

STRATEGIES TO HELP INDIVIDUALS WITH ASD DEVELOP INDEPENDENCE AND ADAPTABILITY

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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- Outdated and inaccurate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

- Social Communication
- Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning
 - Very limited initiation of social interactions, and minimal response to social overtures from others
- RRB
- Inflexibility of behavior
 - Extreme difficulty coping with change
 - RRBs markedly interfere with functioning in all areas

Substantial Support

- Social Communication
- Marked deficits in verbal and nonverbal social communication skills
 - Social impairments apparent even with supports in place
 - Limited initiation of social interactions and reduced or abnormal responses to social overtures from others
- RRB
- Inflexibility of behavior
 - Difficulty coping with change
 - RRBs appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts

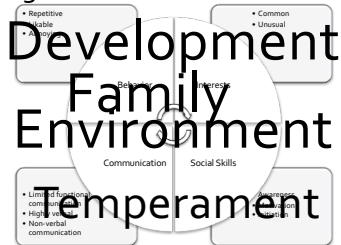
Support

- Social Communication
- Without supports in place, deficits in social communication cause noticeable impairments
 - Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others
 - May appear to have decreased interest in social interactions.
- RRB
- Inflexibility of behavior causes significant interference with functioning in one or more contexts
 - Difficulty switching between activities
 - Problems of organization and planning hamper independence

LEVEL OF SUPPORT MAY HELP WITH "OFFICIAL"

But what about family, self, and public?
And don't we need a little more information?

Capturing That One Person



Now we can think about

- How that individual experiences the world
- How the world experiences that individual
- What might be pertinent for others to understand: Control the message
- How the individual with ASD can develop self-awareness, self-respect, and be poised for self-advocacy
- What do we need to put in place, take away, increase or decrease (and do we need a label to do this)

Comprehensive Assessment

- Cognitive
- Achievement
- Adaptive behavior
- Social Communication
- RRBs
- Speech and Language
- Occupational Therapy
- Broad Based rating scales (emotions, behavior, development)
- Interview
- Observations
- Should take into account all of capturing that individual PLUS yield "official" diagnosis

BUT, REMEMBER

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
- Times when the individual is very focused on doing or not doing

Think

- Were there supports in place?
- Do demands exceed capacities?
- Are symptoms being masked?
- Are symptoms being misunderstood?

OPENING DOORS

OR SLAMMING DOORS?

Effects of Disclosure

- Increased opportunities
- Access to supports, funding
- Protections through the law
- Assistance with jobs
- Understanding, kindness from others
- Understanding, insight, self-awareness, possible avoidance of mental health disorders

Effects of Disclosure

- Stigma
- Discrimination
- Fewer opportunities
- Life under a microscope
- Mixed Findings (Huws and Jones 2008; Mogenson and Mason 2015)

Talking *About* the Individual

- The Parent on the Playground – It's her diagnosis
- Person-First language vs. Disability-First language
 - #actuallyautistic #describingautism Twitter handles

CONTROLLING THE MESSAGE

The label is yours to use (or not)

- To manage your own anxieties or discomfort
- To manage expectations
- To let others know they may need to adapt
- To elicit kindness or understanding
- To decrease negative judgements (and, often, as a result parental anxiety)

Disclosure Cards

- Austin et al., 2016
- Participants were presented with different scenarios – imagine you are at a playground and you see...
- Disclosure Cards
 - "My loved one has autism. Autism is a neurological condition that can cause children to be overwhelmed in different environments. Those affected by autism have trouble with social interactions and communication, often leading to misunderstood behaviors. Please be patient with us and our loved one as we try to help him adapt to everyday life as you know it. Thank you."

Disclosure Cards

- Group who did not receive disclosure cards rated the mother as having a greater deficit in parenting skills and had a more negative reaction overall
- Supports previous research on the efficacy of disclosure (Chambres et al. 2008)
- Provides preliminary support for the use of disclosure cards to reduce negative perceptions from community parents of a child with autism and the caregiver of a child with ASD

Go Beyond The Label

- And explain that individual
- Use qualifiers like "sometimes," "maybe"
- Use forgiving and empowering language

Empowering Phrases

- “has trouble with”
- “gets confused”
- “has big feelings”
- “feels uncomfortable”
- “a little time”
- “working on”
- “needs a little help with”

If Cards Feel Too “Official”

- Use your words!
- “Just a heads up – we’re working with Charlie on sticking with the family for activities. As we’ve told you before, he gets pretty overwhelmed with a lot of activity and that can lead to meltdowns pretty quickly. We let him bring a bag of his Legos and some books about Legos so he can take some breaks by himself when he’s starting to feel overwhelmed. Is there a spot where he can go in your house when he needs some alone time?”
- “Charlie has been having trouble leaving the playground lately. We’ve been working with him on moving from one activity to the next. You might hear some yelling and melting down. My plan is to give him a little space as I walk towards my car. It usually ends pretty quickly, but it helps when people aren’t talking to him. I know people want to help and they try calming him down, but that normally has the opposite effect! So, if we leave without hugs and goodbyes, please excuse us.”

Grandparents

- Autism Speaks toolkit
- <https://www.autismspeaks.org/family-services/community-connections/celebrating-grandparents>
- How to Form an Emotional Connection – podcast for family members of children with social delays
- <https://connectingforkids.org/page-1861522>

DOES THE PERSON "KNOW?"

Talking to the Individual

- Focus on capturing the individual and less on the label
- Remember to use words like "sometimes" and "maybe"
- Check in about agreement or disagreement
- Present a balanced account
- Highlight tools
- Matter-of-Fact and calm

STRUCTURING THE SELF-TALK

ELI'S GUIDE TO STAYING CALM AND MOVING ON

What's it like to have Asperger's for Me

- It's also called Autism
- It's not a problem, it makes me special
- I am really creative and think differently – like Albert Einstein and Thomas Edison and Steve Jobs
- I like to think about solving problems and how to make the world a better place
- Sometimes I have pretty intense feelings
- Sometimes I am pretty positive about things, sometimes I am pretty negative about things

Some things scare me

- ALICE drills
- Dying
- Being alone in the dark
- Mythological creatures
- The Mind Mist (Beyond Stranger Things)

Some things excite me

- Special holidays, time spent with family
- Playing with Legos
- Playing with Plants vs. Zombies
- Rollercoasters
- Sledding

Some things that frustrate me

- Not having enough time to get stuff done
- If I ask a question and no one replies to me (mostly happens in class or in person conversations)

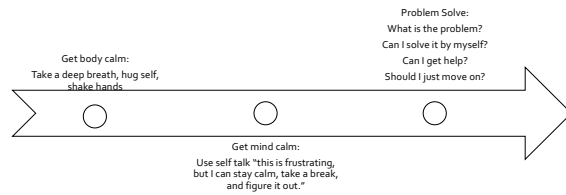
Some things stress me out

- Being rushed
- Having to repeat something in conversations
- Having to do a lot of stuff I don't want to do
- Writing if I have a hand cramp
- Math
- Being with new friends because I have to get to know them
- Loud noises when I'm trying to focus

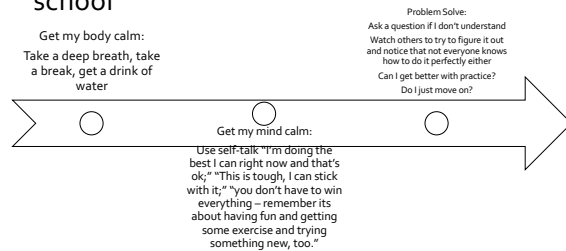
What Helps?

- Growth mindset
- Fidgets
- Clicking on a new thought
- Taking a pause or a break from what is bothering me
- Shaking my hands
- Hug myself - it helps me get ahold of myself
- Moving around, walk in circles
- Doing something fun

My guide for managing frustration at home



My guide for managing frustration at school



TALKING TO THE CLASS

A Social Story in Reverse

- Explain to others necessary information
- Communicate what they might expect and why
- Provide directions for how they can behave, respond
- Indicate how the person with ASD will respond in turn

A LITTLE BIT ABOUT JACK

A little bit about me

- I LOVE history, especially the Civil War
- I really like Social Studies and since I spend a lot of time reading about history and watching movies about events from history, I know a lot of interesting facts about what we're learning
- I love to share what I've learned with other people, because I get so excited about cool facts
- Sometimes I forget that other people want to answer questions and that the teacher wants to share certain information with the class
- Sometimes I like to keep talking about the Civil War, even at recess or lunch and I forget that other people have interests and cool stuff they want to talk about, too

How You Can Help

- Teachers can remind me that we have to move on by saying "We have to stick to the lesson plan today."
- I like it better when people are honest and say what they mean. It's easier for me than when I have to guess what I should do.
- Classmates can also be honest with me – if you don't want to talk about (or hear about) the Civil War, you can say, "let's change topics." That will remind me that I've become too focused on one topic and need to let other people talk about what they're interested in, too!

Time Alone

- Even though I try my best to stay calm in school, sometimes I do get very frustrated.
- When I am getting frustrated, even the tiniest things can build up to be really hard for me to deal with.
- I'm getting pretty good at learning to ask for a break. When teachers let me leave the classroom to get a drink or take a walk in the hallway, it helps me get some of my frustration out and to calm down.
- If I ignore you or walk away from you, please don't think I'm being rude. It may be that I'm just working hard to keep myself calm and I can't concentrate on being friendly at the moment.

Or, If You're More Tech Savvy

- Make a video!
- My Autism – by George
 - George Jolley, You Tube

DISCLOSURE FOR PROTECTIONS AND SUPPORT

In the School and Community

- Educational Services
- Protection relating to discipline for behavior
- Discrimination laws
- With law enforcement
 - Disclosure cards
 - Calling police to share information

In General

- Autism Canada (autismcanada.org)
- Provincial & Territorial Funding Programs for Autism Therapy
- Autism service directory (Autism Junction)
- The Canadian Autism Spectrum Disorders Alliance (CASDA)
- Working on a national ASD strategy for increased federal support
