

# AGEING (DIS)GRACEFULLY


**Christine Jenkins**

Spectrum Women  
Correspondent,  
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Mother of Re-invention

NAS WOMEN & GIRLS CONFERENCE  
SEPTEMBER 11, 2019





You may have met  
one artistic woman,  
but you haven't met  
me (yet)!

Christine Jenkins, Canada

LINEKING



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## 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

## SHOCKING SITUATION

Pam Button,  
Canadian  
autistic  
pioneer

1949-2012

Nevertheless,  
she persisted



Christine Jenkins, September 11, 2019

## SHOCKING SITUATION

- 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



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

## SHOCKING SITUATION

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

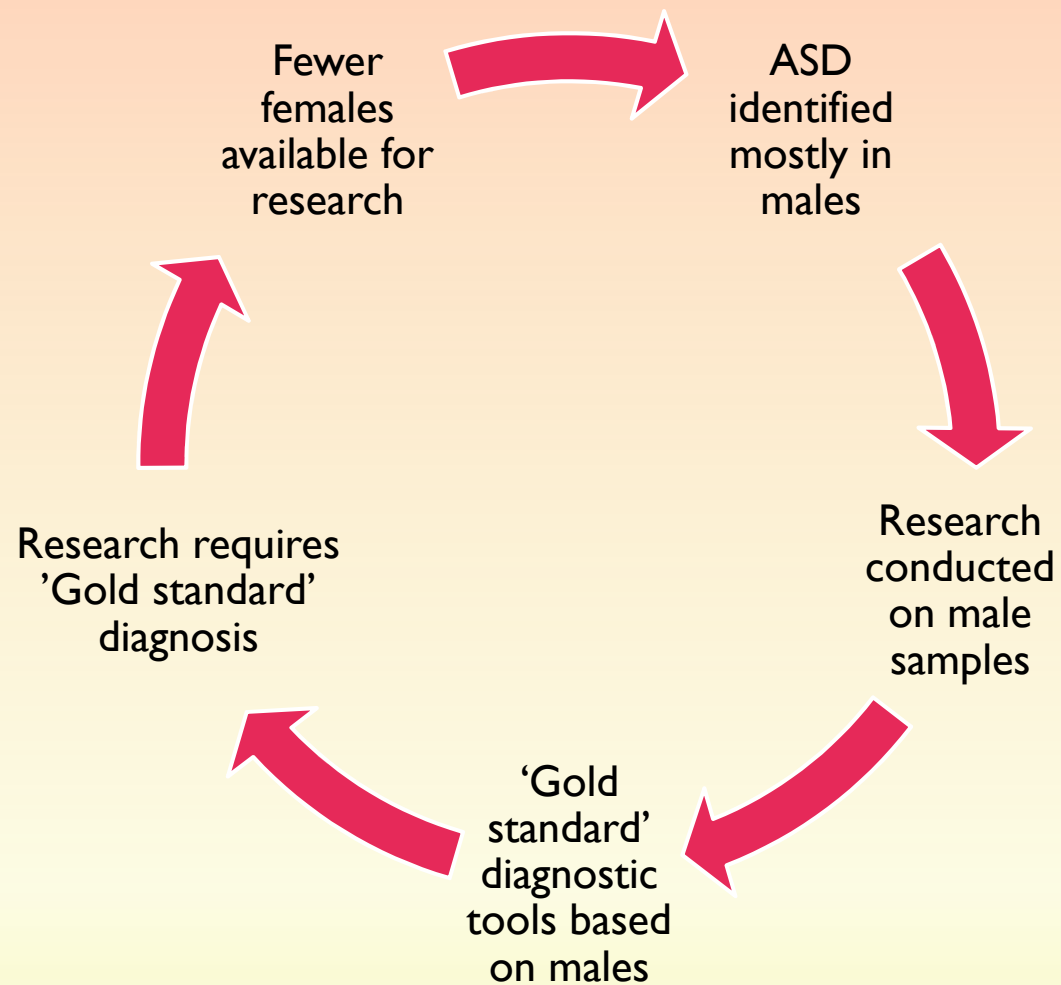


## Greta Thunberg on Swedish television



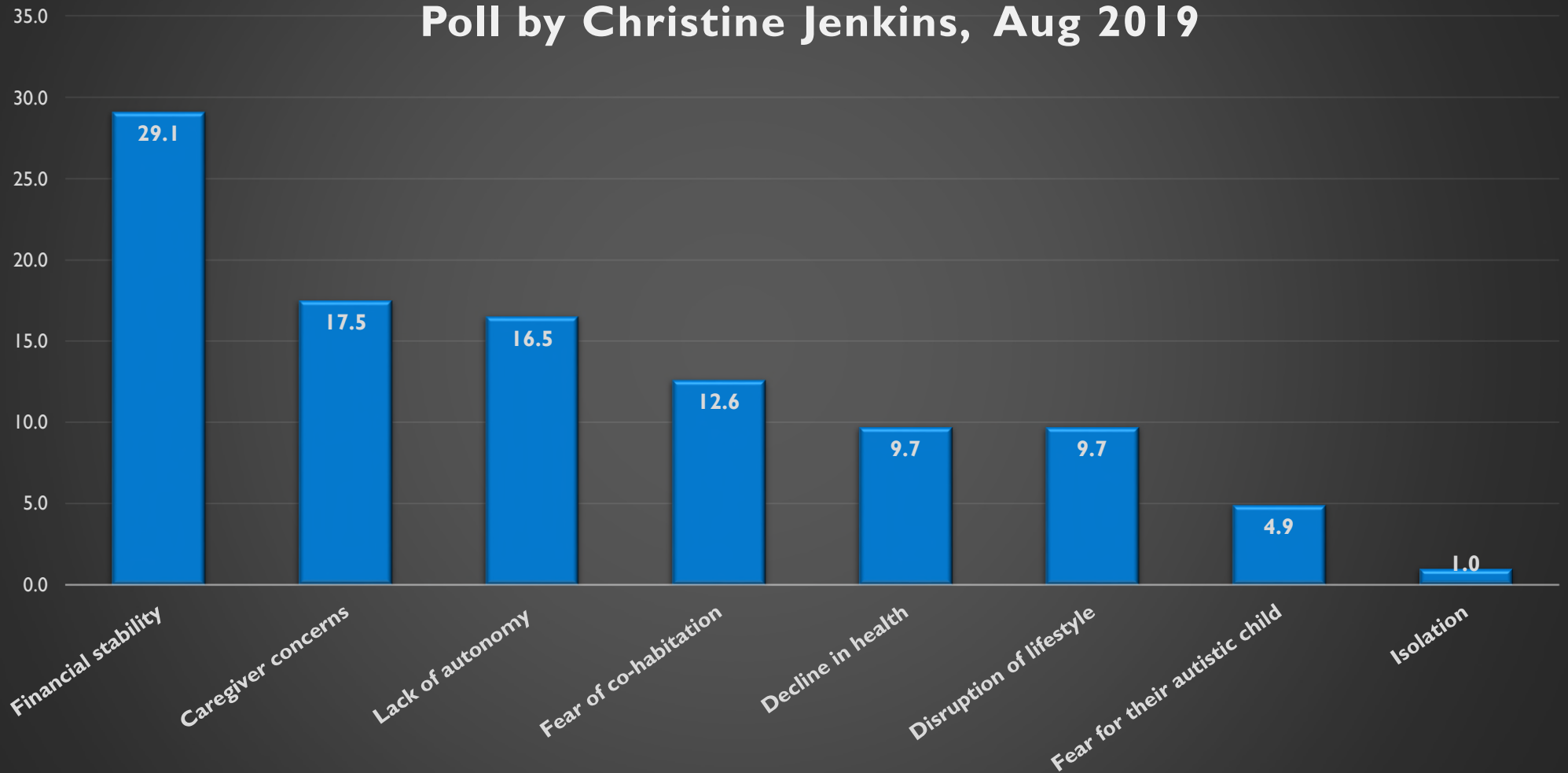
“...we can’t continue like this, because you don’t end up anywhere on a hamster wheel....”

Christine Jenkins, September 11, 2019



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



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*





## 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

# RAISE THE ROOF

Lyndsay Green,  
Sociologist

Phone interview  
August 12, 2019:

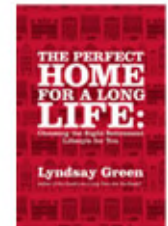
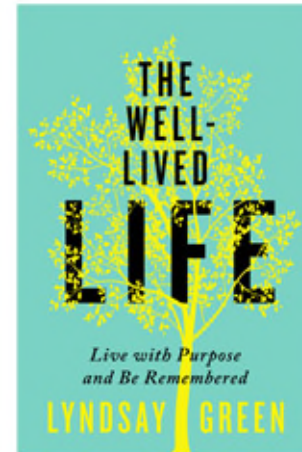
“If you don’t move  
by the time you’re  
80, you won’t move  
into a place that’s  
appropriate for you.

Christine Jenkins, September 11, 2019



## RAISE THE ROOF

# LYND SAY GREEN



We are all ‘temporarily able-bodied’  
—Stroke victim in her forties

Christine Jenkins, September 11, 2019



## Autistic people at greater risk of becoming homeless – new research

June 12, 2018 5.02am EDT

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


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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.



## What happens when people with autism grow old?


October 10, 2016 4.57am EDT

tomertu/Shutterstock.com


Email Twitter 242 Facebook 4.2k

If you mention autism to most people they will think about children, but it is a lifelong diagnosis. Children with autism grow up to be adults with autism. Little is known about how the symptoms change with age. This is

Author

 **Rebecca Ann Charlton**  
Senior Lecturer Goldsmiths

Christine Jenkins, September 11, 2019

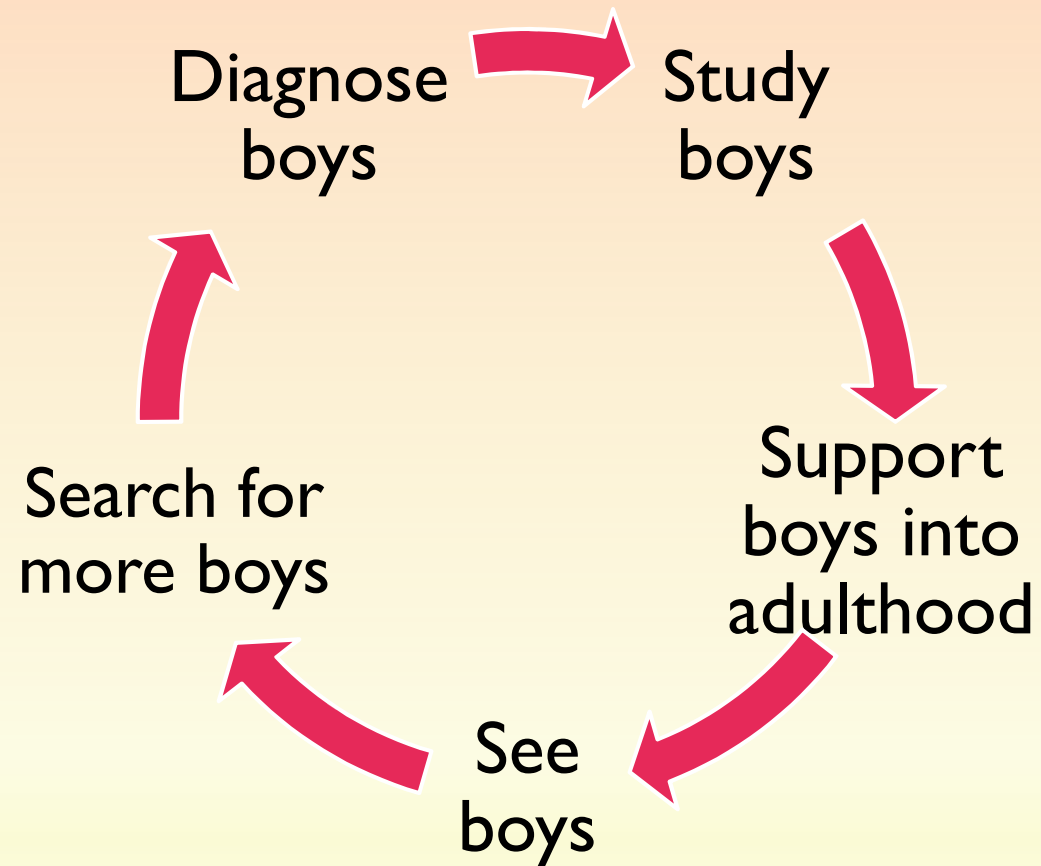


Many of us will have to work under whatever circumstances are offered, and we'll be fish out of water for most of our lives. No matter what our age, we must start now, creating the right livelihood for our social, sensory and cognitive issues.

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

## Christine's Hamster Wheel of Gender Data Bias



## MANAGE MEH-NOPAUSE

- 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

## Discussion points: in summary...

- ▶ The menopause is a time of huge change, within a time of huge change! We need to look at the menopause within the ageing process as a whole, how it fits in with other life changes around this time – **we need to pay attention to ageing in autism.**

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

## Discussion points: in summary...

- ▶ 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

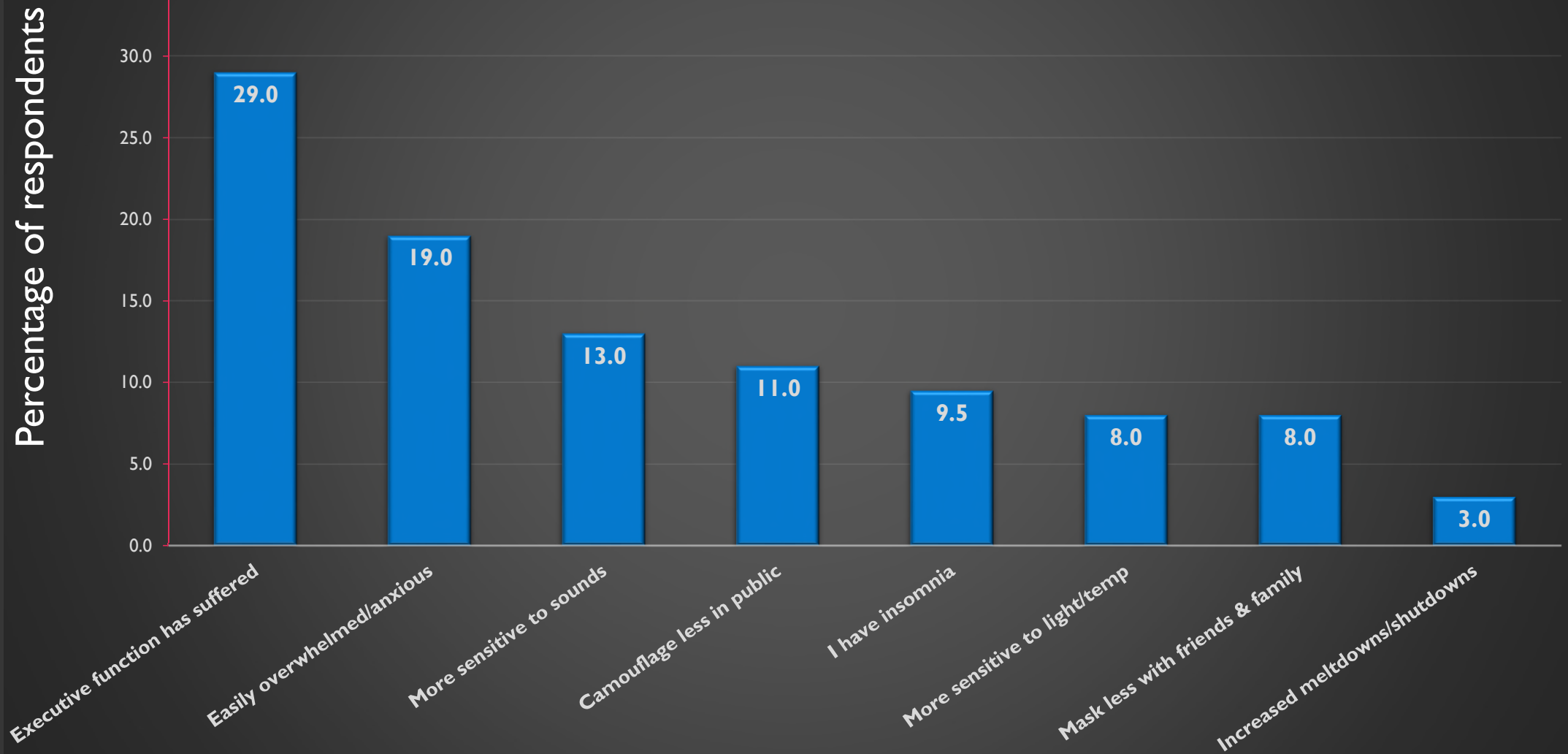
## Discussion points: in summary...

- ▶ Negative experiences with doctors is sadly really consistent with other research: autistic people find it very hard to access healthcare for their physical and mental health (Crane et al, 2019; Mason et al, 2019)...
- ▶ ... and recent reviews also suggest that doctors don't receive enough training in autism, and they don't feel confident helping patients with complex needs (Morris et al, 2019)

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



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



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## THE WEB OF WOMEN

- 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)



## THE WEB OF WOMEN

(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.



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**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 -*



## THE WEB OF WOMEN

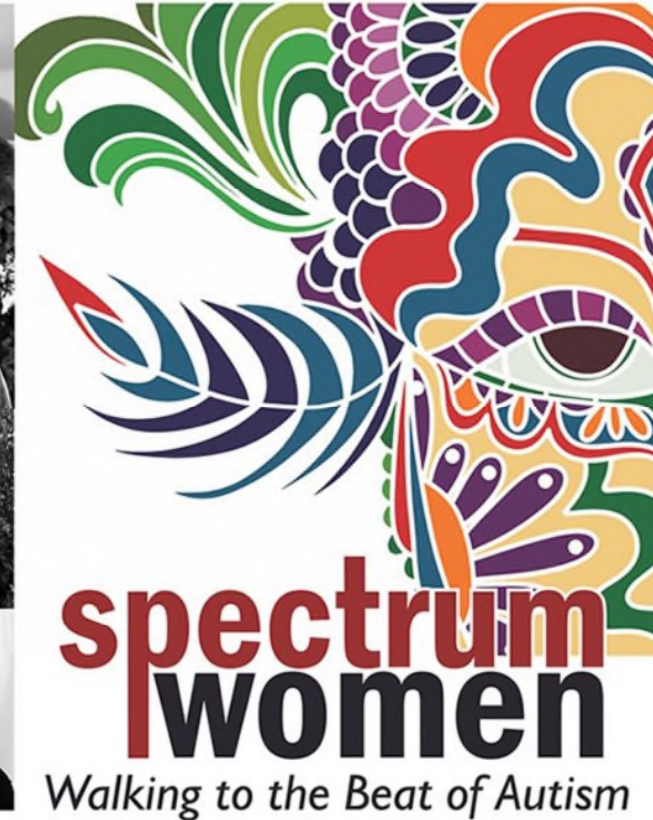
Endorsement of the anthology  
*Spectrum Women: Walking to the Beat of Autism*

“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

A woman with short blonde hair and black-rimmed glasses is speaking. She is wearing a blue top. The video frame has a black bar at the top and bottom. The text is overlaid on a black background at the bottom of the frame.

to make peace with all the parts  
of ourselves that we previously rejected

Kristín Vilhjálmssdóttir,  
Narrator,  
*Seeing the Unseen*  
documentary,  
Iceland, 2019

From the poem  
“We are Proud  
Autistic Women”  
by Kristy Forbes



*Nothing like an  
Asper Dame!*

Christine Jenkins, September 11, 2019

## THE WEB OF WOMEN

“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.



Groundbreaking study by  
Rachel Groves and team on  
importance of intense  
interests.  
Cited in my Resources list.

[Autism Res.](#) 2018 May;11(5):766-775. doi: 10.1002/aur.1931. Epub 2018 Feb 10.

### **Special interests and subjective wellbeing in autistic adults.**

[Grove R](#)<sup>1</sup>, [Hoekstra RA](#)<sup>2</sup>, [Wierda M](#)<sup>3</sup>, [Begeer S](#)<sup>3</sup>.

#### **Author information**

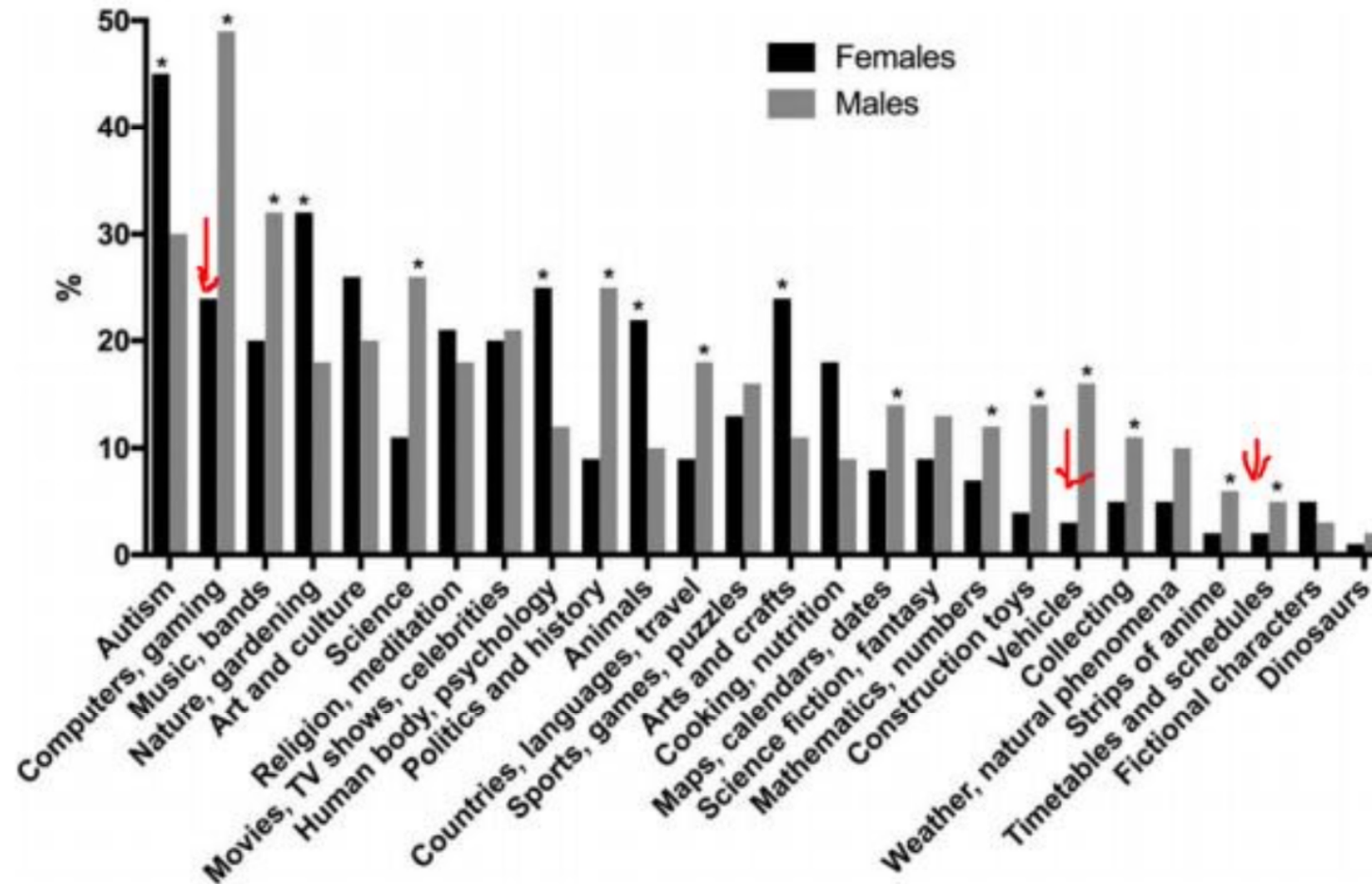
- 1 University of New South Wales, Australia.
- 2 Institute of Psychiatry, Psychology & Neuroscience, King's College London, UK.
- 3 Vrije Universiteit Amsterdam, The Netherlands.

#### **Abstract**


Special interests form part of the core features of autism. However, to date there has been limited research focusing on the role of special interests in the lives of autistic adults. This study surveyed autistic adults on their special interest topics, intensity, and motivation. It also assessed the relationship between special interests and a range of quality of life measures including subjective wellbeing and domain specific life satisfaction. About two

“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.





Christine Jenkins, September 11, 2019



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

Christine Jenkins, September 11, 2019

## 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

## 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?
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10. Who is campaigning for older autistic women? NAS? Age UK?

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



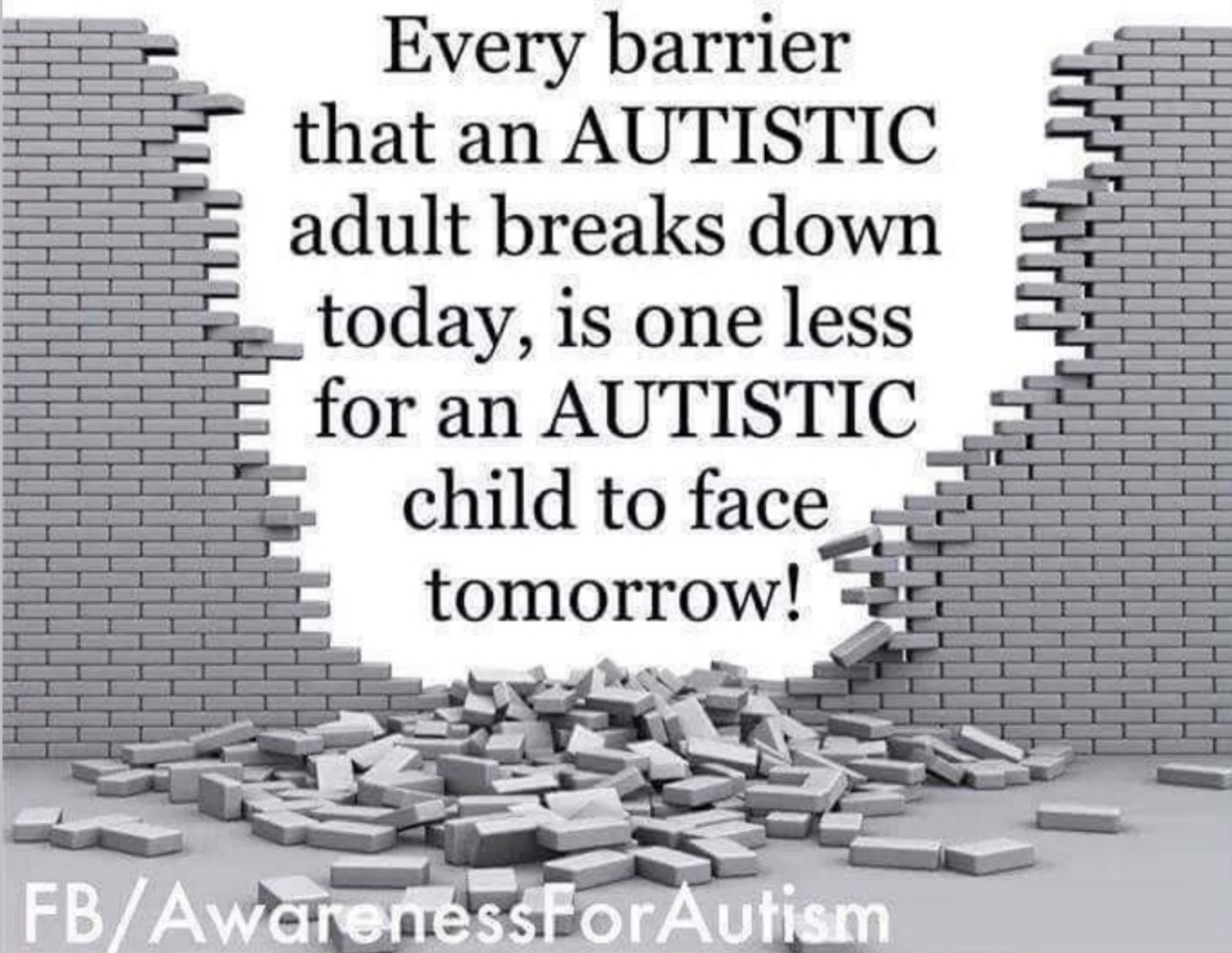
“I feel like #ActuallyAutistic people are our own welfare organization. I find little in the way of autism organizations as helpful. Quite the contrary, actually.

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

Christine Jenkins, September 11, 2019

*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?

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



## FORGING THE FUTURE

“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

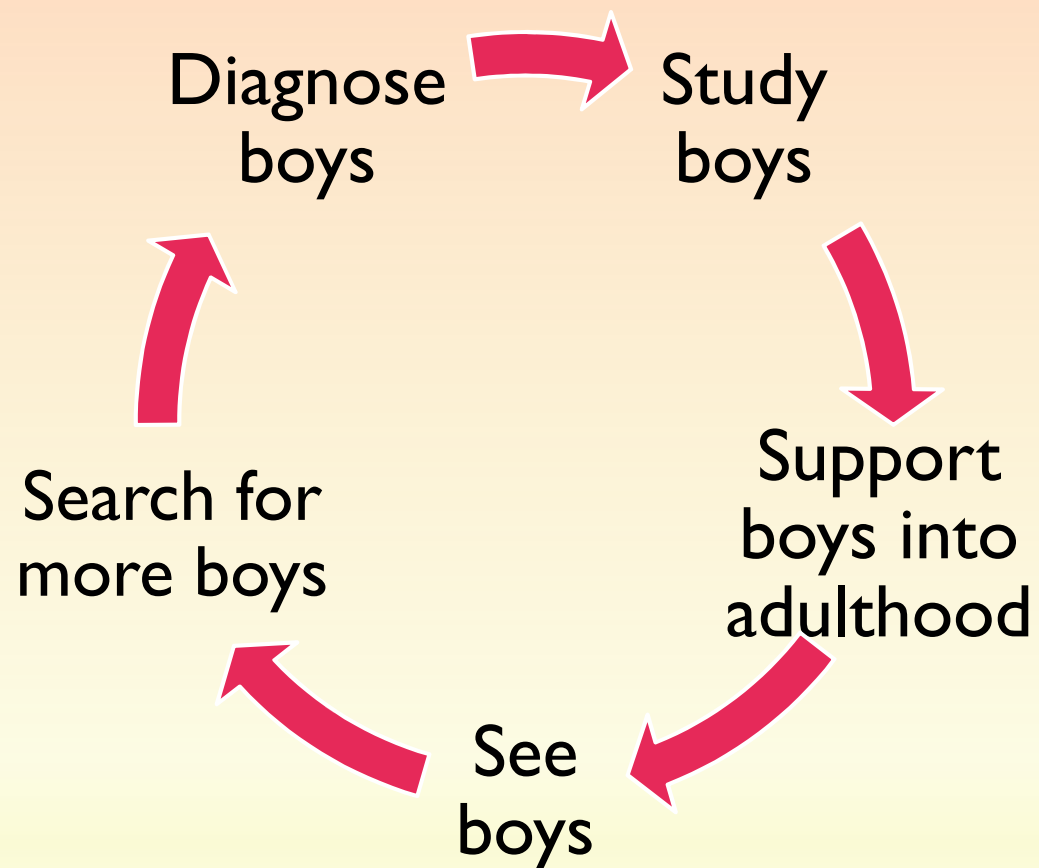
Three separate silos of elder/palliative care, autism, and  
(mental) health that don't communicate

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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







## Researching Autistic People?

Imagining that all of us are children or teenager/students?

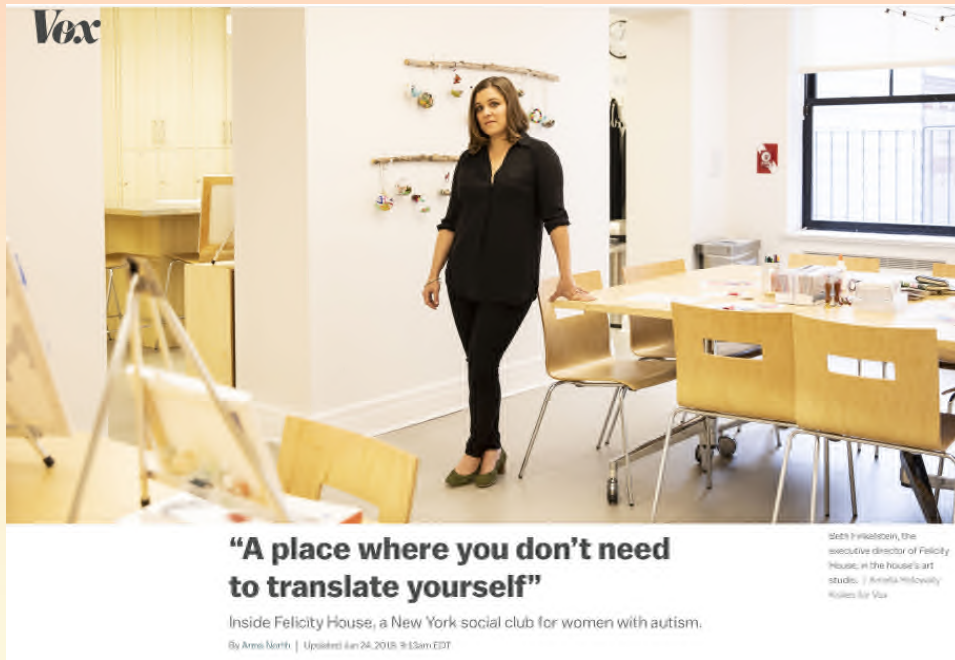
In reality, we're more likely to look like the pictures of older people here....Think carefully...when nearly every person you study is a younger male or a child.



Julia Bascom,  
Executive Director,  
Autistic Self  
Advocacy Network  
(ASAN),  
Felicity House  
advisory board

Christine Jenkins, September 11, 2019

## FORGING THE FUTURE



The quiet room is a space for members to go when they don't feel like talking. | Amelia Holowaty Krales for Vox

Today, Felicity House is open to any woman with a documented autism diagnosis. If people believe they have autism but do not have a diagnosis, Felicity House can help find a clinician. Membership and all events are free (Felicity House is a private foundation), and anyone who identifies as a woman, including trans women, can join. Felicity House has nonbinary and gender-nonconforming members as well.

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

Christine Jenkins, September 11, 2019

## FORGING THE FUTURE

“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



## FORGING THE FUTURE

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





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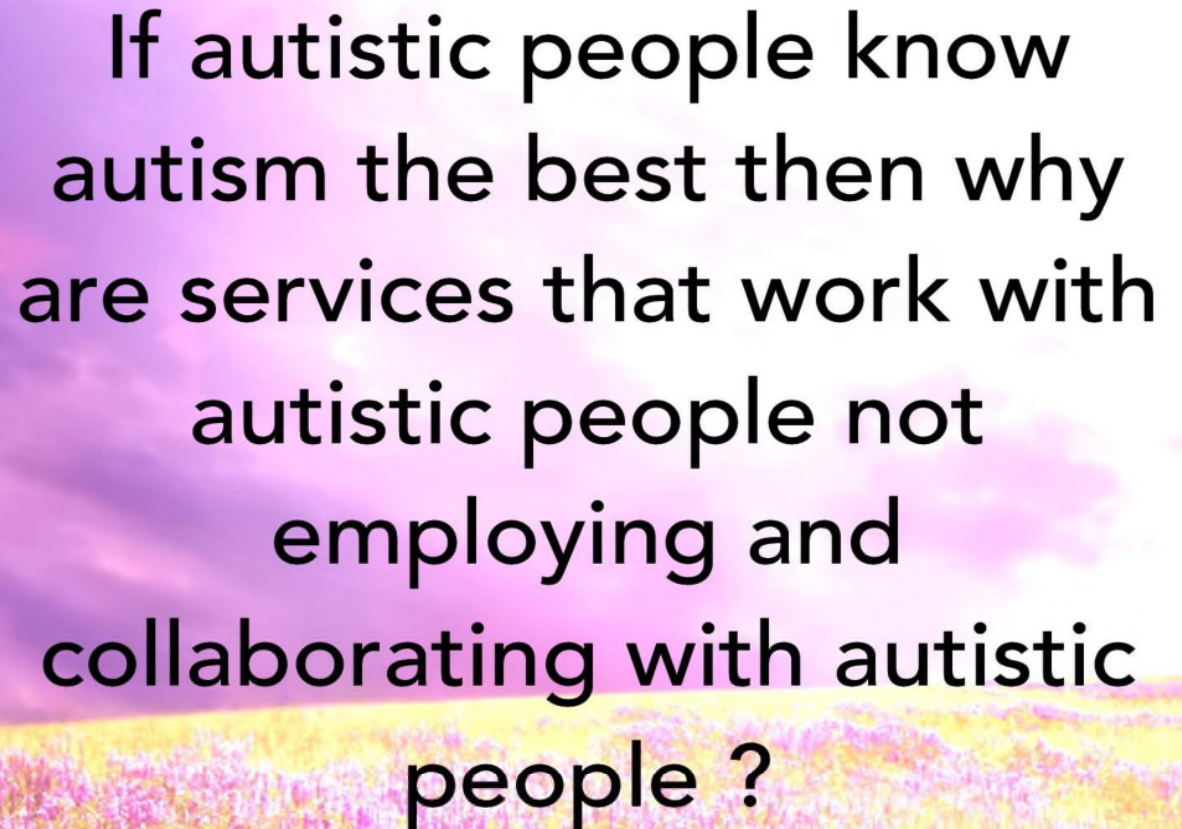
Heading home from INSAR 2019



## 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*

“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

Christine Jenkins, September 11, 2019



FB/Sue Fitzmaurice, Author  
photo (c) Ari Seth Cohen

**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?!"**



Many thanks to the NAS for inviting me.

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