Autism Spectrum Disorder 101 and Positive Support Strategies

For
Caregivers
and Family Members of People with ASD

ausm®

autism society of minnesota

Minnesota's First Autism Resource®

Table of Contents

- ASD 101: <u>What Is Autism</u>

- <u>Importance of Respite</u> for Caregivers

- <u>Positive Support Strategies</u> and Interventions

- <u>Glossary</u> of Terms

- Autism <u>Links</u>

This learning module was developed by The Autism Society of Minnesota (AuSM) in collaboration with the Dakota and Ramsey County Autism Grant and was made possible by funding from the Minnesota Department of Human Services.

ASD 101:
What Is Autism?

What Is Autism?

A neurodevelopmental disorder, or a "Pervasive Developmental Disorder"

- "Pervasive": Affects most parts of life

- "Developmental Disorder": Children are born with it and will have it all their lives. There is no cure (and many people with autism don't *want* to be cured)

- It's not a mental illness, not a disease, not contagious. *It's not the fault of parents.*
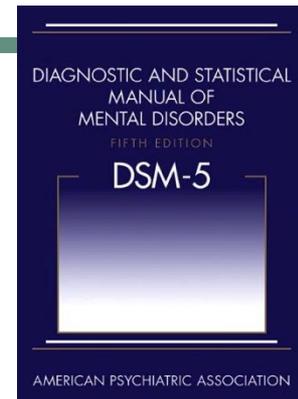
Autism Defined

The standard definitions of psychological conditions, including autism, come from the *Diagnostic and Statistical Manual* of the American Psychiatric Association, fifth edition (DSM-5)
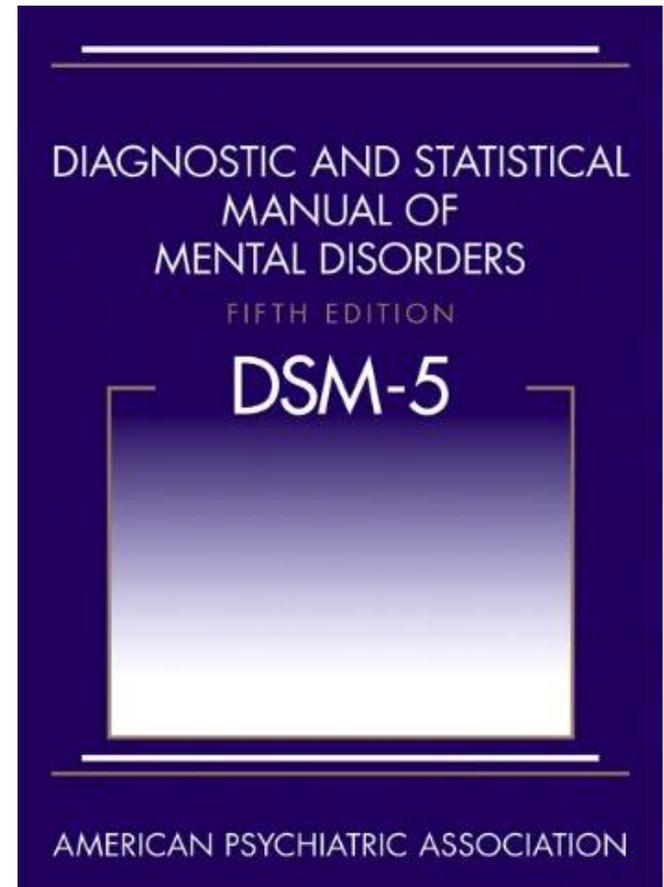
ausm
autism society of minnesota

A. Qualitative impairment in social communication and interaction:
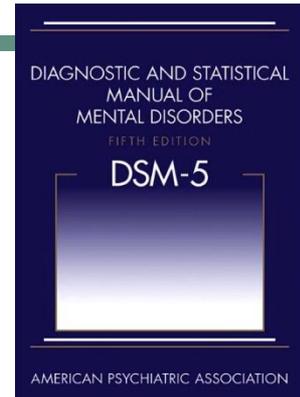
1. Deficits in social-emotional reciprocity

2. Deficits in nonverbal communicative behaviors used for social interaction

3. Deficits in developing and maintaining relationships, appropriate to developmental level

DSM-5 Criteria, Part B

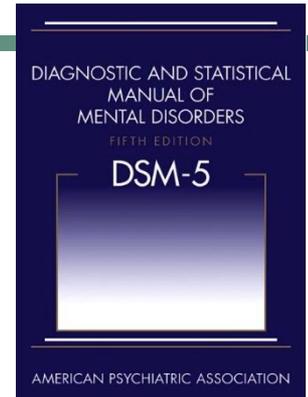**B. Restricted, repetitive patterns of behavior, interests, or activities (must meet two of four):**

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

2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change

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

4. Hyper- or hypo-reactivity to sensory input

DIAGNOSTIC AND STATISTICAL
MANUAL OF
MENTAL DISORDERS
FIFTH EDITION
DSM-5

AMERICAN PSYCHIATRIC ASSOCIATION

Restricted, repetitive patterns of behavior, interests, or activities, continued:

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

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

What This Means In Practice

- Challenges in communication, reciprocity, and social interactions
- Challenges with "Theory of Mind"
- Challenges with "Executive Function"
- Unusual Splinter Skills and Interests
- Challenges with emotions (e.g. meltdowns)
- Challenges with imagination (not creativity!)
- Sensory challenges
- Challenges with change and a reliance on routine

Communications Challenges

- About one person in six with autism has no functional speech.

- Echolalia is when a person mimics sounds and words, and can be immediate or delayed.

- Others may use stereotyped language

Echolalia: repeating what others say

ausm
autism society of minnesota
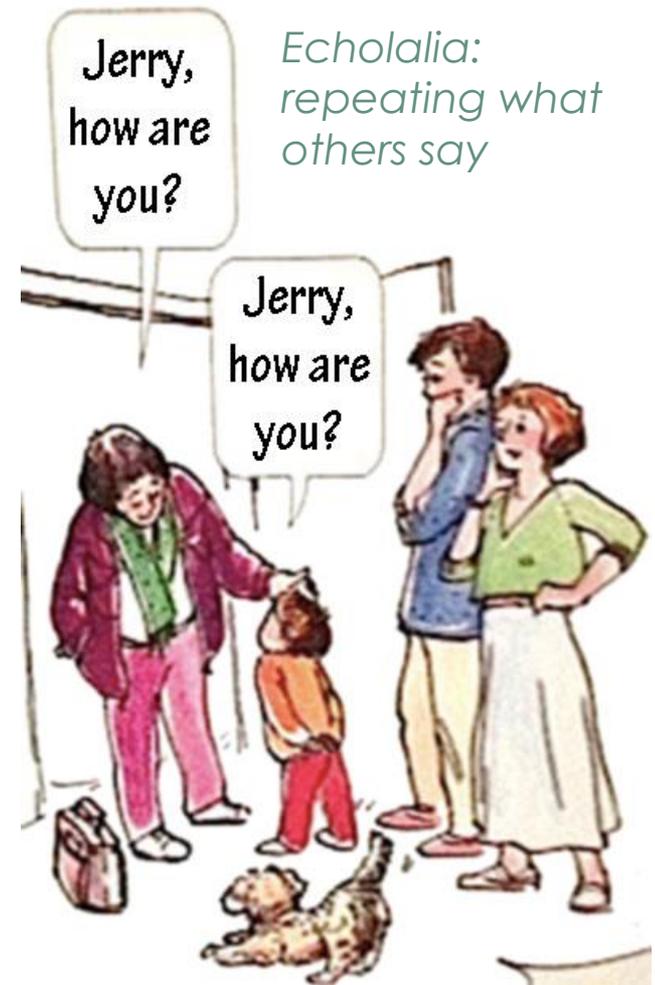
Communication Challenges

- Lack of "give and take" in conversation
- Unusual eye contact
- Lack of social expression, flat affect (unreadable face)
- Facial expressions, body language that don't reflect actual feelings
- Dislike of "small talk"
- Doesn't learn unwritten rules/social norms from their peers as easily

grizelda

"I don't believe I've bored you yet...."

Failure of Social-Emotional Reciprocity

People with autism often don't know what others want, and may not know when or how to take turns.

They may not respond to others' actions, or may respond too much; or may learn to repay, but not in the way others want.

Thanks for dusting my desk. I got you this.

Minnesota's First Autism Resource®

Failure of Social-Emotional Reciprocity

People with autism may not realize that what *they* want is not what others want.

I know you hate "Star Wars," so I got you eight "Star Wars" movies to help you learn.

A common example is failing to recognize others' personal space — standing too close to people they don't know, e.g.

"Theory of Mind"

"Theory of Mind" is the ability to understand that others have thoughts and knowledge that doesn't match yours.

"Neurotypical" individuals develop theory of mind typically between the ages of three and five, allowing them to better read others' minds and signals (non-verbal communication).

Some people with autism don't seem to realize that other minds exist; some know that minds exist but can't guess what they are thinking.

ausm
autism society of minnesota

What Happens If You Lack Theory of Mind?

- Difficulty explaining your own behaviors (don't understand how others see you)

- Difficulty understanding emotions (your own and/or others'). *About half of people with autism can't even identify their own emotions ("Alexithymia")*

- Difficulty predicting the behavior or emotions of others

- Difficulty empathizing/sympathizing with situations that haven't been experienced first-hand

What Happens If You Lack Theory of Mind?

- Challenges inferring the intentions of others (can't "mind read")
- Fail to realize that one's own behavior affects how others think and/or feel
- Challenges meeting or understanding social expectations
- Challenges differentiating fiction from fact (don't understand that people tell stories, or that people lie)

Executive Function

Executive Function is the ability to plan, organize, and execute ordinary tasks. In other words, knowing what to do *and getting up and doing it.*
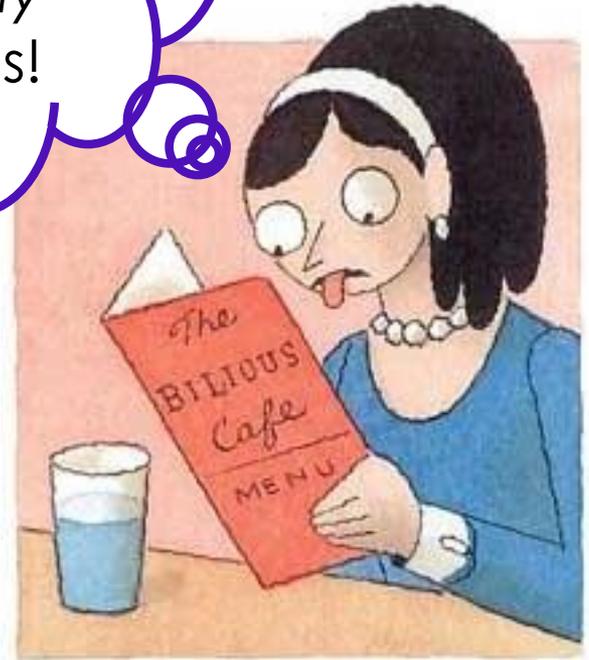
Executive Function

- Executive function is the set of mental processes that helps connect past experience with present action

- Basis for cognitive and social skills

- Needed for planning, organizing, strategizing, prioritizing, paying attention to/remembering details, and managing time/space

What If You Lack Executive Function?

- You may struggle to plan strategically (for future needs and successes)
- You may fail to estimate the time a project will take to complete
- You may struggle to communicate details in an organized, sequential manner
- You may struggle to memorize and retrieve information from memory

What If You Lack Executive Function?

- You may have trouble starting tasks or generating ideas independently

- You may not retain information while doing something with it (e.g., remembering a phone number while dialing; remembering what to do after finishing the current task)

- You may not be able to react to surprises in a timely way

Splinter Skills: Patterns in Development

- Most children, as they grow up, gain skills at a certain level — all their skills are at about the same percentile. This is "typical development."

- Some children gain skills more slowly than typical peers, but gain all the different skills at the same rate. They are slow, but have the same pattern as peers. This is "delayed development."

- Some children, including those with autism, gain certain skills far more completely than others. This is "disordered development":

ausm
autism society of minnesota

Splinter Skills: Patterns in Development
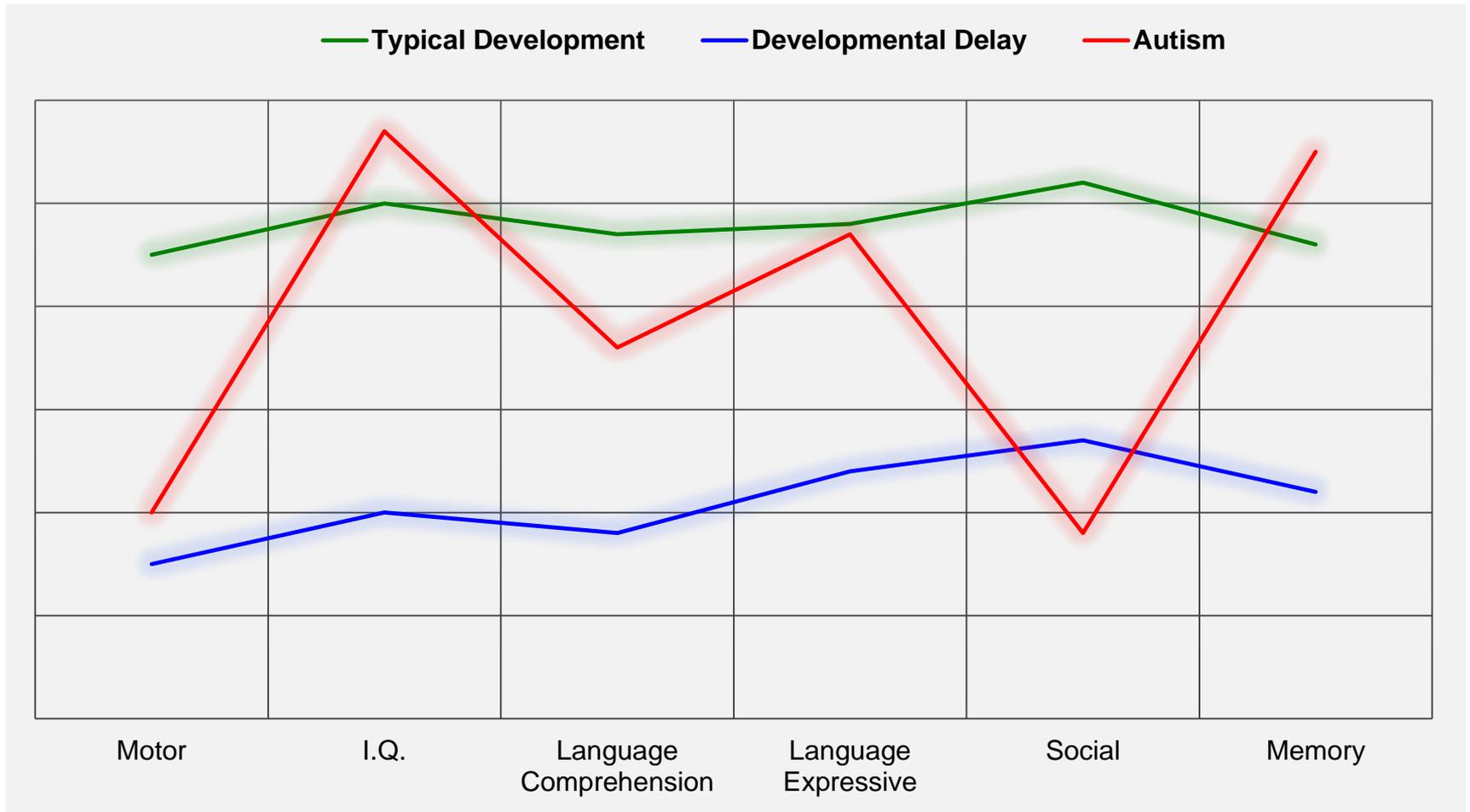
Note how the *typical* and *delay* lines are almost straight, but the *autism* line is "crooked."

Minnesota's First Autism Resource®

© 2018 Autism Society of Minnesota

What Are Splinter Skills?

Splinter skills means having a specific ability without having related skills.

- A person may have an ability *far in advance of what is expected at one's age,* or

- A person whose abilities are otherwise normal may *lack* a skill commonly found

People with autism are often asked, "If you're so smart, why can't you...."

Splinter Skills Examples

The prime factors of 969 are 3, 17, and 19

- Someone who can do advanced math but can't tie her shoes

- Someone who speaks five languages but can't order from a menu

- Someone who can play a piano concerto by ear after one hearing but can't talk

ausm
autism society of minnesota

Sensory Sensitivities

It's too *loud!*

It's too *bright!*

It *smells bad!*

People with autism are often *hypersensitive* or *hyposensitive* — they may *seek* sensations or *avoid* them.

Sensory Sensitivities

We have more than five senses, and a person with autism may have sensitivity in any of them — often in more than one:

1. **Sight**
2. **Hearing**
3-4. **Smell, Taste**
   (operate as one sense)
5-6. Touch (two separate senses):
   Pressure
   Temperature

7-9. *Body senses:*
Vestibular
   (balance)
Proprioceptive
   (body position)
Interoceptive
   (internal sensations)

ausm
autism society of minnesota

Emotions and Emotional Regulation

- People with autism often have strong emotions which can be misunderstood: unquestioning loyalty, truthfulness, extreme friendships, excessive sense of rejection

- Because people with autism may show emotions differently, or not recognize their emotions, you may be shocked by what seems a sudden change *(meltdowns)*

Black and White Thinking and Perfectionism

Many people with autism think that if something isn't perfect, it's no good it all (and may never finish anything as a result).

Imagination

People with autism often have trouble with imagining consequences — that is, foreseeing the results of action. They often get in trouble as a result.

This is not the same as lacking creativity; many are extremely creative.

TYPICAL INVENTOR — FAILING TO SEE THE CONSEQUENCES OF HIS OWN CREATION.

CHRIS MADDEN
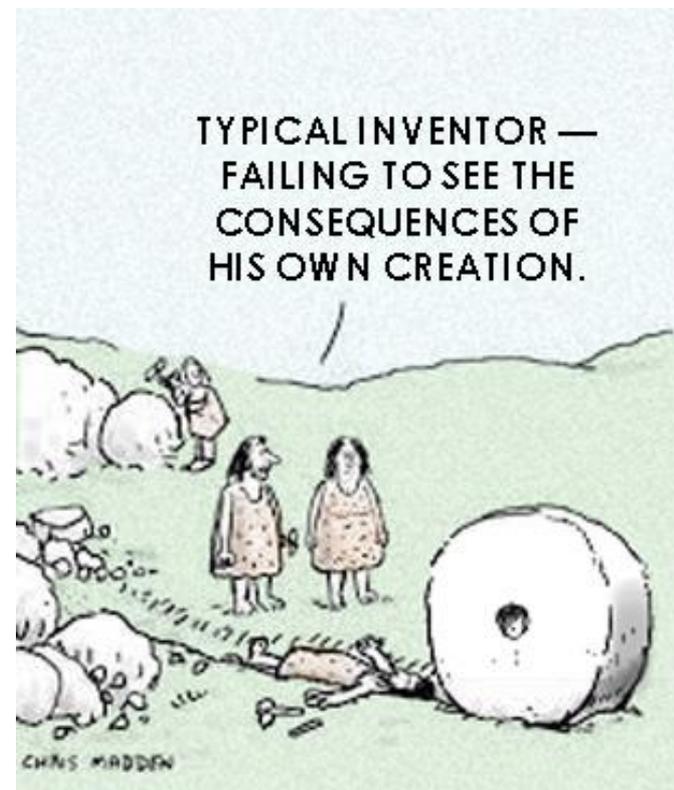
Need for Routine

Deficits in imagination result in stereotyped behavior:

- – Dependence on highly structured activities
- – Obsessive about a topic or interest
- – Strict adherence to routine or steps
- – Need for self-stimulation for self-calming: Rocking, Pacing, Flapping, etc.

Special Interests

"Oh, don't mind Neville. He's always working on some project or another."

- Often involve something obscure and "boring"; may change over time
- Can involve graduate-level expertise (but doesn't always)
- Can be used as a motivation to change behavior

Literal Thinking

People with autism may have trouble with metaphor and non-literal language, open-ended or *implied* questions or idioms.

ausm
autism society of minnesota
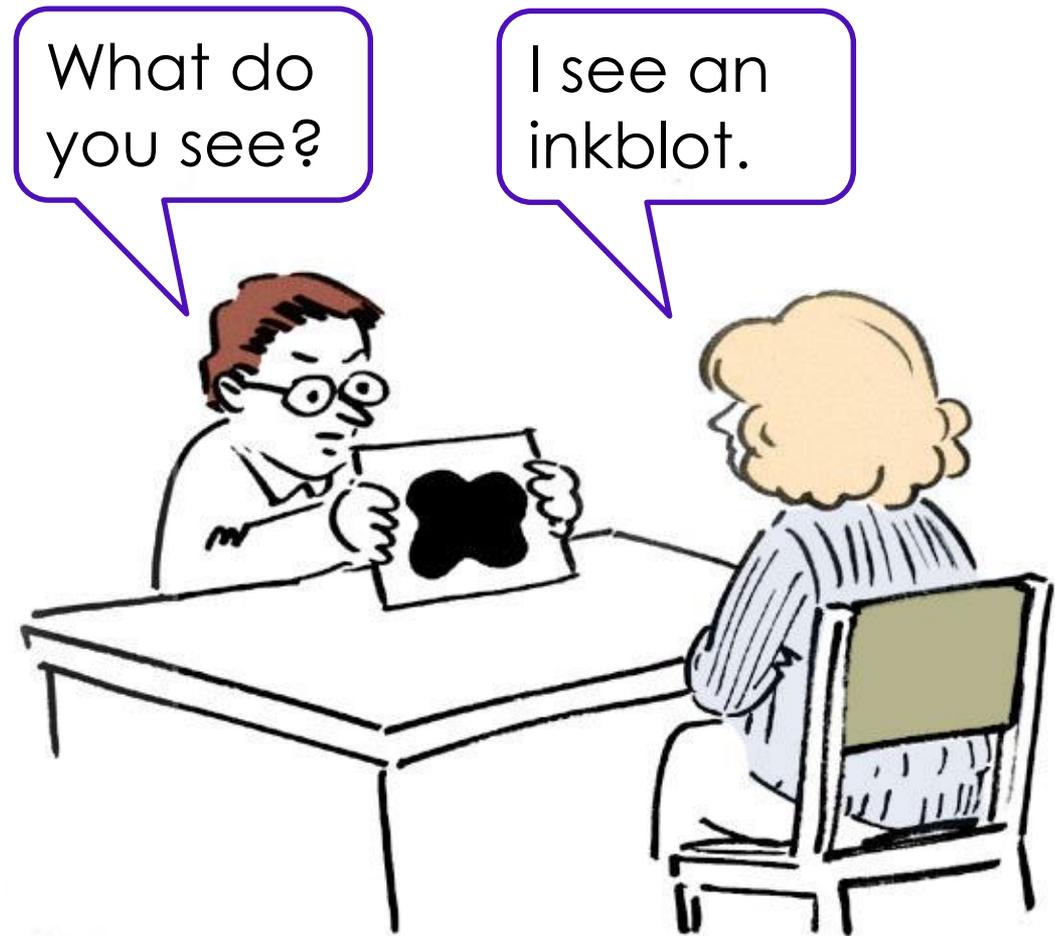
Repetitive and Stereotyped Behaviors

Often called "stimming"

- Hand-flapping
- Jumping
- Rocking
- Spinning
- Swinging
- Repeating words
- Use of fidgets

This Doesn't Mean They Don't Like People

Having autism doesn't mean not liking people, it means not understanding people very well.

Will you be my friend? No one else here will.

Some False Stories about Autism

- People with autism have no empathy
- People with autism are all savants
- People with autism are all stupid
- People with autism are all boys or have "extreme male brains"
- Autism is caused by vaccines, parents, LED lights, something. *Many things cause autism, but mostly genes.* There is no single, simple cause of autism.

Minnesota's First Autism Resource®

Brain Physiology in Autism

Brain scans show that the brains of people with autism aren't like "neurotypical brains" — *but they aren't like each other either.* We say, "When you know one person with autism, you know… one person with autism." When you know one brain with autism, you know one brain with autism, too.
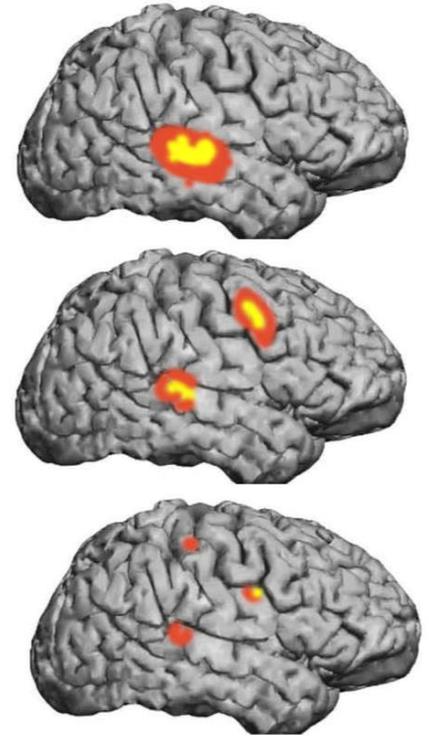
Scans showing how the brain of one neurotypical person and two people with autism respond to hearing words

ausm
autism society of minnesota

Autism Is a Spectrum

- Not all people with autism are alike — no two people with autism are alike!

- Autism is a spectrum — but not a spectrum from "not too bad" to "very bad."
  Abilities in a particular area may range from extremely limited to extraordinary.

- Some people with autism live independently; some do not.

- *All people have skills to contribute!*
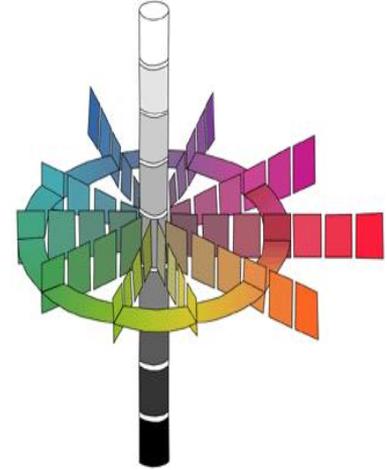
History and Prevalence

The term "autism" was first applied by Leo Kanner in 1943.

(Hans Asperger also found it in the 1940s.)

Kanner thought it was a rare condition, found in only a few children in a hundred thousand.

Now it's found in **1 in 59**.

2018 Prevalence:
NUMBER OF CHILDREN IDENTIFIED WITH ASD
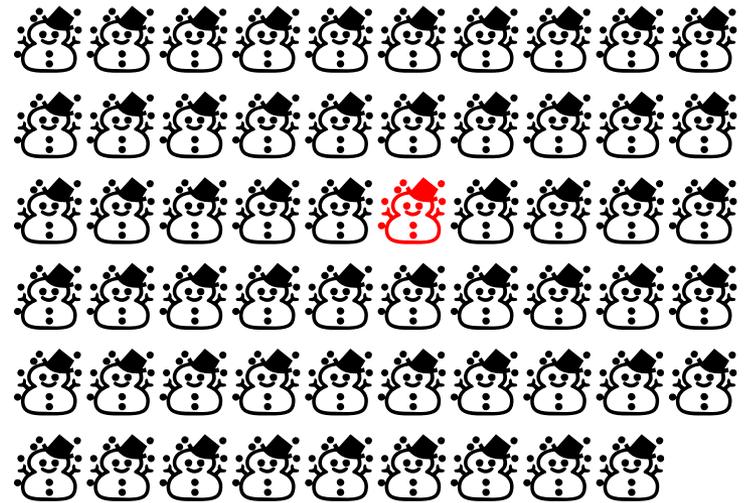
1 in 59

Prevalence, Continued

- Affects all racial, ethnic, & economic groups; income, lifestyle, education do not affect chances of having ASD

- Boys: 4.5x more common than in girls
  - 1 in 42 boys, 1 in 189 girls (CDC, 2016)

  But odds are that the difference is not really that high; rate in girls is increasing 75% faster than in boys; girls are often better at hiding symptoms; plus there is diagnostic bias (looking for it more in boys than girls).

ausm
autism society of minnesota

Comorbid Conditions

DSM-5 says at least 70% of those with ASD have a comorbid psychological condition. Our experience is that it's even more than that. Many conditions are much more common in the ASD population:

Legend: ■ In Those With ASD ■ In General Population

Categories (left to right): Anxiety, Depression, Sleep Disorder, Gastro-Int'nal, Seizures, ADHD, Intellectual Dis., Miscellaneous
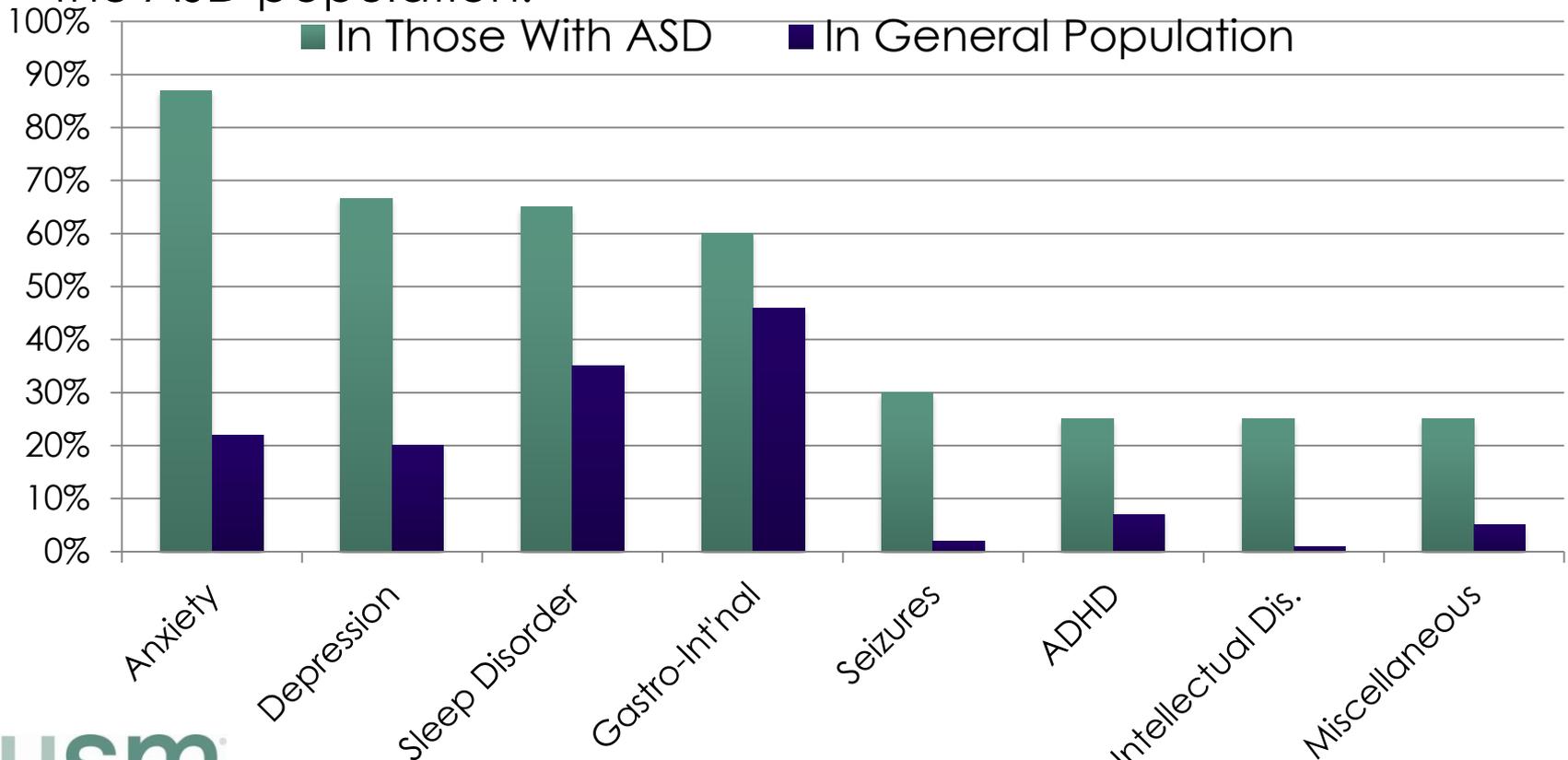
Effects of ASD on Life

- Only 30% of adults diagnosed with ASD are employed (many more are **under**employed)

- Marriage rate is below general population

- Life expectancy is below general population by 20+%

- Suicide rate is 9x general population

The two most common questions in ASD support classes

How do I get a job?

How do I get a date?
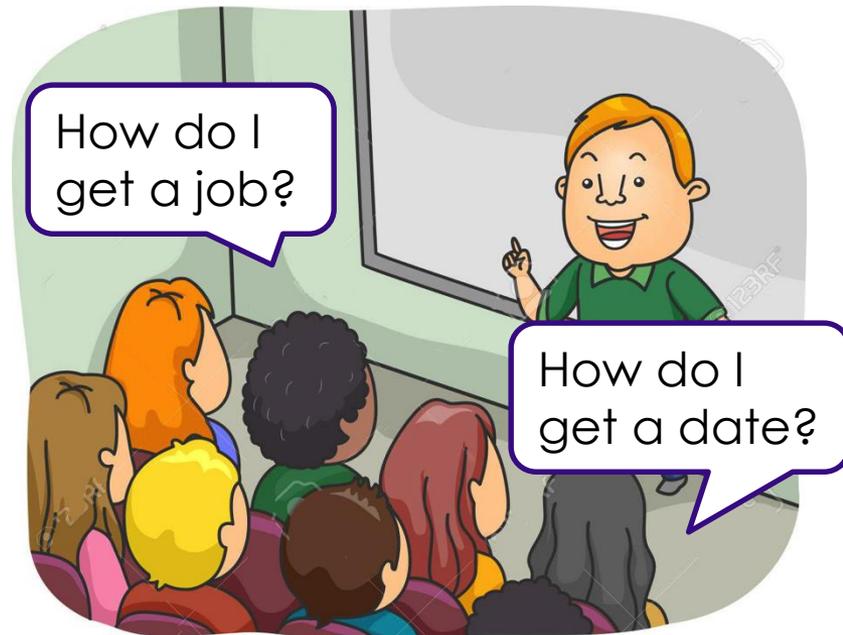
Treatments

There is no cure for autism, but there are ways to help with specific challenges:

- Cognitive Behavioral Therapy for psychological challenges

- Applied Behavioral Analysis for problem activities

- Sensory therapy, Occupational therapy

- Reasonable Accommodations (as defined by the Americans with Disabilities Act)

- *Supports…(see next page)*

Supports

- Reminders such as schedules, planners, lists
- Visual tools such as timers, visual menus, match-to-sample templates
- Teaching methods such as video modeling, PowerCards, Social Stories™ Smartphone, tablet, laptop apps
- Emotional regulation tools such as the Five Point Scale (www.5pointscale.com)
- Note: See the *Positive Support Strategies* section or the Links page for more.

Getting a Diagnosis

- A diagnosis is given by a trained therapist. Contact your health care provider to arrange an evaluation.*

- Before the first session, gather as much data as you can: results of past assessments and diagnoses, school information, etc.

- In diagnosing adults, try to find people who knew them as a child and can describe their childhood symptoms, as well as people who know them today. Descriptions by people who know them are a key part of a good diagnosis.

* NOTE: An educational determination of disability not the same as a medical diagnosis. To qualify for county or state services, a person must have a medical diagnosis and meet all other eligibility requirements.

Importance of Respite Care

Why Respite Care for Autism?

- In the United States, one child in 59 has autism.

- That means that Minnesota has about 95,000 people with autism — and more than 20,000 children with autism.
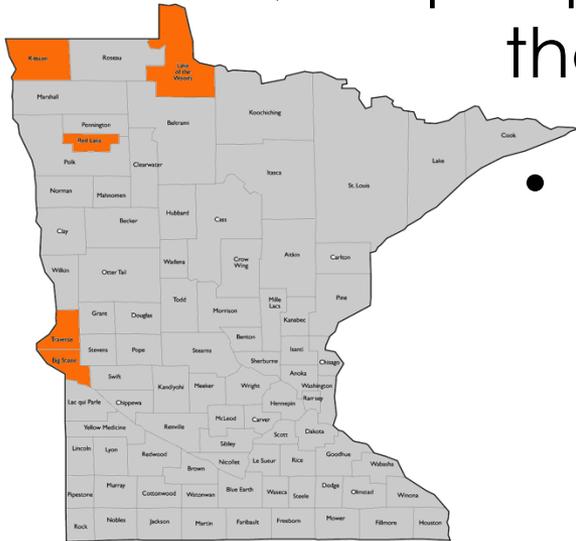
  - That's more people with autism than the entire population of Bloomington or Duluth, and as many children with autism as the population of five counties *combined!*

Why Respite Care for Autism?

- Many people with autism have emotional regulation difficulties

- Many people with autism have difficulty in social situations

- Many people with autism need regular care

Their parents and families need a break!

autism society of minnesota

For Families: What Is Respite Care?

Respite is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

Respite may last a few hours or a few days.

ausm
autism society of minnesota

For Families: Who Receives Respite Care?

- Many people can use respite care:
  - People with disabilities
  - People with ASD
  - The elderly or the ill.
- Individuals may be any age or at any ability level.
- *The amount of respite provided corresponds to the level of support needed.*

ausm
autism society of minnesota

For Families: Where Does Respite Occur?

Respite can be provided in the individual's home *or* out of the individual's home in a variety of settings, such as:

- Camp
- Hotel
- Family foster care home
- Residential facility/corporate group home
- Community recreation settings (parks, museums, sporting events, etc.)

What Activities Take Place During Respite?

This depends on the needs of the individual being supported. Typical activities include:

- Recreational opportunities
- Community activities
- Support with daily living skills
- Positive behavior supports

Why Is Respite Important?

- Being a caregiver can be exhausting both mentally and physically.

- Caregivers tend to put the needs of others before their own — and do not take care of their own needs or the needs of others in the family.

- This can cause stress in the family relationships.

- Everyone needs time to decompress.

Some parents say that respite care saved their marriages or family because they had time to be together by themselves

ausm
autism society of minnesota

What Do Caregivers Do During Respite?

Anything they want! — or nothing at all:

- Spend time with other family members
- Go shopping
- Go to a movie
- Go to the gym
- Do a household project
- Stay at a hotel
- Sleep

It doesn't matter, just as long as they aren't caregiving.

What If A Family Is Worried During Respite?

- It is totally normal to be worried. It's hard to give up control!
- It is especially stressful when your child is with a new respite provider.
- They are leaving a loved one with someone else. *No one knows and cares for the loved one like they do.*

Reducing Anxiety for Family

- Families and respite providers should get to know each other.

- If respite will be provided in the family home, the provider should get to know the child, the family, and the home.

- Get together for a meal, or for part of the day, or join each other for a community activity.

The goal is to make everyone more comfortable!

Reducing Anxiety for Family

Watch and listen to how they interact with their child. Try to respond in the same way — work to understand the person for whom you will be caring. Try to understand the person behind the autism, and also show that you accept the person's autism.

Respite Providers and Funding

Respite may be provided by:

- A licensed agency or family foster care provider
- A neighbor or family friend
- Unlicensed community organizations

Many of these services have a fee, which may be covered by:

- Disability services programs (Home and Community Based Waivers, Consumer Support Grant, Family Support Grant, etc.)
- Children's Mental Health Services through the county

Locating Respite Services

There are several sources of information on respite providers:

- MinnesotaHelp.info is a searchable database of licensed providers

- Case managers can refer you to providers

- Many counties maintain directories that include local community resources. Dakota County's Recreational Directory: https://www.co.dakota.mn.us/HealthFamily/Disabilities/Services/Documents/RecreationalDirectory.pdf

- ARCH National Respite Network and Resource Center's Respite Locator https://archrespite.org/respitelocator

Often the most effective method is looking at who you already know that may be able to provide respite care.

Tips for Families

Families will have better experiences if they do their homework and gather information:

- Get to know the person or organization that will be providing respite

- Go see the setting where it will take place.

- If services will be provided by an organization, learn their policies regarding background checks and staff training.

- Seek references from other families who use their services

But the Most Important Thing Is:

Providers need to show that they understand the person and how best to support them.

The next section provides an overview of strategies that are effective for supporting people with an Autism Spectrum Diagnosis.

Positive Support Strategies & Interventions

Choosing a Strategy

People with autism often have trouble understanding life situations. This section will describe some evidence-based methods to improve communication.

- Communication should be detailed, literal, unambiguous, and should not make assumptions about what the person with autism knows
- Communication should be based on the abilities of the person

Explaining What to Do: Social Narratives

When you want to explain something that's going to happen, or describe how to do something, a Social Narrative or "Social Story"™ is a good tool.

- Describe upcoming events
- Describe reoccurring situations
- Explain expected behavior
- Explain others' emotions (when appropriate)

Sample Social Narrative: The Library

- I am going to the Library.
- At the Library I will talk in a quiet voice, so others can focus.
- I can choose three books to check out.
- I will take my chosen books to the front desk.
- I will give my Library Card to the Librarian.
- The Librarian will check out my books, which I can take home for two weeks.

Avoid Idioms and Ambiguity

Example:

- *Don't* say "I'm going to drop on him like a ton of bricks."

- *Do say, "I'm going to tell him clearly what he did wrong."*

Language should be concrete, literal, "positive," and explanatory.

ausm
autism society of minnesota

Use Positive Language: What *To* Do

What's wrong with these instructions? They all say what *not* to do, not what *to* do.

Explaining What to Do: Video Modeling

Make a video of a behavior you want to teach. Use the person you are trying to teach for as much of it as possible. Use digital technology to piece together parts the person hasn't learned.

Video Modeling Advantages

- Can work even for those who don't understand words

- Can show *all* parts of the task

- For people who think visually, easier to process and remember than words

- If properly edited, can appear to show the person with doing the task, so the person can *believe* he or she can do it!

ausm
autism society of minnesota

Executive Functioning: Time Management

Many people with autism have trouble keeping track of time.

A timer can help a person track time and know how much more time there is until the next task.

autism society of minnesota

Executive Functioning: Visual Schedules

- A visual schedule can make it clear what things will happen in what order. Try using velcro stickers to make one you can change regularly!

ausm
autism society of minnesota

Executive Functioning: Planners/Schedules

An ordinary schedule allows longer-term planning.

	1	2	3	4	5	6	7	8	9	10	11	12	13
7:30-7:45		breakfast	breakfast	breakfast	breakfast	breakfast	breakfast	breakfast	breakfast	breakfast	breakfast	breakfast	breakfast
7:45-8:45	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music	specials: M/W/Th: gym, Tu: art F: music
8:45-9:00	morning group/DI							quiet reading	quiet reading	language	language	reading	reading
9:00-9:15	break							reading	reading	quiet reading	quiet reading	language	language
9:15 -9:30	work	morning group/DI	morning group/DI	morning group/DI	AM Routine	AM Routine	AM Routine	language	language	reading	reading	quiet reading	quiet reading
9:30 - 9:45	break	break	reading	language									
9:45 - 10:00	sensory	work	language	reading	morning group/DI	morning group/DI	morning group/DI	AM Routine	AM Routine	AM Routine	AM Routine	AM Routine	AM Routine
10:00 - 10:15	break	break			language	reading	reading						
10:15 - 10:30	work	work	factory	factory	quiet reading	language	reading						
10:30 -10:45	break	break			reading	quiet reading	language	morning group/DI	morning group/DI	morning group/DI	morning group/DI	morning group/DI	morning group/DI
10:45 - 11:00	work	work	break	break	break	break	break						
11:00 - 11:10	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition	bathroom/ transition
11:10 - 11:35	recess	recess	recess	recess	recess	recess	recess	recess	recess	recess	recess	recess	recess
11:35 - 12:00	lunch	lunch	lunch	lunch	lunch	lunch	lunch	lunch	lunch	lunch	lunch	lunch	lunch
12:00 - 12:15					table time & break	table time & break	table time & break	table time & break	table time & break	table time & break	table time & break	table time & break	table time & break
12:15 - 12:30													
12:30 - 12:45	work/break with Ms. Carl		301: break, work station, art	301: break, work station, art	work station	work station	work station	math group (403)	math group (403)	math group (403)	math group (403)	math group (403)	work station
12:45 - 1:00		break			science	science	science						science
1:00 - 1:25	table time	table time	table time	factory	math group (301)	math group (301)	math group (301)	social studies	social studies	social studies	social studies	social studies	math group (301)
1:25 - 1:45	break	break	break	math group (301)	social studies	social studies	social studies	science/work station	science/ work station	science/ work station	science/ work station	science/ work station	social studies
1:45 - 2:00	work	work	factory										
2:00 - 2:15	break	break	break	break	break or inclusion	break or inclusion	break or inclusion	break or inclusion	break or inclusion	break or inclusion	break or inclusion	break or inclusion	break or inclusion
2:15 - 2:30	work	work											
2:30 - 2:45		home	home	home				home	home	home	home	home	home

Executive Function: Defined Choices

For a person who has difficulty making decisions, offering a limited set of choices can make decisions much easier. It also lets the person know which choices are possible.

Here again, *velcro is your friend!*

Sensory Integration and Regulation

Many undesirable behaviors are caused by sensory issues. Dealing with the issues can deal with the behaviors. Examples:

- Having the person do wall pushups

- Noise-cancelling headphones

- Sunglasses, hats

Sensory Integration and Regulation

More sensory integration tools:
- Fidgets
- Weighted blankets

Routines and Transitions

- Establish routines for starting an activity
  - Process for getting materials
  - Consistent first step
- Structured transitions
- Scheduled breaks
- Reinforce flexibility
- Recognize and announce changes in routine. *Social stories™ are good for this.*

Rules and Boundaries

Teaching with consistent language
- – Safe vs. Unsafe
- – Appropriate vs. Inappropriate
- – Expected vs. Unexpected
- Color coding can help person understand

ABSOLUTE RULE

MAKE A DEAL

YOUR CHOICE

ausm
autism society of minnesota
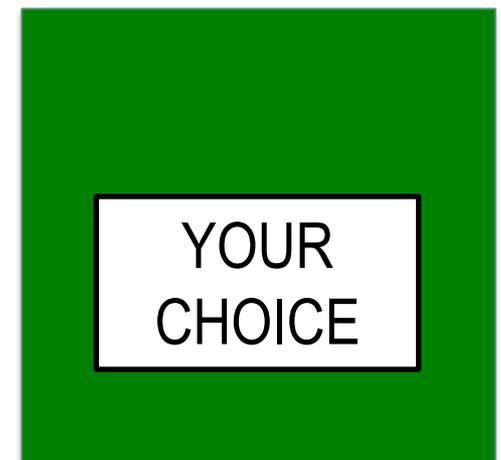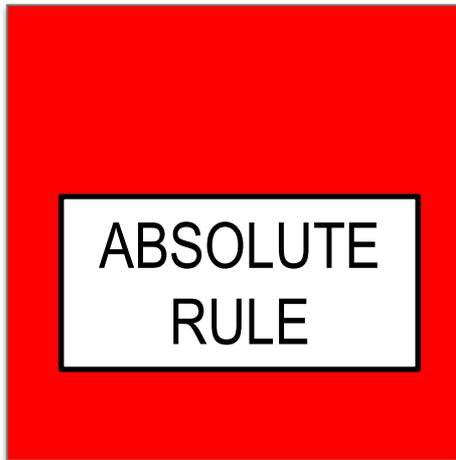
Socialization: Understanding Relationships

The "Relationship Circle" can help define and explain boundaries. You can do more things with those near the center of the circle than those in the outer rings.

Relationship Circle showing concentric rings labeled (from outer to inner): Strangers, Acquaintances, Friends, Close Friends, Family, ME.
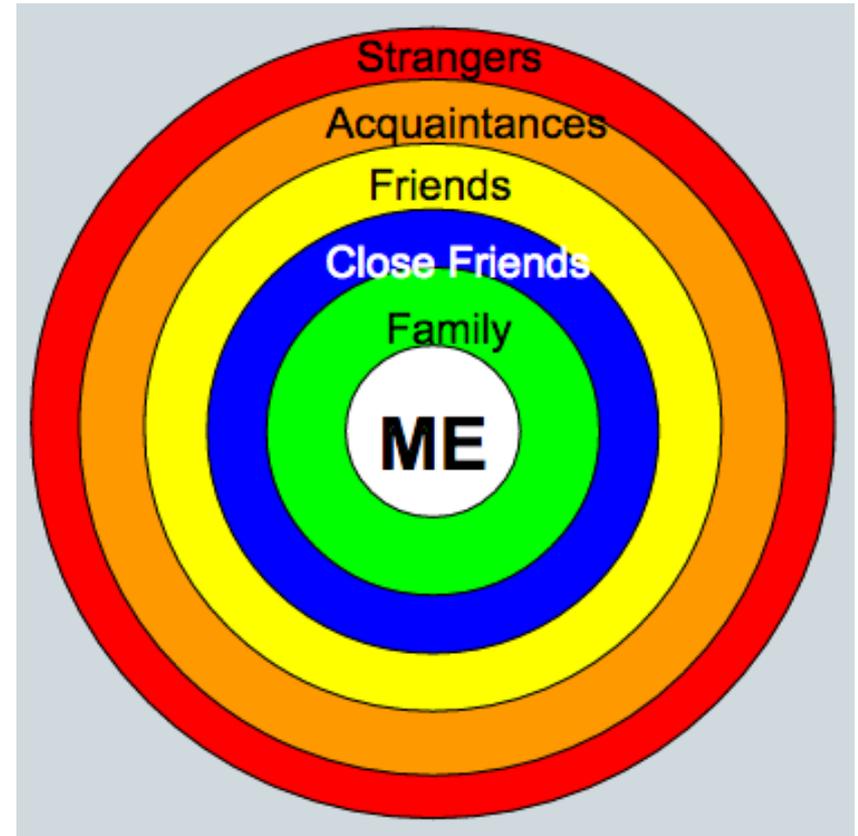
More Proactive Strategies

- Chewy Candy and Gum
- Utilize special interests to redirect
- Music
- Squeezes vs. light touch
- Therapy Balls/Bouncing
- Going for a Walk
- Changing the environment
- Changing the person giving directions
- Show, Don't Tell

- Visual Cues (Written or Pictures)
- Using preferred subjects and characters
- Body Language and Positioning
- Pre-teaching/staying one step ahead
- Positive Language
- Not getting into power struggles

Cognitive Behavioral Therapy

- A great tool for helping people with autism (or without autism!) is cognitive behavioral therapy

- CBT looks at what people are doing, what motivates those actions, and tries to address that underlying motivation

- There are many applications for CBT that can be used without formal training

Cognitive Behavioral Therapy, Continue

- Main feature of CBT: Use rational thought to manage feelings
- Example: 5-Point Scale. *Measure feelings and have a strategy to respond. This lets you know when a feeling is out of control.*
- Application: Describe emotions, physical feelings, and strategies. Specific or general.

ausm
autism society of minnesota

The Five Point Scale, Examples

	On an anger scale, this might mean:	On a "how loud is my voice?" scale, this might mean:
5	Furious, out of control, dangerous. Total meltdown.	Screaming. You're making people's ears hurt.
4	Very angry. Not able to think or learn.	Loud enough that your hearers are uncomfortable.
3	Irritated. Snappish.	A little too loud. Quieter would be better.
2	A little bit irked, but still rational.	Conversational level
1	Calm and happy.	Whisper, or not talking at all

Using the Five Point Scale: Have a Plan!

- There is a book, *A 5 Is Against the Law*. What does a 4 or 5 look like in each person you work with?

- What do **you** do when you get to a 4 or a 5?

- Do you have a de-escalation technique? Can you teach one?

- Can this plan be integrated into a formal BIP?

ausm
autism society of minnesota

The Anxiety Curve

The Anxiety Curve (next slide) is a variant of a Five Point Scale showing the stages of an emotion (e.g. anger, anxiety) over time. Note that:

- Once you reach a 4, you can't just calm down. You have to hit your peak and *then* calm down.

- You can't teach or learn at a 4 or 5 Don't try. Just wait for it to end.

This could include hitting, throwing, biting, swearing and crying

This is peak anxiety. It is not a time to talk, direct or problem solve

5

This is not a time to ask the person to make choices. Model calming strategies

4

Redirection here can result in a ripped assignment. The person should be encouraged to relax rather than make any decisions

4

3

Use encouraging, supportive words here. If possible, don't discuss the incident.

3

This is where signs of early stress need to be recognized. This is the best time to refocus the person's attention away from the stress.

Now is the time to leave the anxiety producing event if possible

Use calm redirection here

2

2

This is the staff or parent curve. You need to control your own anxiety during a crisis in order to help to diffuse the person's anxiety. Your instincts tell you to engage in fight or flight, you can do neither. Use silence and your own calming sequence.

1

1

This is the foundation of your plan. This is where positive and valuing relationships are built and where you teach skills needed to function successfully in challenging situations. Examples might include the 5-point scale, Social Stories, Power Cards, a calming sequence, yoga, or social skills.

Tips For De-Escalating

- Slow down
- Be aware of signs of increasing anxiety (frequent questions, stimming)
- Limit the use of language, use visuals if possible
- Model the calm behavior you want to see
- Affirm the feelings, not the behavior ("I'm sorry that happened, I would be upset too.")
- Use "First/Then" (First take 5 deep breaths. Then we can discuss.)

The End.
Congratulations!

GLOSSARY: Some Words to Know

Using the Glossary

- The glossary contains more than sixty autism-related terms. Links for some of these topics are on the Links page.
- In the entries below, a * marks a word defined elsewhere in the glossary.
- Main entries marked † are linked to a page in the presentation. These pages do not always explain everything about the term in the glossary, but serve to illustrate it.

An Autism Glossary: Aa-Ar

ADHD: See *attention-deficit hyperactivity disorder.*

Affect, Flat Affect: Affect is the non-verbal expression of emotions — facial expressions and the like. "Flat affect" is the lack of these signs of emotions, e.g. by failure to show facial expressions or a monotone voice. Some, not all, people with autism, have flat affect (but still feel emotions!).

Alexithymia: fancy Greek term meaning "no-word-(for)-feelings," i.e. the person who has it can't describe his or her own emotions

Antecedent: That which precedes, and is assumed to induce, a *behavior.

Anxiety, anxiety disorder: An anxiety disorder is the state of being anxious much of the time and in situations where most people would not be anxious. Most people with autism have *comorbid anxiety, usually social anxiety or general anxiety.

Applied Behavior Analysis: A tool for understanding and changing the behavior of someone with autism. See *Behavior Theory.

autism society of minnesota

An Autism Glossary: As-B

ASD: Shorthand for "Autism Spectrum Disorder." See *autism.

Asperger's Disorder/Syndrome: Term used in the *DSM-IV for people with autistic traits but no major language problems. In practice, synonymous with "high-functioning autism." The name was eliminated from the DSM-5, because there was no way to distinguish those with Asperger's from those with "high-functioning autism," but some people who were given the Asperger's diagnosis still prefer to use it.

Attention-deficit Hyperactivity Disorder: A disorder marked by inattention or inability to keep one's attention focused. Often called "ADHD." Many people with autism have ADHD traits, and vice versa, and many of the same supports work for both conditions.

Autism†: Now properly labeled "Autism spectrum disorder" (shorthand form "ASD"). A neurodevelopmental condition marked by deficits in social communication and by repetitive behaviors.

An Autism Glossary: B

Behavior: As used in *Applied Behavior Analysis, a term for any observable and presumably volitional activity by the person being studied. Behaviors are not good or bad (although you may find them desirable or not), and they should not be confused with the reasons for the behavior. See *Behavior Theory*

Behavior Theory: A psychological model based on observing what people do rather than what we believe they are thinking. Behavior theory consists of looking at what someone does (the *behavior), examining what comes before (the *antecedent) and what results (the *consequence), as well as trying to understand why the behavior continues. By this means, it seeks to change behaviors with undesirable effects. For people who cannot communicate, this is the primary means of therapy. See also *Cognitive Behavioral Therapy. For some behavior terms, see *Antecedent, *Behavior, *Consequence, *Function, *Punishment,* Reinforcement.

An Autism Glossary: C-De

Classic Autism: Often used for those whose *autism is relatively obvious and disabling, e.g., those whose speech is severely affected. Compare "Kanner's autism."

Cognitive Behavioral Therapy (CBT)†: Form of therapy which has been shown to be best in dealing with the problems of autism, based on examining what the person is thinking, and how it interferes with life, and creating an alternate way of thinking and acting. *CBT, and its relatives such as ACT, are the only forms of therapy which have been shown to work with autism;* some others, such as psychodynamic therapy, may do more harm than good.

Comorbid, comorbidity†: Two conditions are comorbid if they both occur at the same time. So if a person has both *autism and an *anxiety disorder, the person has comorbid autism and anxiety. Anxiety is almost always comorbid with autism, and *depression is frequently comorbid as well.

Concrete Thinking: see *Literal thinking*

ausm
autism society of minnesota

An Autism Glossary: Da-De

"Dedicated to Autism": A term sometimes used for those whose autism is relatively obvious: "He can't talk; he's very dedicated to his autism."

<u>Defined Choices</u>†: Making it clear (often with a visual menu) what choices are available, e.g., if the choices for dessert are pie and ice cream, say "Do you want pie or ice cream for dessert," not, "What do you want for dessert?" (which might get an unexpected answer).

Depression: The *DSM defines a range of depressive conditions (Major Depressive Disorder, Persistent Depressive Disorder, etc.) marked by low mood and other symptoms such as change in appetite and sleep. People with autism often have *comorbid depression.

Developmental Disorder: A Disorder which is present from birth and affects all stages of life, as opposed to something like Post-Traumatic Stress Disorder, which (although there seems to be a biological predisposition) arises as a result of life events.

An Autism Glossary: Di-DZ

Disorder: In the language of the *DSM, a mental condition which causes behavior not usually found (at least to the same degree) in "normal" people. Disorders thus include such things as Major Depressive Disorder, various Personality Disorders, and of course Autism Spectrum Disorder. ASD is a *developmental disorder, meaning that it is there from birth and affects many aspects of growth and social function

DSM: Diagnostic and Statistical Manual of the American Psychiatric Association. The guidebook for diagnosing autism and other conditions. Current edition is the DSM-5, i.e. the fifth edition. Most diagnoses of autism (and its deprecated relative, Asperger's Syndrome) come from the DSM-IV (the fourth edition) or DSM-5.

autism society of minnesota

An Autism Glossary: E-Fi

Echolalia†: Greek for "echoing-speech," which is what it is: a person with echolalia repeats things he or she heard, now or in the past.

Emotional Regulation: The ability to recognize emotions and keep them from going out of control. Many people with autism have trouble with emotional regulation — hence meltdowns and tantrums. The *Five Point Scale is a very effective tool for emotional regulation.

Executive function†: The ability to manage time and tasks, and to make decisions. The ability to *get up and go*. It is linked to the lack of *imagination. It is vital to living a full life. A key deficit in autism.

Fidget: A toy or tool which a person can manipulate to relax. Fidgets can often be part of *stimming.

Five Point Scale™: A method of measuring and teaching *emotional regulation, based on learning to recognize symptoms of dysregulation and knowing when to employ a calming strategy.

ausm
autism society of minnesota

An Autism Glossary: Fl-H

Flat Affect: *see Affect*

Function: In *applied behavior analysis, the reason why a person undertakes a *behavior. Note that the function is always inferred; you cannot just assume you know why a person with autism does something!

Functionality: We sometimes speak of people with "high-functioning" or "low-functioning" autism. While it is true that some are better at living in society than others, *all* people with autism have strengths and weaknesses. If you call someone high-functioning, you ignore the weaknesses; if you say someone is low-functioning, you ignore the strengths. AuSM discourages functionality labels.

High-functioning Autism: see *functionality

An Autism Glossary: I

Idiot Savant: Strongly deprecated term (for obvious reasons). See *savant.

IEP — Individual Education Plan: All children with disorders are supposed to have these, to assure they are properly educated. Be prepared to hear parents complain about them.

Imagination†: In an autism context, refers to the ability to understand the consequences of action. "Foresight" might be a clearer word.

Imitation: The ability to do as others do. An important tool for fitting in socially. People with ASD, especially men, are often poor at imitation (and at understanding the need for it). Women with ASD have been found to be better at imitation, and so tend to blend in more (and so not get diagnosed).

An Autism Glossary: K-L

Kanner's Autism: Saying that someone has "Kanner's autism" means that that person meets Leo Kanner's original definition of autism, which was more restrictive than the current DSM definition. Hence typically used for those whose autism is relatively obvious and disabling, e.g., those whose speech is severely affected. Compare *Classic autism.

Literal Thinking†: People with autism often understand words to mean exactly what they say, and so have trouble with idioms and metaphors. So if you say, e.g. "A penny for your thoughts" — the person with autism might tell you and then ask to be paid!

Low-functioning Autism: see *functionality

An Autism Glossary: M

Medication: There are no medications approved for autism; there are only a few approved for specific manifestations of autism (specifically irritability). Nonetheless many people with autism have prescriptions for some sort of psychoactive medication or other — often for *comorbid *anxiety, *depression, or *ADHD.

Meltdown: An explosion of anger or other extreme emotions. Anyone can have a meltdown, but in people with autism, it can be harder to see the warning signs. Often a response to stress.

Mimic, Mimicry: see *Imitation*

Mindreading: see *Theory of mind*

An Autism Glossary: N-O

Negative Punishment: see *punishment.

Negative Reinforcement: see *reinforcement.

Neurotypical: Term often used in the autism community for those who don't have autism or another mental condition that causes unusual life function. "Normal" people.

Non-verbal Communication: Communication of thoughts and feelings by means other than words. It is thought that 80% of emotional information is communicated non-verbally.

Non-verbal Person/child: A person who cannot communicate thoughts or feelings using words, sometimes because of not understanding language and sometimes because of lack of control of the vocal apparatus (such people can *understand* language without using it). Not all non-verbal people have autism, but about a sixth of those who have autism are non-verbal.

An Autism Glossary: Pa-Po

PDD-NOS: See *Pervasive Developmental Disorder-Not Otherwise Specified.

Perfectionism†: Never being satisfied with something that is less than perfect. This is a common trait in autism, and can result in a person with autism never finishing a project because it isn't "just right."

Perseveration: Persisting, or persevering, in a behavior. In other words, engaging in it again and again.

Pervasive Developmental Disorder-Not Otherwise Specified: A deprecated term from the *DSM-IV. Officially used for those who had traits similar to autism but who did not meet all the criteria; in practice, often used as a substitute for an autism diagnosis because it didn't carry as much stigma.

Positive Language†: saying what to do, not what not to do, e.g. "walk to the next room," not "don't run to the next room."

Positive Punishment: see *Punishment.

Positive Reinforcement: see *Reinforcement.

autism society of minnesota

An Autism Glossary: Pr-Pz

Prevalence of autism†: as of 2018, 1 in 59 children is estimated to have autism.

Psychosis: The state of experiencing illusions and confusing them with reality — e.g. hearing voices. Autism does not cause psychosis unless there is a comorbid psychotic illness, but some people with autism can give the impression of having poor contact with reality because they understand the world so differently.

Punishment: In *behavior theory, anything which decreases a *behavior is a punishment, whether *you* think it's punishment or not. So, e.g., making a person sit in a "normal" way may be a punishment even if *you* think sitting with your legs in a pretzel looks like it hurts. Punishments can be either *positive* or *negative*. A "positive" punishment is not a "good" punishment; it is when you *add* something to a situation, e.g. make a loud noise. A "negative" punishment is when you take something away, e.g. a fidget. Although punishment can change behavior, it is not likely to produce the behavior you desire, because it does not teach the person what to do instead. Contrast *reinforcement.

autism society of minnesota

An Autism Glossary: Ra-Rei

Repetitive Behaviors†: see *ritual, *stim

Reciprocity†: In simplest terms, social exchange. Knowing what to give and take in relationships. This can be very problematic for people with autism, because, due to lack of *theory of mind, they do not realize that other people do not want the same things that they themselves do.

Reinforcement: In *behavior theory, anything which causes a behavior to increase is a reinforcement. Reinforcement is generally preferred to punishment to change behavior. *Positive* reinforcement means to add something as a reinforcement (e.g. a reward); *negative* reinforcement means to take something away (e.g. quiet a loud noise). Contrast *punishment.

An Autism Glossary: Rel-Rz

Relationship Circle†: A visual tool for explaining what to share with others, based on how close they are to the person with autism.

Rett's Disorder: A genetic disorder found only in girls which has some autism-like syndromes. In *DSM-IV it was listed among the pervasive developmental disorders; it has been moved in DSM-5.

Ritual†: Also called "routines," which is perhaps a less stigmatizing description. An act repeated in response to a particular situation, e.g. always knocking exactly three times on a door or always having corn flakes for breakfast. People with autism often develop many rituals, because they make it easier to know how to respond to a problem. A *stim shows some of the characteristics of a ritual.

Routine: see *Ritual.*

An Autism Glossary: Sa-Sel

Savant, Savant Skill: The extreme case of *splinter skills. A savant skill is a particular *specific* ability far in advance of one's general capabilities — e.g. being able to play a piano concerto by ear after one hearing but not being able to speak a complete sentences. So being a "good doctor" does not make you a savant, e.g.; the talent *must* be in a highly specific area and must be *very much* beyond the person's other abilities. Savant skills tend to fall into a few categories: calendar calculation, number theory, art, musical performance, memorization (e.g. of dates). The large majority of savants are autistic, but very few people with autism are savants, although most are better in one area than another. Most experts seem to believe that *training the talent is especially helpful in dealing with savants.

Self-stimulation: Dirty as it sounds, in an autism context, this just means engaging in some activity to relieve anxiety and maintain attention, e.g. flapping, rocking, swinging. Often referred to briefly as "a stim."

An Autism Glossary: Sem-So

Sensory Integration (therapy): In people with autism, sensory input is often confused and a source of discomfort. Sensory integration therapy is designed to make sensory problems more manageable. This may be done via training or via a device to control the input.

Sensory Sensitivities/Processing Disorder†: Abnormal responses to sensory inputs such as sounds or smells. For example, inability to deal with loud sounds or fluorescent lights or particular odors (although one may also fail to detect particular sensory information). Occupational therapists may use *sensory integration techniques to reduce the burden of sensory processing disorder.

Social Narratives/Social Stories™†: A written account told to a person with autism to help prepare for upcoming events or changes in routines. There are books with pre-packaged stories that you can modify to fit your occasion.

Social communication: The ability to interact with others in such a way as to exchange thoughts and feelings. See also *reciprocity.

An Autism Glossary: Sp-Sz

Special Interest†: Many people with autism are deeply interested in a particular topic, from Thomas the Tank Engine to video games to the history of Balkan religious manuscripts. Special interests count as a diagnostic criterion for autism. They can often be used to motivate the person who has them. Special interests are usually very intense, but they can and do change over time.

Spectrum, (on the) Spectrum: Shorthand for being "on the autism spectrum," i.e. having autism.

Splinter skills†: To have certain skills without other skills that seem to be related — e.g. to be able to do advanced mathematics but be unable to count money, or to be able to sing without being able to talk coherently.

Stimming, a Stim: Stimming is an activity, such as spinning or hand-flapping, intended to meet a sensory need. See *Self-stimulation.*

Support/A support: A tool or intervention used to help a person with autism more comfortable or capable.

An Autism Glossary: T

Theory of mind†: Sometimes called "mindreading." The ability to realize that others think in different ways, and to guess what they are thinking or how they will react. Theory of mind is usually deficient in those with autism, although the degree of deficiency varies; some hardly seem even to understand that others exist, while others are merely somewhat limited in their ability to guess what others think.

Train the Talent: A method for dealing with *splinter skills, consisting in giving the greatest attention to the person's special abilities. It will often be found that this will encourage the person to develop other abilities to support the main talent. For example, a person who really enjoys performing on the piano may learn how to talk to people in order to be allowed to play the piano in public.

Trigger: The immediate stimulus which provokes a (usually undesired) *behavior. See *antecedent, a broader term for the same thing.

An Autism Glossary: U-Z

Video modeling†: A visual technique to show how a task is done. Can be edited so that the person with autism actually seems to be doing the activity.

Visual Schedule†: What it sounds like: a schedule which *shows* what the person is to do at a particular time, not just *say* it. This makes it easier to read and understand what is coming up.

Autism Links

Resource Links

About Autism:

- Autism Society of Minnesota: https://www.ausm.org/
- Autism Society of Minnesota Resource Directory: https://ausm.org/resources/resource-directory-2.html
- Minnesota Department of Human Services Autism Portal: http://www.mn.gov/autism
- National Institutes of Health Autism Page

Therapists and Specialists

- American Association of Occupational Therapists: https://www.aota.org/
- Minnesota Occupational Therapy Association: http://www.motafunctionfirst.org/
- Board Certified Behavior Analysts: https://www.bacb.com/bcba/

Resource Links

Tools & Supports:

- The Relationship Circle: http://trainingpack.personcentredplanning.eu/index.php/en/communityconnecting/relationships

- The Incredible Five Point Scale: https://www.5pointscale.com/

- Social Stories™: https://carolgraysocialstories.com/social-stories/

- Dakota County's Recreational Directory: https://www.co.dakota.mn.us/HealthFamily/Disabilities/Services/Documents/RecreationalDirectory.pdf

Respite Care

- ARCH National Respite Network and Resource Center's Respite Locator https://archrespite.org/respitelocator