, if it happens in school, you will try to hide it by _____
 - Or, you might think about _____
 - And you might wear clothes like jeans or longer shirts so people won’t notice
 - Don’t mention it if you notice someone else has an erection

Wet Dreams

- Teach about wet dreams, what happens
- Explain ejaculation
- Explain the wetness is semen, not urine
- Normalize
- Teach how to clean up
- Reinforce privacy

Voice Changing

- Teach that men have deeper voices than boys
- When boys grown into men and their bodies change, their voices change, too
- Sometimes it sounds like the voice changes pitch or it might sound squeaky
- Explain that it might be embarrassing and that others might laugh
- Come up with a plan for what to do when it happens or how to respond when people laugh

Masturbation

- Both for males and females
- Normalize
- Privacy concepts – talking about it, doing it, seeing it

What is that *SMELL*?

- Showers
- Deodorant
- Teeth brushing
- Changing pads
- Be respectful, but be direct: You smell and people will notice it. They will not like it and will not want to be close to you.



General Appearance and Related

- Girls: If you're wearing a skirt, learn how to sit
- Keep your pants up
- Wear clothing that fits
- Make sure others can't see your underwear/bra

ASD, Sexual Identity, and Gender Identity

- No evidence of any causal link
- More that ASD is a heterogeneous group, which includes differences in sexuality as well

Education and Your Rights

- Healthy sexuality and relationships
- It is ok to refuse to be touched or to refuse to touch
- Even though sex is private, it does not have to be a *secret*
- You do not (and probably should not) compromise or make deals with friends, partners, or people about touching or being touched
- It is ok to ask for clarification and help from _____

Others' Rights

- Teach what is against the law
 - Online activity
 - Masturbating in public
 - Invading someone's personal space
- Teach what will get you fired
 - Jokes about sex
 - Masturbating at work
 - Commenting on coworker's bodies, sexuality, etc

Self-Advocacy

- Help individual recognize what they like, dislike, what feels good, what is uncomfortable
- Help develop language for setting limits, talking about what feels good/uncomfortable
- Teach how to break up with someone

Start Transition Planning

- In high school?
- In elementary school?
- In pre-school?
- Early intervention?

Start Transition Planning

- At diagnosis, with the first intervention
- Remember to ZOOM

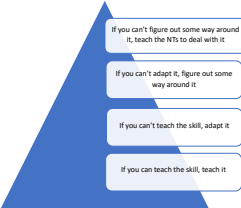
Priorities of Instruction for Transition

- Suggested in Wehman, 1992 *Life Beyond the Classroom*
- Student and family input (1 year, 5 year, 10 year)
- Survey current and potential future environments based on the above desired outcomes
- Assess skill needs in potential environments in terms of production, social, and navigation skills

Priorities of Instruction for Transition

- Prioritize skills that occur across multiple environments
- Attend to safety skills
- Attend to skills that reduce dependence
- Attend to skills NT cohorts will need to be taught

Gerhardt's Shortcut



Ultimate Criteria

"If the student does not learn to do the task, will someone else have to do it for them?"

Lou Brown, 1985

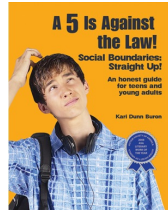
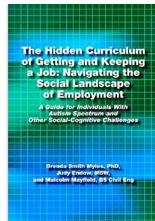
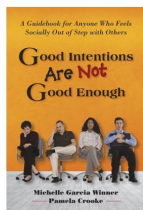
Focus on Functionality

- When developing treatment plans
 - Include the phrase "in order to _____"
- Include a sibling or trusted NT peer
 - Or get feedback from a trusted NT peer

Motivation

- Help individuals see who the work is for (ahem: not us)
 - Treatment planning
 - Social Behavior Maps
- Teach motivation directly – what it is, why it's hard to find, *everyone struggles* at times
- What's getting in the way?
 - Feeling overwhelmed
 - Wanting control?

Resources for Adults



Resources for You to Find

- Familiarize yourself with government agencies that can provide support
- Find local or area non-profits that can help with job skills, job training, job search
- What internships or employment opportunities are nearby?

Resources For You to Find

- Find local or area non-profits to help with housing, independent living
- Are there relatively nearby resources for independent living?
- What do Universities offer for students with disabilities?
- Summer programs?

And If They Don't Want Help?

- Motivational interviewing
- Social Behavior Maps
- That's their choice
- But I'm going to try my hardest not to be someone/something to be avoided
- And it might not be their final choice

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