AGEING (DIS)GRACEFULLY

Christine Jenkins
Spectrum Women
Correspondent,
Co-founder, AsperDames,
Ottawa, Canada

Mother of Re-invention

NAS WOMEN & GIRLS CONFERENCE
SEPTEMBER 11, 2019
You may have met one autistic woman, but you haven’t met me (yet)!

Christine Jenkins, Canada
AGEING (DIS)GRACEFULLY: THE OTHER TRANSITION

• Shocking Situation—scant research on older autistic women
• Raise the Roof—safe, sensory-friendly accommodation
• Manage Meh-nopause—asking how it is different for autistic women
• The Web of Women—finding each other online
• Forging the Future—help for ourselves and the next generations
Pam Button,
Canadian autistic pioneer
1949-2012
Nevertheless, she persisted
• What documents exist on the ageing population?  
  So few on women, even fewer on women over 45
• NAS and other studies (see Resource list); I chose to focus on 2015-present
• What are concerns re old age? Results of my poll
• Effect of late or misdiagnosis, leading to failure to thrive, early death (Sarah Cassidy, Anne Kirby among researchers)
• What we don’t know yet (start with Cos Michael’s list)
Females on the Autism Spectrum (assessed at Canadian clinic) (in order of % of women) N=60 Aged 17-68, mean age 36 years old

100% of the women reported sensory processing problems
80% of the women reported movement planning problems (dyspraxia)
73.3% of the women met clinical criteria for anxiety disorder
58.3% of the women met clinical criteria for depression
51.7% of the women rated themselves as having alexithymia
31.7% of the women had respiratory concerns (asthma/allergies)
21.7% of the women had eating disorders (anorexia/bulimia)
16.7% of the women met clinical criteria for OCD
10% of the women had gastrointestinal concerns

Source: Burke, Stoddart, Abdelsayad, Redpath Centre, Toronto 2012

Christine Jenkins, September 11, 2019
Females on the Autism Spectrum (assessed at Canadian clinic) (in order of % of women) N=60  Aged 17-68, mean age 36 years old

Additional Diagnoses N=36 (60%)

29% ADHD
17% Panic disorder
17 % PTSD
  8% Tourette’s
  6% Social phobia
  3% Attachment disorder
  3% Psychosis
  3% Adjustment disorder

Source: Burke, Stoddart, Abdelsayad, Redpath Centre, Toronto 2012

Christine Jenkins, September 11, 2019
6. What would help ageing autistic women to continue living independently?
7. How are autistic women supported at times of bereavement?
8. Is progress being made towards female autism awareness for health and social care providers?
9. What is being done to reduce social isolation among ageing autistic women?
10. Who is campaigning for older autistic women? NAS? Age UK?

Cos Michael, “Autism, ageing and women: not invisible, just ignored,” NAS, 2015

Christine Jenkins, September 11, 2019
“…we can’t continue like this, because you don’t end up anywhere on a hamster wheel…."

Christine Jenkins, September 11, 2019
ASD identified mostly in males

Research conducted on male samples

‘Gold standard’ diagnostic tools based on males

Research requires ‘Gold standard’ diagnosis

Fewer females available for research

Slide from INSAR 2019 Panel presentation by Allison Ratto, Children’s National Health System, Washington DC
Prime Ageing Concerns  N=103
Poll by Christine Jenkins, Aug 2019

Percentage of respondents

- Financial stability: 29.1%
- Caregiver concerns: 17.5%
- Lack of autonomy: 16.5%
- Fear of co-habitation: 12.6%
- Decline in health: 9.7%
- Disruption of lifestyle: 9.7%
- Fear for their autistic child: 4.9%
- Isolation: 1.0%
I struggle because no one sees my struggle. I struggle because my anxiety over the repercussions of being treated badly is dismissed. I struggle because some days I just don’t have the strength or support to withstand the hostility I face simply because I am misunderstood.

Resilient Chameleon

Christine Jenkins, September 11, 2019
RAISE THE ROOF

• Stuck in our silos, need to connect the dots
• Financial stability primary concern on my poll
• Affording retirement living
• Interview with Lyndsay Green, Canadian sociologist and author, expert on ageing
• How do we prepare for senior housing/elder care units: education, training, sensory awareness
Lyndsay Green, Sociologist

Phone interview August 12, 2019:

“If you don’t move by the time you’re 80, you won’t move into a place that’s appropriate for you.

Christine Jenkins, September 11, 2019
We are all ‘temporarily able-bodied’
—Stroke victim in her forties

Christine Jenkins, September 11, 2019
Of the 106 homeless people we screened, 13 showed strong signs of autistic traits that would be consistent with an autism diagnosis. At 12.3% this is a much higher proportion than the 1% of people in the general population who are autistic.

“The prevalence of autism traits in a homeless population.”
Churchard, Mandy et al. 
*Autism*, April 2019
146 people were referred for assessment aged 18 to 74. Two thirds received an ASD diagnosis. “(O)lder age was associated with higher ratings of ASD traits and better cognitive performance.”

Developing coping strategies may mitigate the effects of ageing.

JADD Nov 2016, Happe, Charlton et al.
Many of us will have to work under whatever circumstances are offered, and we’ll be fish out of water for most of our lives. No matter what our age, we must start now, creating the right livelihood for our social, sensory and cognitive issues. This is of particular importance for those of us with no partners and no one to help take care of us as we get older.

Rudy Simone/Artemisia “Getting Older on the Spectrum” in Aspergirls, JKP, 2010
• Gender data bias makes menopause hard to study
• Women dealing with own children getting diagnosed—realization of traits in themselves
• First generation of menopausal women diagnosed autistic
• What is the most drastic change noticed—poll Aug 2019
• Are new body symptoms due to ageing or autism?
• Preliminary results from Rachel Moseley at Bournemouth University—more in-depth interview results to come
MANAGE MEH-NOPAUSE: QUESTIONS ASKED BY COS MICHAEL

1. Do hormonal changes during menopause affect autism, anxiety and depression?
2. During menopause, processing often slows down. Does it return to normal for post-menopausal autistic women?
3. If a woman has been on anti-depressants for years, how will that affect severity of osteoporosis, post menopause? (Studies show long term use of Selective Serotonin Reuptake Inhibitors (SSRIs) can increase risk of fractures)
4. What reasonable adjustments can be expected in hospitals and hospices?
5. What residential support is available for older autistic women?

Cos Michael, “Autism, ageing and women: not invisible, just ignored,” NAS, 2015
Discussion points: in summary...

- The menopause may exacerbate existing problems, and generate new ones.

- Because we know so little about the menopause in autism, there is little support out there, and autistic people often have to deal with it on their own – not knowing ‘what is normal’. We need to systematically research the impact of the menopause, and how it differs between autistic and non-autistic people.

Dr. Rachel Moseley, Bournemouth University, initial findings of qualitative menopause study of focus group of autistic women  Discover Conference 2019

Christine Jenkins, September 11, 2019
Dr. Rachel Moseley, Bournemouth University, initial findings of qualitative menopause study of focus group of autistic women  Discover Conference 2019

Christine Jenkins, September 11, 2019
The worsening of difficulties around menopause may ‘crack the mask’ and be the catalyst for undiagnosed people seeking assessment – but does self-awareness and acceptance of autistic status help to cope with the menopause and with mental health difficulties during it? **We need to know!**
Dr. Rachel Moseley, Bournemouth University, initial findings of qualitative menopause study of focus group of autistic women  Discover Conference 2019

Christine Jenkins, September 11, 2019
Most drastic menopause change N=63
Poll by Christine Jenkins, Aug 2019

- Executive function has suffered: 29.0%
- Easily overwhelmed/anxious: 19.0%
- More sensitive to sounds: 13.0%
- Camouflage less in public: 11.0%
- I have insomnia: 9.5%
- More sensitive to light/temperature: 8.0%
- Mask less with friends & family: 8.0%
- Increased meltdowns/shutdowns: 3.0%
• Authors, bloggers and vloggers build communities
  Helping direct and take part in research—clients not patients.
  Females more likely to take part online

• Need for role models to provide women to admire

• Sisters are doing it for themselves—finding support online at
  intersection of race, gender, disability, and age
  e.g. Groups like Autistic Women and Nonbinary Network (AWN),
  Yellow Ladybugs, the Spectrum Women writers and the rise of the
  AsperDames (spring 2018)
(Will) Mandy’s team has found another way to recruit girls and women with autistic traits: online. Some of the most active bloggers, tweeters and commenters discussing autism online are women, he says, highlighting another intriguing way that autistic women may differ from autistic men: They are driven to connect.

Emily Sohn, “Righting the gender imbalance in autism studies,” Spectrum News, 2019

Christine Jenkins, September 11, 2019
ROLE MODELS OF TODAY

Hannah Gadsby, Tasmania, comedian
Fundraising for Autistic Women and Nonbinary Network in NYC with her new show Douglas.

Christine Jenkins, September 11, 2019

Greta Thunberg and Jane Goodall, activists

“What you do makes a difference, and you have to decide what kind of difference you want to make.”
- Jane Goodall -
Endorsement of the anthology
*Spectrum Women: Walking to the Beat of Autism*

“A friend once told me that getting an autism diagnosis in mid-life was like finding the Rosetta Stone to herself. This marvelously honest and historically important book will be that Rosetta Stone for many women on the spectrum…”

Steve Silberman, author of NeuroTribes, winner of six awards for 2015

Christine Jenkins, September 11, 2019
We formed a literary sisterhood!
We wrote and edited our book online.

Christine Jenkins, September 11, 2019
Kristín Vilhjalmsdóttir, Narrator, *Seeing the Unseen* documentary, Iceland, 2019

From the poem “We are Proud Autistic Women” by Kristy Forbes.
Nothing like an AsperDame!

Christine Jenkins, September 11, 2019
“We did not specifically look at camouflaging in different age groups, but I do recall there was a negative correlation between age and camouflaging. The older people reported slightly lower levels of camouflaging.”

--Will Mandy, email to C. Jenkins, August 5, 2019 in reference to study released by Hull et al. in July: “Gender differences in self-reported camouflaging in autistic and non-autistic adults”

Limitation: We need larger samples of women and non-binary autistics, especially those identified in childhood, to make meaningful conclusions.

Christine Jenkins, September 11, 2019
Groundbreaking study by Rachel Groves and team on importance of intense interests. Cited in my Resources list.

“Special interests were associated with a number of positive outcomes for autistic adults.” Note how the ‘female-type’ presentation differs, and how this may lead to disqualification for diagnosis, based on stereotyped Rigid/Restrictive and Repetitive Behaviours (RRBs) in DSM-5.
It’s much better to be a first-rate version of yourself than to be a second-rate version of someone else.

Judy Garland on authenticity
FORGING THE FUTURE

• Being humble to admit what we don’t know yet: List of priorities for research from the 2015 NAS conference presentation by Cos Michael

• Creating autistic safe space, physical and online: Felicity House, virtual meet-ups, live conferences

• Training of carers—what does society ‘afford’ us?

• A bright outlook where women don’t need to mask A perfectly good [older] female life (L H Willey) with Autonomy, Accountability and Avoidance of harm

Christine Jenkins, September 11, 2019
FORGING THE FUTURE

A look at those research priorities again….

6. What would help ageing autistic women to continue living independently?
7. How are autistic women supported at times of bereavement?
8. Is progress being made towards female autism awareness for health and social care providers?
9. What is being done to reduce social isolation among ageing autistic women?
10. Who is campaigning for older autistic women? NAS? Age UK?

Cos Michael, “Autism, ageing and women: not invisible, just ignored,” NAS, 2015

Christine Jenkins, September 11, 2019
“I feel like #ActuallyAutistic people are our own welfare organization. I find little in the way of autism organizations as helpful. Quite the contrary, actually.

Where is the help for Autistic adults? Where is the compassionate care for us?”

Louise Tardif, researcher and self-advocate, New Brunswick, July 6, 2019

Christine Jenkins, September 11, 2019
Every barrier that an AUTISTIC adult breaks down today, is one less for an AUTISTIC child to face tomorrow!

FB/AwarenessForAutism

We are like your child. Believe it or not!
FORGING THE FUTURE

What is success across the autistic lifespan? Who gets to determine this? We are the first generation of women to ask.

How can women 40-60 advocate now for better care as they age? Will I age gracefully or disgracefully? Or, as I prefer, ‘mature’ like a fine red wine?

“There is my comfort zone? A simple place to call my own…. There will be no turning back!” Annie Lennox, Pavement Cracks, 2003

Christine Jenkins, September 11, 2019
“A successful old age is relying on a successful adulthood. We work with people to give them healthy, fulfilling lives…. We want people to live longer and well.”

Carol Walker, professor of Social Policy, University of London, 2012 in NAS interview

Three separate silos of elder/palliative care, autism, and (mental) health that don’t communicate

Christine Jenkins, September 11, 2019
CONFIRMATION BIAS IS SEEKING CONFIRMATION TO SUPPORT YOUR PRE-EXISTING BELIEFS WHILE ACTIVELY DENYING EVIDENCE TO THE CONTRARY.

-theaspergian.com
Christine’s Hamster Wheel of Gender Data Bias--again

- Diagnose boys
- Study boys
- Support boys into adulthood
- See boys
- Search for more boys

Christine Jenkins, September 11, 2019
Researching Autistic People?
Imagining that all of us are children or teenager/students? In reality, we’re more likely to look like the pictures of older people here….Think carefully…when nearly every person you study is a younger male or a child.

Christine Jenkins, September 11, 2019
Julia Bascom, Executive Director, Autistic Self Advocacy Network (ASAN), Felicity House advisory board

Christine Jenkins, September 11, 2019
Felicity House, New York City, a model for autistic safe space. 
"(S)upport groups for women with autism are few and far between. Clubs geared toward socializing, rather than treatment or behavior modification, are rarer still."

Vox Magazine, June 24, 2019
“Women with autism often don’t see any reason why they shouldn’t do something due to age, gender or any other factor. This is enormously liberating, and the reason why you’ll find older women with autism doing all sorts of crazy stuff.”

Sarah Hendrickx, *Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age*, page 239
Christine’s advice on Being a Positive Force to stop the Fight, Flight, Freeze, & Fawn responses (Pete Walker)

You can assist to:
Educate others to embrace difference, rather than use compliance training like ABA;
Improve interoception (inner body sense) and avoid sensory triggers that lead to autistic shutdown and burnout;
Use beneficial stims and sensory aids, and carefully metred medication as necessary;
Create autistic safe space to allow spectrum elder sisters to unmask safely, and help others to do likewise
Christine Jenkins, September 11, 2019  Heading home from INSAR 2019
FORGING THE FUTURE

We are the experts on our own autism.

Women deserve to age gracefully, not precariously.

If autistic people know autism the best then why are services that work with autistic people not employing and collaborating with autistic people?

Autistic Creativity

Christine Jenkins, September 11, 2019
“I'm just wondering why I feel so all alone, Why I'm a stranger in my own life….

Every day is a winding road:
I get a little bit closer to feeling fine…”

*Everyday is a Winding Road*, Sheryl Crow, 1997

When I get old, they're never going to say
"What a sweet old lady".
They're gonna say
"What on EARTH is she up to now?!"

Christine Jenkins, September 11, 2019
Many thanks to the NAS for inviting me.

Contact info:
Christine Jenkins,
Spectrum Women Correspondent,
Ottawa Canada

CJ@spectrumwomen.com