



INVESTing in Girls and Women with Autism

November 2nd, 2018

Simon Fraser University - Harbour Centre
Vancouver, Canada

Presented by
Dori Zener, MSW, RSW

Co-Sponsored by



SIMON FRASER UNIVERSITY

Event Schedule

8:30 – 9:00	Registration
9:00 – 10:15	Session 1
10:15 – 10:45	Morning break - Refreshments served; Book browsing available
10:45 – 12:00	Session 2
12:00 – 1:00	Lunch - Bring or buy your own; Book browsing available
1:00 – 2:15	Session 3
2:15 – 2:30	Afternoon break - Refreshments served; Book browsing available
2:30 – 3:30	Session 4

Accessing SFU's Wi-fi Network

1. Connect to the wireless network "SFUNET"
2. Open a web browser and navigate to any HTTP page
3. Enter the Computing ID and Password:
ID: lw4763
Password: Gu#;6hfn

Tips for Improving the Conference Experience

- Please turn off your cell phones or put them on vibrate.
- In respect for the speakers and fellow participants, please do not whisper
- This workshop is being web streamed to an online audience. Please ask questions using a microphone so that everyone can hear.
- Personal recording of any kind is strictly forbidden.
- Please secure your belongings! ACT cannot take responsibility for theft.
- Many of your fellow participants require a scent-free environment.

Acknowledgements

ACT is very grateful to Dori Zener for agreeing to travel to British Columbia to share with us her expertise on this important topic. We also appreciate the response of our registrants who are joining us in person and as a group via web streaming to gain more knowledge about the needs of women and girls with autism spectrum disorder.

ACT – Autism Community Training depends on the many parents and professionals across British Columbia who volunteer their time to support our work. We also thank Simon Fraser University's Department of Psychology which facilitates ACT enjoying SFU's excellent downtown facilities at a reduced cost.

In 2018, ACT provided training to nearly 2,000 registrants. As funding from registrations does not cover the full costs of running events, we are grateful for those who donate to ACT. Unfortunately, our funding for 2019 is insufficient to continue with live events unless we find new sources of funding which ACT is actively seeking. If you would like to support ACT's training in 2019, please see www.actcommunity.ca/support-us/donating for more information on donating.

Free Resources from ACT


Autism Videos @ ACT (AVA) - nearly 30 quality online videos available free – without a log-in, thanks to our sponsors. www.actcommunity.ca/videos

ACT's Autism Information Database (the AID) – Keyword search nearly 1500 curated AID records for evidence-informed, practical information resources useful to families and community professionals. www.actcommunity.ca/aid

ACT's BC Community Resources Database – search by your postal code for professionals and service providers throughout BC: www.actcommunity.ca/aid-search/community/

ACT's Autism Manual for B.C – 13 chapters! www.actcommunity.ca/autism-manual-for-bc -

ACT's Monthly News Round-Up & Event Alerts - sign-up to keep in touch with developments affecting the special needs community www.actcommunity.ca/updates



INVESTing in Girls & Women with Autism

Autism Community Training
November 2, 2018

Dori Zener, MSW, RSW
www.dorizener.com
"Embracing Neurodiversity"





Dori Zener
@dorizener

[#AskingAutistics](#) Prepping for a workshop for [#parents](#) of [#autisticgirls](#). I'd love your input:

- 1 What do you wish your parents had known/done to have made your life easier?
- 2 What did your parents do that helped your wellbeing?

Encouragement, Acceptance, Patience, Support

"Encouragement, encouragement and encouragement. To be who I am and not telling me I should be like others."

"To let me grow and breathe the way I needed to without being embarrassed of me."

"They could've been accepting and supportive of me instead of trying to fix me. Especially during meltdowns, they could have provided support and kindness instead of being embarrassed and shamed of me."

"Mom let me be who I am and told me never to try to be someone else."

#AskingAutistics

Celebrate Differences

"What would have made the difference for me was having my difference acknowledged and loved, not acknowledged and criticized."

"Tell them that they are Differential but don't tell that they are disabled. They shall have the possibility to unfold. "

"My parents never compared me to other kids and never tried to raise me according to outside standards. They figured out what would be right for me and acted accordingly. It made all the difference."

#AskingAutistics

Sensory Experiences

"I wish they realized that our sensory experiences are vastly different than yours"

"I really wish they took my sensory pains seriously and not gaslight me by saying it's a "small problem"

"Big birthday parties were sensory hell, so in grade 2 I started hiding class party invitations under the paper in my sock drawer. My mum found them, sat me down and said "If you don't want to go to a party, you don't have to go." She had such trust and respect for her kids"

"I couldn't vocalize how I was feeling when I was melting down because the feelings were so intense, I myself did not know what was causing them or what was wrong. I did not know everyone else doesn't experience the sensory onslaught and had no words to explain."

"They allowed me to have downtime. They let me be in my room and never forced me to socialize."

#AskingAutistics

Encourage Interests

"Help them to discover their interests. For every person in this world it is important to be good in something and to enjoy something with full passion"

"Don't shame us out of our special interests. I was 13 and playing with toy horses, setting up barn scenes was great fun. My mother came in and complained "Don't you think you're too old for that?" I was so ashamed. I put the horses away and never played with them again. I don't really remember how to play now."

#AskingAutistics

Body

"I would've liked more direct, explicit, detailed advice and information about 'growing up' stuff. Like periods, sex, relationships, etc. I didn't get enough info and the info I did get wasn't frank enough."

Make friends with my body – "My kind, pragmatic parents had taught me to approach physical activity on my own terms."

<https://www.refinery29.com/en-us/autistic-personal-trainer>

"Enrolling me in dance. I'm not a dancer, but learning how to stretch & move helped so much. Finding me activities, w/ good teachers, in small groups w/ individual learning, where social interaction wasn't paramount (dance, swimming, etc) was the best thing they did for me."

#AskingAutistics

School

"Fight for better treatment in school. Many teachers don't understand the reasons behind behaviors & accommodations. Girls tend to be considered "not autistic enough" b/c they tend to mask better. It doesn't lessen their challenges, it compounds them."

"I wish they got me tested sooner and considered home schooling."

"I wish they had been persistent about school. My lack of formal education was a real gap in my perceived development. That eroded my self-confidence until recently (age 45)."

#AskingAutistics

Workshop Overview

- Female Autism profile
- INVEST Approach
 - Identify Needs
 - Validate
 - Educate
 - Strengthen
 - Thrive
- Lifespan Perspective



A Brief Word on Language

- Person-first vs. Identity-first
Person with autism \leftrightarrow Autistic person
- Neurodiversity and Autism Spectrum Disorder
- Gender: Girl & Woman = Not limited to sex



= Discussion or Exercise

Session One: Female Profile & Identify Needs

1. Female Autism Profile
2. Missed and Misdiagnosis
3. Late in Life Identification
4. INVEST Therapeutic Approach
5. Reasons for seeking therapy

Autism Spectrum Disorder DSM V - Diagnostic Criteria

A. Persistent deficits in Social Communication across multiple contexts

1. Social emotional reciprocity
2. Nonverbal Communication
3. Developing, maintaining, and understanding relationships

B. Restricted, repetitive behavior, interests or activities

1. Stereotyped or repetitive motor movements, use of objects, speech
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior
3. Highly restricted, fixated interests that are abnormal in intensity
4. **Hyper- or hyporeactivity to sensory input**

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

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



NeuroDivergent Rebel
Autism Advocate,
Vlogger, Blogger

Female Autism Profile: Social Communication



Amythest Schaber
Advocate, Vlogger
"Ask an Autistic"

- Awareness that being social is valued and expected. Less autistic behaviour in social situations (Lai, M-C).
- Camouflage – study and imitate others, create rules. 'Look the part'. Exhausting.
- Continues to acquire more social skills with age. Autism emerges when demands exceed skills.
- Skilled one on one but struggles in groups. Communicates openly in safe settings.
- Introvert: One or two close friends. Relationships can be dependent and possessive.
- Extrovert: Loud, bubbly, unaware of personal space and boundaries. Unknowingly offends others.

Female Autism Profile: Restricted Repetitive Behaviour



Becca Lory
Autism Advocate
Podcast: Spectrumly
Speaking


- "Special interests" similar to neurotypical peers - animals, fantasy, dolls, art, reading, music, make up, celebrities
- Intensity and depth of knowledge and quality of play differs
- Rich imagination – escape into fantasy world/ imaginary friend
- Less obvious than males – hair twirling, nail and scab picking, squeezing
- Internalized – perseveration, replaying events, thought loops
- Thrive with structure, routine and clear expectations

Female Autism Profile: Sensory Processing

Sensation	Challenge
Sight	Fluorescent light, cluttered visual spaces
Hearing	Crowds, sudden loud noises, layering of multiple noises
Touch	Soft vs. firm touch, can feel painful
Taste	Food rigidity
Smell	Intense, gag reflex
Proprioception & Vestibular	Clumsy, uncoordinated
Interoception	Difficulties recognizing pain, fatigue, hunger, arousal, emotion

Public spaces are draining & anxiety provoking ie. public transit, grocery stores, waiting rooms.
Downtime needed for sensory deprivation.

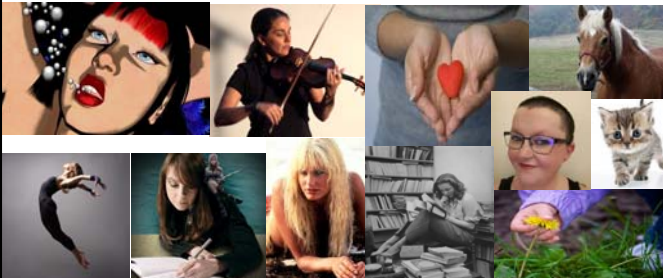
Female Autism Profile: Associated Challenges



Seeking Sara
Autism Advocate
Blogger

Emotional Regulation	<ul style="list-style-type: none"> Internalizes struggles: anxiety, depression, ED, self harm, substance abuse. Alexithymia and theory of mind challenges Empaths, poor emotional boundaries. Struggles with identity and self esteem.
Executive Functioning	<ul style="list-style-type: none"> Challenges with attention, memory, planning, organizing information and materials. Inconsistent abilities. Can be incredibly self-reliant. If overwhelmed, can avoid tasks and revert to preferred activities. Difficulty performing tasks outside of comfort zone.

Creativity, Empathy, Animals & Information




Share some of the amazing qualities of a girl or woman with autism that you know.

Start this presentation to see the content. Still not the content? Refresh this app or go back to the app's main page



Missed & Misdiagnosis

- A gendered presentation of autism - masking
- Gender bias in autism research
- A lack of knowledge of the female autism profile
- Diagnostic tools developed and normed for a male population that are not sensitive to the female phenotype
- System divisions
- Autism is not on people's radar



The Mental Strain of Unidentified Autism

I have a long history of depression and anxiety-related issues, which is not so surprising, when you consider my childhood was marred by troubled times. My Asperger's went undiagnosed, probably because, like so many girls on the autistic spectrum, I learned how to blend in and mimic the social norms, and because my sometimes strange behaviour and anxiety could be explained away by a 'bad childhood'. (O'Leary, F.P. 2014).

Fiona O'Leary
Autism Advocate

Co-occurring Mental Health Issues			
Mental Health Condition	Prevalence	Features	Factors
Anxiety	Up to 66% Risk factors: age and IQ 1 in 4 social anxiety	In women: Separation anxiety, social phobia, panic disorder and generalized anxiety disorder.	Anxiety and autism go hand in hand. - Difficulties with change - Confusion and overwhelm - Sensory sensitivities
Depression	50% (Hedley, et al., 2017) Suicidal ideation VERY high esp 35-65 years 75-89% (Cassidy, S. et al. 2014).	Depression: Social exclusion, isolation, victimization. Suicide: Loneliness, feeling burdensome, lack of community belonging.	- Risk factors: female, high IQ, victimization, alexithymia.

Mental Health Condition	Prevalence	Symptom Overlap	Differences
Attention Deficit Hyperactivity Disorder	30-80% co-occurring Rommelse, N. et al. (2010)	Executive functioning difficulties, inattentive, impulsive/hyperactivity.	Cause of social challenges defer ie. Personal space. ADHD excited, impulsive, ASD, not aware of boundary
Obsessive Compulsive Disorder	Genetic link – OCD twice as likely to occur with autism. Have OCD go on to get autism 4x.	Compulsive repetitive behaviours and obsessive thoughts.	Social communication challenges. Repetitive behaviours in girls missed.
Bipolar Affective Disorder	Prevalence of autism and BPAD to be 7% Skokauskas, N. & Frodl, T., 2015)	Irritability, mood dysregulation, sleep dysfunction and quasi-manic behaviour	Cause of meltdowns vs. mood swings. Social challenges, rigid repetitive behaviours.

Mental Health Condition	Prevalence	Symptom Overlap	Differences
Borderline Personality Disorder	Minimally studied. One study 15% of BPD sample met criteria for ASD (Rydén, G. et al. 2008)	- Interpersonal difficulties, challenges with affect regulation, self harm. - High rates of systemizing. - Trauma history.	BPD self harm due to interpersonal distress & emotional dysregulation; autistics self harm due to sensory overload
Substance Abuse	Autism doubles the risk of addiction, individuals IQ of 100+ at particularly high risk	Soothes anxiety. Highly ritualistic. Assists with peer belonging.	Not typically associated bc autistics are rule followers.
Eating Disorders	Up to 30% of women with anorexia meet criteria for Autism	Shared cognitive profile: rigidity in behaviour & thinking, perfectionism, theory of mind deficits, executive functioning challenges, mood & anxiety disorders	Reasons for developing ED different – sensory, social, rigidity, medication side effects.

Late in Life Diagnosis



Families on the Spectrum













[illegible]

Introducing Christine Jenkins!

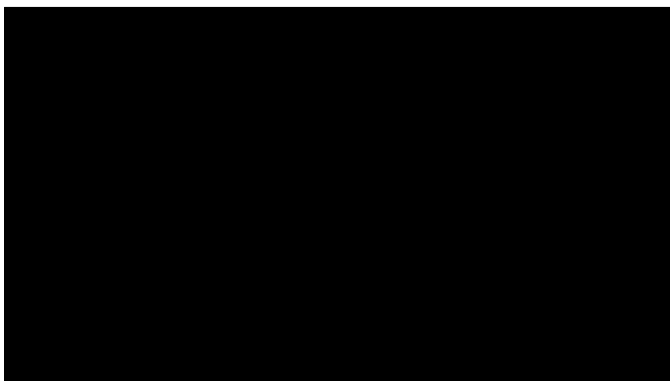


Authors:
Jeffrey Cohen
Rebecca Campbell
Barb Cook
Suzanne Craft
Jane DeRubeis
Dana Gossamer
Elaine Hurlburt
Christine Jordan
Rosanne Karkovitz
Julia LaRue
Reese Lary
David Meyer
Jennifer Parks
Julie Runt
Christina Stewart
Foreword by Lisa McGinn

Barb Cook and 14 other autistic women describe life from a female autistic perspective, and provide thoughtful, helpful and supportive insights from their personal experience for fellow autistic women. Dr. Michelle Gossamer's comments validate and expand the experiences described from a clinician's perspective, and provide extensive recommendations.

Release Date: August 21, 2018

See us go [pre-order now](#) at [Amazon](#) [Spectrum Women](#)

[illegible][illegible]



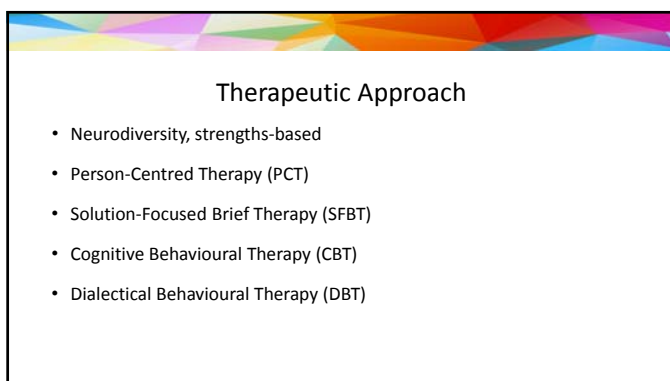
Identify Needs

identify needs



Therapeutic Environment

- Natural light, reduce fluorescents
- Neutral colours, simple decor
- Fidget toys
- Art by autistic artists
- Plants



Therapeutic Approach

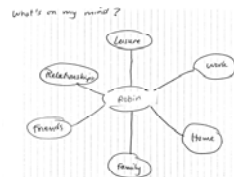
- Neurodiversity, strengths-based
- Person-Centred Therapy (PCT)
- Solution-Focused Brief Therapy (SFBT)
- Cognitive Behavioural Therapy (CBT)
- Dialectical Behavioural Therapy (DBT)

Reasons for Seeking Services

- Understand unique autism profile
- Function in this world without getting confused, overwhelmed and drained
- Improve day to day lives, enhance executive functioning, minimize sensory bombardment
- Develop self worth and self-esteem
- Enhance emotional regulation, manage distress, develop positive coping strategies
- Life transitions ie. post-secondary, employment, family changes
- Couple and family therapy to improve relationships and develop effective communication

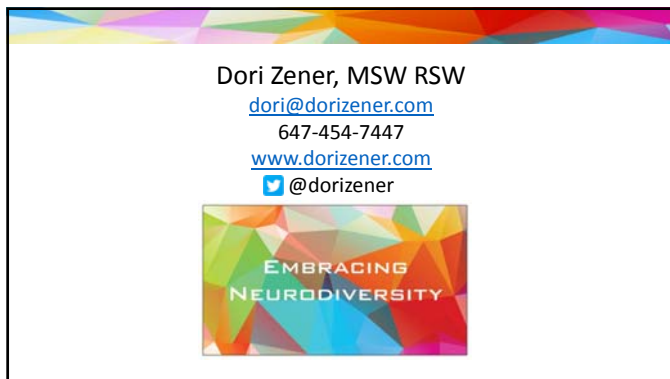
Goals for Therapy

- Prior to starting therapy
- In their own words
- Explore meaning
- Mind-mapping

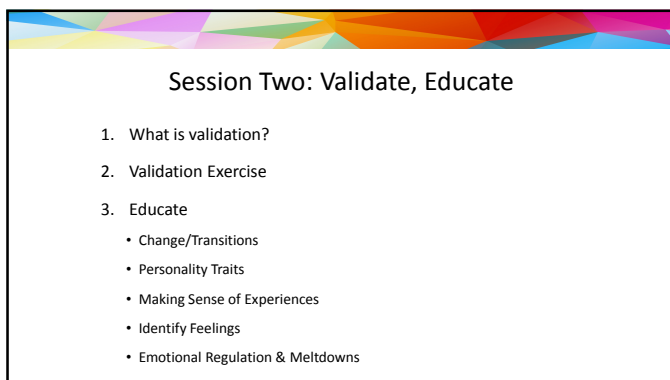


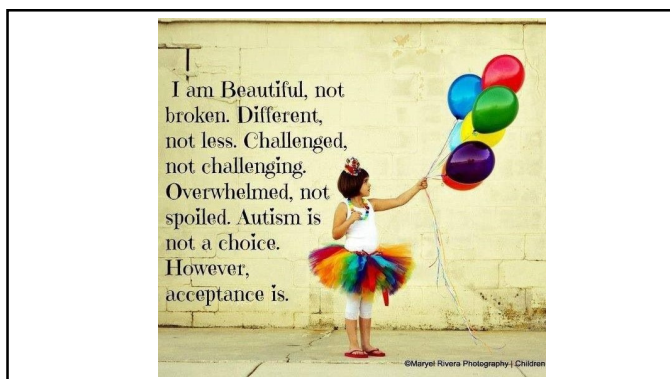
Questions?











What is Validation?


- Curious, caring, compassionate, 'That sounds hard, tell me more'
- I see you, I hear you, you matter, 'What was that like for you?'
- Recognition and acceptance of another person's thoughts, feelings, sensations, and behaviors as understandable
- A way to communicate that the relationship is important and solid even when you disagree
- Both verbal and nonverbal
- Emotional invalidation: when a person's thoughts and feelings are rejected, ignored, or judged





Validation Stage	Behaviour
1. Be present	Show interest in the other person through verbal and non-verbal cues ie. nodding, 'Tell me more...', 'Then what happened?'
2. Accurate reflection	Summarize what they are saying, then ask 'is that right?' Take a non-judgemental stance
3. Mindreading	Read a person's behaviour, guess what they might be thinking. Imagine what they could be thinking, feeling or wishing for. Check for accuracy. ie. 'You're wishing that you never met x.'
4. Understand the person's behavior in terms of their history and biology.	'That makes perfect sense that you would feel that way considering what you've been through' 'Since _____ happened, I can see why you don't want to do _____.'
5. Normalize or recognize emotional reactions that anyone would have.	Communicate that the person's behavior is reasonable and meaningful. 'It seems totally normal to feel anxious before going to the dentist'
6. Radical genuineness.	Give the person respect, treat them like an equal. Be genuine with your responses to their experiences.

<https://www.psychologytoday.com/au/psychology/relationships/understanding-validation-how-communicate-acceptance>
<https://www.dailymail.co.uk/health/article-3812122/understanding-validation-how-communicate-acceptance.html>
<https://www.psychologytoday.com/au/psychology/relationships/understanding-validation-how-communicate-acceptance>



Validation: Role Play & Discussion

Instructions: Part One - Invalidation

Get into pairs. One of you will be Person 1, the other Person 2.

Person 1: Turn to Person 2 and tell them something annoying that happened to you today before you got here.


Examples:

- "I got stuck in traffic on the way here and was worried I was going to be late".
- "My coffee shop ran out of my favourite muffin"
- "I had a terrible night's sleep and feel like a zombie"

Person 2: Respond by saying something dismissive or minimizing:

- "That wouldn't have happened if you planned better."
- "You should be thankful. Muffins are really cupcakes in disguise".
- "Suck it up and grab a cup of coffee like the rest of us"

Person 1: How did their response make you feel? (Call out)



Validation: Role Play & Discussion

Instructions: Part Two - Validation

Let's try it again.

Person 1: Repeat your annoying occurrence.

Person 2: Respond in a validating way. Use both verbal and non-verbal communication.

- "I can understand how you're upset. It's important for you to be on time and feel calm when you arrive"
- "They didn't have your favourite muffin? I hate it when that happens".
- "A bad night's sleep is the worst. I know what that's like. Hang in there!"

Discussion:

- **Person 1:** How did it feel to be on the receiving end of those validating messages?
- **Person 2:** What did you notice in yourself when you were being dismissive vs. validating?
- Did anyone have any difficulty coming up with a validating statement?



educate

Educate at all levels

- Build self-awareness
- Enhance understanding and communication in the family
- Understand needs at school and in employment
- Educate broader community



Change and Transitions

- Too fast or not enough information will lead to anxiety, confusion and overwhelm
- Changes = explained and gradual
- Connect change to past experiences
- Be explicit about what to expect & what is expected of them
- Normalize anxiety



Positive Self-Talk

"I've been through something like this before, and I can do it again!"

"I can do this. Even though it feels stressful, I know it's the best thing for me right now."

Personality Traits

Positive	Negative
Considerate, thoughtful	Inconsiderate, thoughtless
Cooperative	Uncooperative, unhelpful, combative
Courageous	Cowering, fearful
Courteous	Rude, impolite
Decisive	Indecisive
Devoted	Uncommitted, uncaring, hostile
Does what is necessary, right	Does what is convenient
Endures, perseveres	Relents, gives up
Enthusiastic	Unenthusiastic, apathetic, indifferent
Forgiving	Unforgiving, resentful, spiteful
Humble	Arrogant, conceited, ego-centric

Processing

- Longer processing time
- Confusion, overwhelmed, stuck
- Structured check-ins
- Review events
- Unpacking and making sense



Exercise: How are you feeling?



IDENTIFYING FEELINGS									
INTENSITY OF FEELINGS	HAPPY	SAD	ANGRY	CONFUSED	AFRAID	WEAK	STRONG	GUILTY	
High	Ecstatic Elated Enthusiastic Excited Fired-up Optimistic Overjoyed Passionate Thrilled	Alone Crushed Depressed Devastated Disappointed Heart-broken Sorrowful Unwanted Wounded	Betrayed Disgusted Enraged Furious Irate Outraged Seething Vengeful	Bewildered Desperate Directionless Lost Spaced-out Stagnant Trapped Troubled	Abandoned Fearful Horrid Intimidated Panicky Petified Shocked Terrified	Drained Exhausted Helpless Hopeless Impotent Liable Overwhelmed Powerless Vulnerable	Aggressive Courageous Determined Forceful Potent Powerful Proud Super	Ashamed Humiliated Remorseful Somewhat Unworthy Worthless	
Medium	Accepted Cheerful Contented Good Relieved Satisfied	Displeased Down Grieving Hurt Left-out Regret Rejected Upset	Aggravated Agitated Controlled Disoriented Foggy Misplaced Mixed-up Mad Upset	Disorganized Disoriented Foggy Misplaced Mixed-up Threatened Uncertain Uneasy Volatile	Apprehensive Frightened Insecure Scared Threatened Uncertain Uneasy Volatile	Beat Dependent Inadequate Incapable Insecure Lazy Run-down Tired	Ambitious Believed Capable Confident Energetic Hopeful Persuasive Sure	Lowdown Sneaky Sorry	
Low	Use Fine Glad Grateful Mellow Open Pleased Satisfied	Use Bad Lost Moody Sorry Unhappy	Annoyed Grumpy Impatient Irritated Perturbed Put out Touchy Upset	Baffled Bothered Perplexed Puzzled Surprised Uncomfortable Unconvinced Unsure	Apprehensive Anxious Concerned Nervous Skeptical Timid Unsure Worried	Cautious Inconsistent Lethargic Shaky Shy Soft Unsatisfied Weary	Able Adequate Calm Capable Durable Secure	Embarrassed	

Adapted from <http://www.gustafsonpsychology.com/emotions.htm>



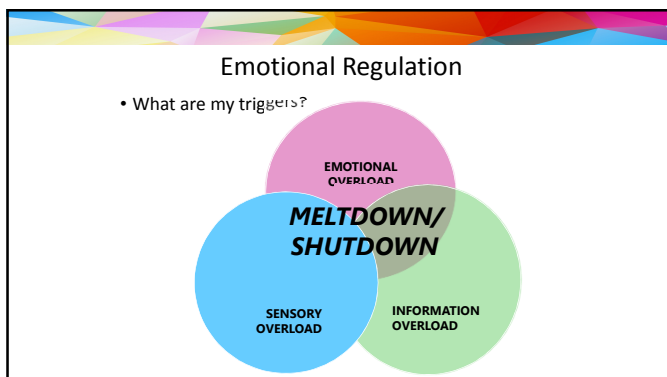
Meltdowns

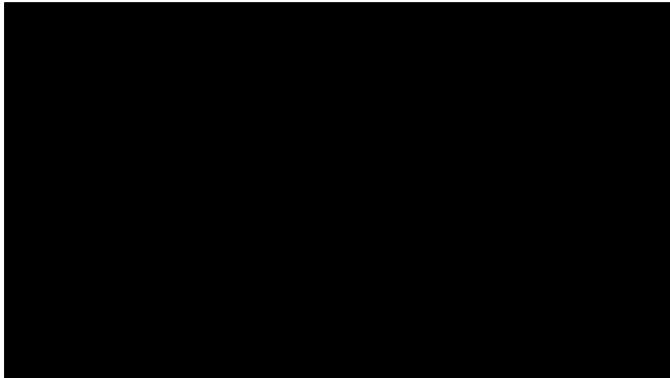
'I lose the ability to reason or be reasoned with. I go mute, absolutely unable to form coherent words or to speak with my mouth.'

'I pace, whimper, choke, sob, pull at my hair, pick at my skin, rock and hang on to myself for dear life.'

'I am infantile, exposed, raw, terrified, paralyzed, utterly humiliated.'


Sara LeeAnn Pryde — Daily Mail 2015





Preventing Meltdowns

- Know yourself and your triggers
- Balanced schedule – structured downtime & sensory deprivation
- Nature
- Find a safe space
- Label and process overwhelming emotions
- Understand how you process information and advocate for your needs
 - “I need to write this down”.
 - “I need to bring someone with me to this appointment”



The Incredible 5-pt Scale, Kari Dunn Buron

5	I can't stand this and ready to explode. I need to be someone, something, or have something. I need an adult to help me go to a safe place so I can calm down.	
4	I am getting too angry. My heart isn't working properly. I might stop or do something I will be sorry for later. I need to go to my safe place to calm down.	
3	I am getting really irritated. I need to walk away from a bad situation. I will tell my teacher that I need a break.	
2	I am doing OK. I'm not pleased, but I'm not upset. I can stop when I am feeling working. I can continue, upset by myself.	
1	I am doing great. I feel good about myself and about what is going on around me.	

[illegible][illegible]

Session Three: Educate
Autism Across the Lifespan



Session Three: Lifespan

1. Childhood


2. Tweens

3. Teenage Years

4. Young Adulthood

5. Adulthood

6. Old Age



Childhood



Autistic Girls: Creative Chameleons

- Promote passions and talents
- Difference as strength
- Model emotional expression, "I feel...because"
- Don't overload her schedule
- Take concerns seriously
- Encourage self-advocacy
- Mom as cheerleader, coach, teacher, advocate, personal assistant, friend
- Find other autism-moms

Strategies: School

- Assess for learning strengths and disabilities
- Find the right learning environment for your child
- Educate teachers on what your child needs for success
- Everyone is on their own timeline
- Little helpers
- Teachers: interest, support, kindness goes a long way

Discussion: School Supports



Parents: What school supports and accommodations have been the most helpful for your child?

People with Autism: What school supports and accommodations were the most helpful for you? If you didn't have any, what do you wish you had?

Educators: What supports have you found the most useful for your learners?

Tweens



Shifting Social Climate

Changes

- Focus shifts from family to peer relationships
- Friendships become more complex - talking about romance, gossip, pointless chatter
- Gendering of friendships - Suddenly being female may interfere in previously strong co-ed relationships
- Bullying, exclusion, rumours

Strategies

- Alert your child to the change
- Help your child identify peers with similar values or interests
- Look into extra-curricular activities in area of interest
- Promote "theory of mind"
- Girls may be tomboyish, genderfluid or identify as transgender. Allow them to present in a way that is comfortable for them.

Puberty

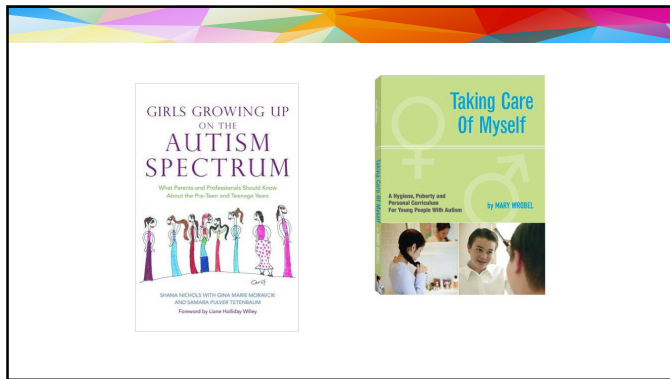
Issue

1. Body changes before social-emotional development – disgusted by changes, dislike for body
2. Unwanted attention
3. Periods may be painful, irregular. Moderate to severe PMS.
4. Hygiene issues



Approach

1. Inform about upcoming body changes and what to expect. Keep information straightforward and factual
2. Identify inappropriate behaviour of others. Create scripts, practice how to respond.
3. Track periods, watch for PMS.
4. Set basic expectations for hygiene. Use external rewards if needed.





Promoting Independence

- Parents need to initiate change, it may not happen naturally
- Baby steps!
- Discuss the benefits of being more independent and acknowledge any losses
- Empower your child to learn their diagnosis so they can understand themselves and advocate

Source: <https://balancechallenge.org>

Discussion: Promoting Independence



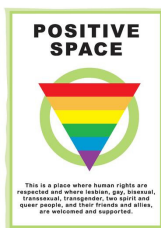
What strategies have you found to be most effective in helping your child, student or yourself:

1. Take on more responsibility for their autonomy?
ie. make their own meal, book their own appointment, advocate for their own needs.
2. Contribute to family responsibilities?

Arousal and Sexual Orientation

Issue	Approach
1. May explore pleasurable sensations not knowing it's sexual.	1. Use resources to teach sexual arousal. Review appropriate places and partners.
2. May not recognize feeling attraction towards others.	2. Discuss what attraction feels like (whoosh, flutter in chest, flushed).
3. Higher rates of non-heterosexuality & gender diversity	3. Use non-heteronormative language, be open.
4. Consent	4. Coach how to say no - thinking no is not saying no.
5. Risk for sexual victimization	5. Teach social and body boundaries
6. Watch out - Crushes can turn into obsessions	6. Teach appropriate ways to express interest in others, and signs that others may be interested in them.
7. Early or promiscuous sexual activity.	7. Ensure safety. Explore reasons behind their actions. Validate underlying need for attention, belonging. Pros/Cons. Look for other sources.
8. Sexting and sexual predators.	8. Monitor online use. Explain don't have to send skin pics.

POSITIVE SPACE



Young Adulthood



Post-Secondary

- Teach life skills in advance
- Register with the Disability Office
- Get familiar with the campus
- Reduced course load
- Internships/co-ops
- Clubs/interest groups



Friendship & Romantic Relationships

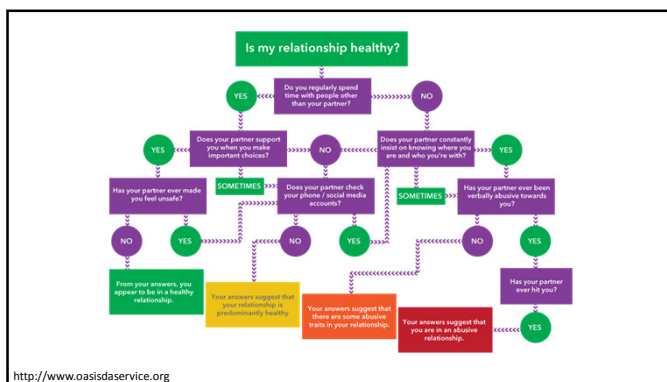
- Understanding and accepting of differences
- Similar lifestyle, interests and social needs
- Open communication, vulnerability
- People on the spectrum or empaths
- Fast and intense or "part-time" relationships
- Being single is good too!



"Autism in Love"
2015 Documentary
Dave Hamrick & Lindsey Nebeker

Relationship Risks

- Abusive partners
 - Emotional
 - Sexual
 - Physical
 - Financial
- Getting stuck in toxic or boring relationships
- Confusing empathy with love



<http://www.oasisdaservice.org>

Adulthood



Barb Cook
Founder
www.spectrumwomen.com
Co-Author "Spectrum Women"
Autism Consultant



Lana Grant
Author:
"From Here to Maternity"
Autism, Pregnancy & Motherhood



Laura James
Author
"Odd Girl Out"



Sarah Hendrickx
Autism Educator, Author,
"Women and Girls with Autism Spectrum Disorder"

Obtaining and Maintaining Work

Issues

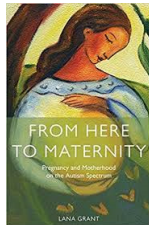
- Under/unemployment
- Social skill challenges
- Slow processing and execution, high quality product
- Executive functioning
- Sensory sensitivities

Ideas

- Turn passions and skills into employment
- Use your network
- Find an open and accepting workplace
- Disclosure
- Self-employment

Pregnancy and Childbirth

- Interactions with multiple health care providers
- Body changes distressing
- Belly as invitation for conversation and touch
- Research intensely, pre-experience outcomes
- Childbirth doesn't always go according to plan



The All Encompassing Nature of Motherhood



Sensory Overload

- Children are loud, messy, demanding, tactile, unpredictable, time-intensive and energy intensive.
- Build in quiet time wherever possible
- Wear earplugs if sounds are overwhelming
- Get sleep
- Get support

Executive Functioning

- Motherhood is the ultimate test of attention, time management, organization, initiation, and emotional regulation. Constant juggling.
- Divide up the tasks with willing partners and other supports
- Plan ahead and get into a routine
- Use alerts, systems and reminders
- Hire someone if you can afford it

Downtime

- Children are a massive disruption to a mother's inner life.
- Partner relationship may suffer if all of the energy and focus has shifted to the kids.
- Understand that recharge time is essential to self-care.
- Find outlets to pursue interests.
- Explain to your partner that you are drained, make time to overlap.

Social Expectations

- Encouraged to provide a socially stimulating environment when this may be the opposite of what the parent is skilled at, comfortable or enjoys.
- If you struggle to teach or model social skills, supplement with family, services or professionals.

Physical Health

- Difficulties identifying and communicating about pain
- Hormonal abnormalities – PCOS, Endometriosis
- Chronic fatigue, pain
- Ehlers-Danlos Syndrome (EDS)
- Sleep disorders
- Gastrointestinal issues
- Migraines (Cassanova, 2008)
- Movement planning problems
- Medications – paradoxical reactions

Comparative Pain Scale	
1	0 to pain 7 is usually healthy normal
Minor	1 Very light barely noticeable pain. Not a moderate like in a person who has had the time to move their mind about the pain.
2	2 Very Mild
3	3 Discomfort
4	4 Moderate
5	5 Very Discomfort
6	6 Severe
7	7 Very Severe
8	8 Unbearable
9	9 Unbearable
10	10 Unbearable

Middle Age and Beyond

- Autistic burnout, fatigue
- Social isolation
- Depression, anxiety
- Prominent autistic traits
- Greater self-acceptance
- Renewed focus on special interests
- Youthful spirits







Session Four:
Strengthen & Thrive




strengthen thrive

Session Four: Strengthen & Thrive

1. Strengthen Distress Tolerance
2. Set Parameters on Energy
3. Passionate Interests
4. Disclosure
5. Peer Support
6. Reflections on Today

Distress Tolerance

- Intense sensations: deep pressure, ice cube
- Grounding exercises
- Animals
- Sensory deprivation
- Self-encouragement: "This will pass"
- Distraction: music, visual
- "Have I faced something like this before? How did I get through it?"



Grounding Exercises



- Find as many black objects in the room as you can. Say them out loud, ie. Black shirt, black chair.
- Find something within reach. Touch the object and describe how it feels ie. "the couch is rubbery, firm but squishy, cold, smells like leather."
- What are your favourite grounding techniques?

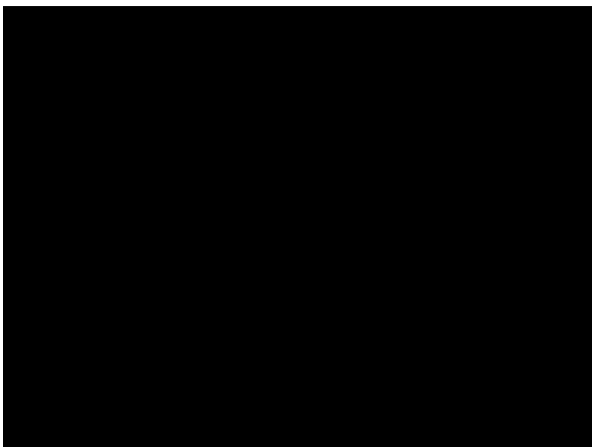
Meltdown Recovery

- Exhaustion
- Slow reintegration
- Self-forgiveness



From others:

- Support and understanding
- Space and time



Set Parameters on Energy

- Spoon Theory (C. Miserandino)
 - Social
 - Emotion
 - Sensory
 - Time
 - Information
- Accept limits



Case Example



- One client repeatedly put herself in danger due to monofocus and difficulties rationing energy. She was very dedicated to her career and engrossed in her work. She would never take a break and would regularly forget to eat. Her job was incredibly draining from the social demands of dealing with large groups of people and the overstimulating sensory environment. She would often stay late, focused on doing her best work. When it was time for her long drive home, she used up all of her spoons. Police had gotten involved several times because she had been found in a ditch on the side of the road. Too tired to carry on, she would pull over and pass out from exhaustion. Luckily, she was never harmed.
- What strategies would you suggest to help this person?


Strengthen Connections

- Enhance social skills & relationships
 - Scripts, texting, role play
 - Common interests
 - Being vulnerable
- Support network




Thrive

- A meaningful life on their terms
- Focus on hope and possibility
- “What do I need and want?”
- Emphasize positive coping, good choices and working towards goals




An autistic person's passionate ('special') interest usually brings joy like little else can. To call it an 'obsession' suggests it is a bad thing when in fact it tends to be a huge positive and motivator in that person's life. Many autistic academics and professionals have made a career pursuing their passion.



Jeanette Purkis Autism Books & Other Things





Reasons to Disclose Diagnosis

Asperfemme Toronto June 2018

- Acceptance
- Strengthen relationships
- Better understanding of myself and others, gain relief
- Accommodations and supports at school
- Access specific employment supports and programs
- Other people disclosed, i.e., "I have Asperger's." "So do I."
- Not enough people are talking about it



Peer Connection and Support

- Find your tribe!
 - Asperfemme
 - AsperDames



asperfemme
toronto
Let's get connected!



Advocacy

- Share your story
- Build awareness
- Help younger generations
- Sense of belonging and common purpose
- Empowering

Reflections on Today



1. What is one change you hope to make in your work, your parenting or in your life as a result of today's workshop?
2. What do you need to do differently to make that change happen?



Questions?





Thank you!

Dori Zener, MSW RSW

dori@dorizener.com

647-454-7447

www.dorizener.com

[@dorizener](https://twitter.com/dorizener)

Works Cited

- Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M. and Baron-Cohen, S. (2014). "Suicidal ideation and suicide plans or attempts in adults with Asperger's Syndrome attending a specialist diagnostic clinic: a clinical cohort study", *Lancet Psychiatry*, Vol. 1, pp 142-147.
- Cassanova, M. (2008). "The Minicolumnopathy of Autism: a Link between Migraine and Gastrointestinal Symptoms". *Med Hypotheses*. 2008; 70(1): 73-80.
- Halladay, A., Bishop, S., Constantino, J., Daniels, A., Koenig, K., Palmer, K., Messinger, D., Pelphrey, K., Sanders, S., Tepper Singer, A., Lounds Taylor, J. and Sattmari, P. (2015). Sex and gender differences in autism spectrum disorder: summarizing evidence gaps and identifying emerging areas of priority. *Molecular Autism*, 6: 36 DOI:10.1186/s13229-015-0019-y
- Hendricks, S. (2015). *Women and Girls with Autism Spectrum Disorder*. London: Jessica Kingsley Publishers.
- Ingudomnukul, E., Baron-Cohen, S., Wheelwright, S., & Knickmeyer, R. (2007). Elevated rates of testosterone-related disorders in women with autism spectrum conditions. *Hormones and Behavior*, 51(5), 597-604.
- Lai, M., Lombardo, M.V., Pasco, G., Ruigrok, A.N.V., Wheelwright, S.J., Sadek, S.A., Chakrabarti, B. & Baron-Cohen, S. (2011). "A behavioral comparison of male and female adults with high functioning autism spectrum conditions." *PLoS ONE*, Vol. 6, No. 6, pp. 10.
- Lai, M., and Baron-Cohen, S. (2015). "Identifying the lost generation of adults with autism spectrum conditions". *Lancet Psychiatry*. Vol. 2, No. 11, pp. 1013-27.
- Lai, M., Lombardo, M., Ruigrok, A., Chakrabarti, B., Auyeung, B., Sattmari, P., Happé, F., and Baron-Cohen, S. (2017). "Quantifying and exploring camouflaging in men and women with autism." *Autism*, Vol. 21, No. 6, pp. 690-702.
- O'leary, F.P. (2014, February 6). I knew I was different long before I was diagnosed with Aspergers.. *Irish Examiner*. Retrieved: <http://www.irishexaminer.com/lifestyle/features/i-knew-i-was-different-long-before-i-was-diagnosed-with-aspergers-257773.html>