



# INVESTing in Girls and Women with Autism

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November 2<sup>nd</sup>, 2018

Simon Fraser University - Harbour Centre  
Vancouver, Canada

*Presented by*  
Dori Zener, MSW, RSW

Co-Sponsored by



SIMON FRASER UNIVERSITY

## ***Event Schedule***

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|                      |  |
|----------------------|--|
| <b>8:30 – 9:00</b>   | Registration                           |
| <b>9:00 – 10:15</b>  | Session 1                              |
| <b>10:15 – 10:45</b> | Morning break - Refreshments served;   |
| <b>10:45 – 12:00</b> | Session 2                              |
| <b>12:00 – 1:00</b>  | Lunch - Bring or buy your own;         |
| <b>1:00 – 2:15</b>   | Session 3                              |
| <b>2:15 – 2:30</b>   | Afternoon break - Refreshments served; |
| <b>2:30 – 3:30</b>   | 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 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](http://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](http://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](http://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/](http://www.actcommunity.ca/aid-search/community/)

**ACT's Autism Manual for B.C** – 13 chapters! [www.actcommunity.ca/autism-manual-for-bc](http://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](http://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  |
|--|--|
| <b>Sight</b>                           | Fluorescent light, cluttered visual spaces                       |
| <b>Hearing</b>                         | Crowds, sudden loud noises, layering of multiple noises          |
| <b>Touch</b>                           | Soft vs. firm touch, can feel painful                            |
| <b>Taste</b>                           | Food rigidity  |
| <b>Smell</b>                           | Intense, gag reflex  |
| <b>Proprioception &amp; Vestibular</b> | Clumsy, uncoordinated  |
| <b>Interoception</b>                   | 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"> <li>• Internalizes struggles: anxiety, depression, ED, self harm, substance abuse.</li> <li>• Alexithymia and theory of mind challenges</li> <li>• Empaths, poor emotional boundaries.</li> <li>• Struggles with identity and self esteem.</li> </ul>  |
| Executive Functioning | <ul style="list-style-type: none"> <li>• Challenges with attention, memory, planning, organizing information and materials.</li> <li>• Inconsistent abilities.</li> <li>• Can be incredibly self-reliant.</li> <li>• If overwhelmed, can avoid tasks and revert to preferred activities.</li> <li>• Difficulty performing tasks outside of comfort zone.</li> </ul> |

## Creativity, Empathy, Animals & Information



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

Start the presentation on live content. Add live content! Read the app or get help at [Pallix.com/help](http://Pallix.com/help)


**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

**Guardian**  
Hundreds of thousands of women with autism may be going undiagnosed because it's a 'male disorder'

Thousands of autistic girls and women 'going undiagnosed' due to gender bias

**The Mental Strain of Unidentified Autism**



**Fiona O'Leary**  
Autism Advocate

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).


**Co-occurring Mental Health Issues**

| Mental Health Condition | Prevalence   | Features   | Factors   |
|-------------------------|--|--|---|
| Anxiety                 | Up to 66%<br>Risk factors: age and IQ<br>1 in 4 social anxiety   | In women:<br>Separation anxiety, social phobia, panic disorder and generalized anxiety disorder.                                     | Anxiety and autism go hand in hand.<br>- Difficulties with change<br>- Confusion and overwhelm<br>- Sensory sensitivities |
| Depression              | 50% (Hedley, et al., 2017)<br><b>Suicidal ideation</b><br>VERY high esp 35-65 years 75-89%<br>(Cassidy, S. et al. 2014). | Depression: Social exclusion, isolation, victimization.<br><br>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<br>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.<br>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 BIPAD to be 7%<br>Skokauskas, N. & Frodl, T., 2015)                 | Irritability, mood dysregulation, sleep dysfunction and quasi-manic behaviour | Cause of meltdowns vs. mood swings.<br>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.<br>- High rates of systemizing.<br>- 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


### The Power of the Right Label



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

My head was spinning all my life with trying to make sense of why these things happened to me, why I was so odd, why I couldn't live like other people. The diagnosis stopped my head from spinning. I was able to breathe a sigh of relief and relax (Hendrickx, 2015).

### Introducing Christine Jenkins!




**Authors:**  
Allison  
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Jenni Mayne  
Jenni Perkins  
Anita Ross  
Christine Stewart  
Foreword by Kate Morgan


**Release date August 21, 2018**

Barb Cook and 18 other autistic women describe the life from a female autistic perspective, and present empowering, helpful and supportive insights from their personal experiences for fellow autistic women. Dr Michelle Connors comments, collates and expands the experiences described from a clinician's perspective, and provides extensive resources/links.

Amazon




### 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)

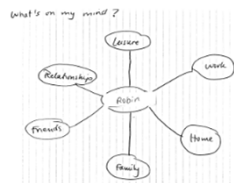
### Reasons for Seeking Services

- 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?




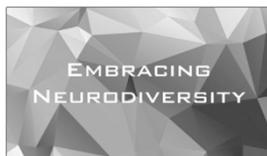
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 @dorizener



## Session Two Validate & Educate

Welcome back!

validate

educate

### Session Two: Validate, Educate

1. What is validation?
2. Validation Exercise
3. Educate
  - Change/Transitions
  - Personality Traits
  - Making Sense of Experiences
  - Identify Feelings
  - Emotional Regulation & Meltdowns



### 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?'<br>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'<br>'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/blog/being-brave/2013/05/understanding-validation-how-communicate-acceptance>  
<https://www.dailymail.co.uk/health/article-2301204/Understanding-validation-how-communicate-acceptance.html>  
<https://www.psychologytoday.com/blog/being-brave/2013/05/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



## Executive Functioning

- Impulse control
  - Think before you act, clear instructions & expectations, consequences
  - Remove temptation, replace behaviour
- Flexible thinking
  - Show multiple view points or ways of doing something
  - Ask - is this similar to a problem I've encountered before?
- Working memory
  - Repeat things out loud, write them down, use visual reminders
- Self-monitoring – set goals and observe your behaviour to evaluate progress
  - Ask – what are you doing that's helping you work toward your goal?
  - What is getting in the way of achieving your goal?



## Executive Functioning

- Planning and Prioritizing
  - Map out the big picture, break it into small manageable steps
  - check-in regularly to monitor progress
- Task Initiation
  - Pair it with established routine, rewards
  - Perfectionism anxiety
- Organization
  - Systems! Calendars, alerts, timers, Habitica – treats your real life like a game
- Emotional control
  - Up next!



Source: <https://unsplash.com/blog/5-therapies-for-managing-overwhelm>

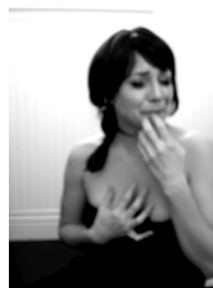
## Exercise: How are you feeling?



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

Adapted from <http://www.guidetopsychology.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.'

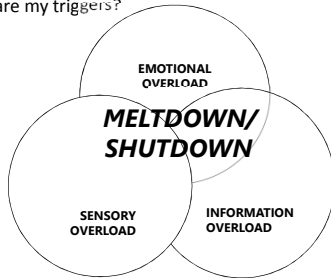
'I pace, whimper, choke, sob, pull at my hair, pick at my skin, rock and hang on to myself for dear life.'

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

Sara LeeAnn Pryde – Daily Mail 2015

## Emotional Regulation

- What are my triggers?



## 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



| Emotional   | Triggers   | Behaviors   | Body   | Thoughts  | Strategies   |
|---|--|---|--|---|--|
| 5<br>Extreme Anxiety<br>Scared, Irritated, Frustrated | World spinning   | Aggressive/Anxious  | Shaking, Sweating, Runny nose, Jumping out of skin, Hyperventilating, Jackhammer racing, Pain, Aches, Injuries | Overwhelmed, "I can't handle this", "I'm overwhelmed"         | Quiet, Calm support, Use sensory tools, Break down tasks, Review back to back, Break down tasks into smaller steps, Give suggestions on what to do |
| 4<br>High Anxiety                                     | Too many changes, Things happening too quickly                       | Outstanding with a, Not saying anything or saying, get it off me        | Shaking, Sweating  | "I can't handle this", "I'm overwhelmed"                      | Tell someone how you feel, Use sensory tools, Break down tasks, Review back to back, Give suggestions on what to do                                |
| 3<br>Agitation  | Demands placed on me, Harsh tone, No choice                          | Rebellious, Repeating words, Cursing                                    | Shaking, Rigidity  | Resentment, "What if I can't handle this?", "I'm overwhelmed" | Tell someone how you feel, Use sensory tools, Break down tasks, Review back to back, Give suggestions on what to do                                |
| 2<br>Neutral/OK                                       | Not too high, Not too low, Not too fast, Not too slow                | Listening, Quiet, Not too high, Not too low, Not too fast, Not too slow | Slightly high, Not too high, Not too low, Not too fast, Not too slow   | "I can handle this", "I'm doing OK"                           | Tell someone how you feel, Use sensory tools, Break down tasks, Review back to back, Give suggestions on what to do                                |
| 1<br>Calm   | Feeling happy, Not too high, Not too low, Not too fast, Not too slow | Feeling happy, Not too high, Not too low, Not too fast, Not too slow    | Feeling happy, Not too high, Not too low, Not too fast, Not too slow   | "I'm happy", "I'm doing great"                                | Tell someone how you feel, Use sensory tools, Break down tasks, Review back to back, Give suggestions on what to do                                |

## Pathological Demand Avoidance (PDA)

- Elizabeth Newson, developmental psychologist, UK 1994
- PDA as subset of Autism
- Extreme avoidance of the demands of everyday life
- "anxiety-driven need to be in control and avoid other people's demands and expectations."
- Intolerance of uncertainty
- Inability to cope with intense emotions



## Key Features of PDA

- Uses social strategies as part of the avoidance
  - Distraction, delaying, fantasy
- Appears sociable but lacks depth of understanding of social situations
  - ie. Authority
- Excessive mood swings
- High interest in roleplay and pretend - blurred lines
- Obsessions with people – real or fictional



### What PDA Looks Like

- Extreme meltdowns at home or school
- Violent outbursts
- Panic attacks
- Shutdowns
- Misdiagnosed as Oppositional Defiant Disorder (ODD), Conduct Disorder (CD), Reactive Attachment Disorder (RAD) and Attention Deficit Hyperactive Disorder (ADHD).



### SAME GIRL – DIFFERENT VIEWPOINT

#### DISTORTED VIEW

- Difficult
- Defiant
- Spoiled
- Rude
- Disrespectful
- Disobedient
- Selfish
- Demanding
- Troublemaker
- Controlling
- Manipulative
- Aggressive
- Stubborn
- Lazy



- Scared
- Anxious
- Overwhelmed
- Overloaded
- Shut down
- Hurt deeply in the past
- Motivated heavily by peers and fitting in
- Poor coping and emotional regulation skills

#### CLEARER IMAGE



- Intelligent
- Loving
- Thoughtful
- Talented
- Funny
- Beautiful
- Supportive
- Caring
- Determined
- Resilient
- Passionate
- Sensitive

Source: Lisa Atkins: Teenagers  
<https://www.pdasociety.org.uk/resources/pda-society-conference-2018/natalie-menagh-and-lisa-atkins-on-parenting-strategies>

### Strategies for Managing PDA

- Recognize anxiety as what is driving avoidance
- Understand the triggers
- Predictable routines & incentives
- Build awareness and teach coping strategies
- Communicate to ensure processing

Resource: [www.pdasociety.org.uk](http://www.pdasociety.org.uk)

Strategies for PDA  
 (Pathological Demand Avoidance)

- ★ Be flexible
- ★ Build relationships
- ★ Plan ahead
- ★ Offer choices
- ★ Choose words carefully
- ★ Use humour
- ★ Remain calm
- ★ Reduce demands
- ★ Pick Your Battles

[www.mindtools.com](http://www.mindtools.com)

### Questions?



Enjoy your lunch!



educate

## 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.

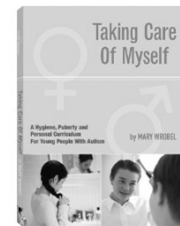
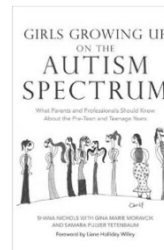
## Puberty

### 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.



## Teenage Years



## 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

1. May explore pleasurable sensations not knowing it's sexual.
2. May not recognize feeling attraction towards others.
3. Higher rates of non-heterosexuality & gender diversity
4. Consent
5. Risk for sexual victimization
6. Watch out - Crushes can turn into obsessions
7. Early or promiscuous sexual activity.
8. Sexting and sexual predators.

### Approach

1. Use resources to teach sexual arousal. Review appropriate places and partners.
2. Discuss what attraction feels like (whoosh, flutter in chest, flushed).
3. Use non-heteronormative language, be open.
4. Coach how to say no - thinking no is not saying no.
5. Teach social and body boundaries
6. Teach appropriate ways to express interest in others, and signs that others may be interested in them.
7. Ensure safety. Explore reasons behind their actions. Validate underlying need for attention, belonging. Pros/Cons. Look for other sources.
8. Monitor online use. Explain don't have to send skin pics.



## 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

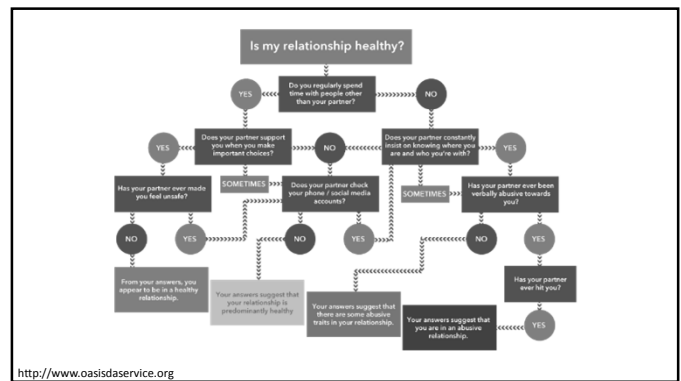
- Understanding and accepting of differences
- Similar lifestyle, interests and social needs
- Open communication, vulnerability
- People on the spectrum or empaths
- Fast and intense or "part-time" relationships
- Being single is good too!



"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



## 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"



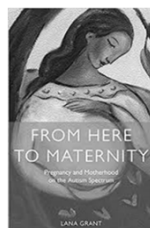
**Sarah Hendricks**  
Autism Educator, Author,  
"Women and Girls with Autism Spectrum Disorder"

## Obtaining and Maintaining Work

| Issues   | Ideas   |
|--|---|
| <ul style="list-style-type: none"> <li>• Under/unemployment</li> <li>• Social skill challenges</li> <li>• Slow processing and execution, high quality product</li> <li>• Executive functioning</li> <li>• Sensory sensitivities</li> </ul> | <ul style="list-style-type: none"> <li>• Turn passions and skills into employment</li> <li>• Use your network</li> <li>• Find an open and accepting workplace</li> <li>• Disclosure</li> <li>• Self-employment</li> </ul> |

## 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.
- Understand that recharge time is essential to self-care.
- Find outlets to pursue interests.
- Partner relationship may suffer if all of the energy and focus has shifted to the kids.
- 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

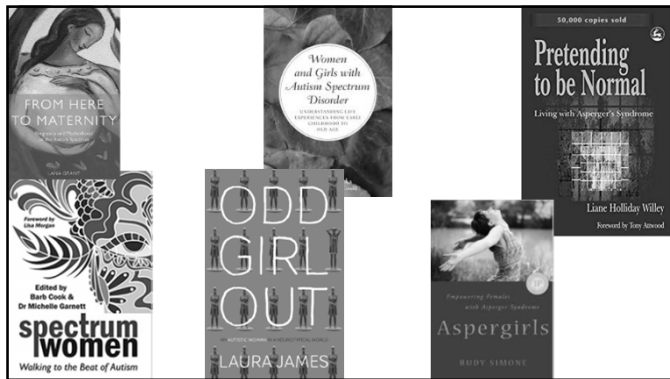
- Difficulties identifying and communicating about pain
- Hormonal abnormalities – PCOS, Endometriosis
- Chronic fatigue, pain
- Ehlers-Danlos Syndrome (EDS)
- Sleep disorders
- Gastrointestinal issues
- Migraines (Cassanova, 2008)
- Movement planning problems
- Medications – paradoxical reactions

| Comparative Pain Scale    |                           |
|---------------------------|---------------------------|
| <b>Minor</b>              | <b>1</b><br>Very light    |
| <b>2</b><br>Discomforting | <b>2</b><br>Light         |
| <b>3</b><br>Tolerable     | <b>3</b><br>Moderate      |
| <b>4</b><br>Disruptive    | <b>4</b><br>Severe        |
| <b>5</b><br>Disabling     | <b>5</b><br>Very severe   |
| <b>6</b><br>Intense       | <b>6</b><br>Very intense  |
| <b>7</b><br>Very intense  | <b>7</b><br>Very intense  |
| <b>8</b><br>Very intense  | <b>8</b><br>Very intense  |
| <b>9</b><br>Very intense  | <b>9</b><br>Very intense  |
| <b>10</b><br>Very intense | <b>10</b><br>Very intense |

## 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





## 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



## Self-care & Healthy Habits

- Sleep
- Exercise
- Healthy eating
- Downtime
- Creativity
- Passions
- Supportive people
- Informed choices
- Accept help, give help
- Self-love

Be gentle  
with yourself



## Autism Acceptance

- Greater self-awareness & understanding
- Accepting and celebrating differences
- #Takethemaskoff
- Sense of belonging
- Autistic pride



## 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!

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