

AGEING (DIS)GRACEFULLY—Resources (a selected list collated by Christine Jenkins)

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281–3294. An excellent qualitative study

Bölte, Sven. Editorial on Inclusion and Neurodiversity August 2019. “Hey autism researcher, what’s on your mind today about inclusion?” <https://journals.sagepub.com/doi/full/10.1177/1362361319870994>

Bowler, DM, Geurts and Howlin, eds. Special issue of *Research in Autism Spectrum Disorders*: Growing older with autism. Volume 63, Pages 1-78 (July 2019). Most articles behind paywall.

<https://www.sciencedirect.com/journal/research-in-autism-spectrum-disorders/vol/63/suppl/C>

Cassidy, Sarah (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* 1(2): 142–147

(2015) Suicidality in autism: risk and prevention. Network Autism link to PDF:

<https://network.autism.org.uk/good-practice/evidence-base/suicidality-autism-risk-and-prevention>

(2018) Risk markers for suicidality in autistic adults, *Molecular Autism* 9, 42

Charlton, Rebecca Ann. October 10, 2016. Links to her study

<http://theconversation.com/what-happens-when-people-with-autism-grow-old-65572>

Churchard, A; Ryder, M; Greenhill, A; Mandy, W; (2018) The prevalence of autistic traits in a homeless population. *Autism* [10.1177/1362361318768484](https://doi.org/10.1177/1362361318768484). (In press)

Crompton, Dr. Catherine <http://dart.ed.ac.uk/research/ageing-residential-care/> Many papers on general ageing under her entry in Google Scholar.

Ferguson, Jill and Val Laurie. Palliative care resources discussed in this article:

<https://network.autism.org.uk/knowledge/policy-guidance/palliative-and-end-life-care-autistic-people>

<http://www.bild.org.uk/our-services/books/health-and-wellbeing/peaceful-painfree-and-dignified/>

Note: their manual discusses a male patient.

Fletcher-Watson, Sue, Jon Adams et al. “Making the Future Together: Shaping Autism Research through Meaningful Participation”, *Autism*, NAS, August 2018

<https://journals.sagepub.com/doi/10.1177/1362361318786721>

Griffiths, Sarah et al. The Vulnerability Experiences Quotient (VEQ): A Study of Vulnerability, Mental Health and Life Satisfaction in Autistic Adults. July 2019 <https://doi.org/10.1002/aur.2162>

<https://www.sciencedirect.com/journal/research-in-autism-spectrum-disorders/vol/63/suppl/C>

Hull, Laura et al. "Putting on my best normal" Social camouflaging in adults with autism spectrum conditions, *JADD* 47, 2017 Qualitative study of 32 adults (with Petrides, Allison, Smith, Baron-Cohen, Lai and Mandy.)

Hull, Laura et al. July 18, 2019, Gender differences in self-reported camouflaging in autistic and non-autistic adults <https://journals.sagepub.com/doi/abs/10.1177/1362361319864804?journalCode=auta>

Kats, D. et al. *Journal of Neurodevelopmental Disorders* 2013, 5:27
<http://www.jneurodevdisorders.com/content/5/1/27> example of paper missing sex-disaggregated data

Kirby, Anne et al. <https://onlinelibrary.wiley.com/doi/full/10.1002/aur.2076>

"A 20-year study of suicide death in a statewide autism population". *Autism Research* Vol 12, Issue 4. April 2019. Suicide risk in females with ASD was over three times higher than in females without ASD.

Lai, Meng-Chuan check his many papers on Google Scholar. I was on his Advisory Group for a recent qualitative study of women with Yani Hamdani and Caroline Kassee. Poster presented at INSAR 2019. Articles to be published soon.

Lai, M-C, Kassee, C et al. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet*, August 2019

[https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(19\)30289-5/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(19)30289-5/fulltext)

Mandy, Will and Lai, Meng-Chuan editorial: "Towards sex- and gender-informed autism research" in *Autism*, July 27, 2017 <http://journals.sagepub.com/doi/full/10.1177/1362361317706904>

Michael, Cos. All her conference and consultant activity <http://www.autismage.com/consultancy.html>
Especially this review of her 2015 NAS talk: <https://network.autism.org.uk/knowledge/insight-opinion/autism-ageing-and-women-not-invisible-just-ignored>

Milner, Victoria et al. A Qualitative Exploration of the Female Experience of Autism
<https://link.springer.com/article/10.1007/s10803-019-03906-4>

Moseley, Dr. Rachel Report forthcoming on menopause study. She has previously been known for her work with Julie Kirkby on the effectiveness of diagnostic tools to diagnose such as RAADS-R to identify women, and On NSSIs (Non-suicidal Self Injuries). Please stay tuned! See below for Video from Discover conference with initial finding on Menopause study

Sohn, Emily "Righting the gender imbalance in autism studies, Spectrum News, 13 March 2019

Tint, Ami and Jonathan Weiss. A qualitative study of the service experiences of women with autism spectrum disorder, *Autism*, 2017 Lead author amitint@yorku.ca

Autism Canada, ARI and PAFN, *Aging and Autism: A Think Tank round table; Autism in Later Life*. Vancouver Canada Oct 28-29 2017 https://autismcanada.org/wp-content/uploads/2018/04/AC_2017-ThinkTank_Final.pdf

Wright, Scott D. Autism Aging - The Odyssey Gerontology Interdisciplinary Program University of Utah Salt Lake City, Utah, Revised Nov 2017 a meta-analysis of studies on autistic aging. He meticulously delineates Legacy Exemplary Literature (LEL) or 2011-2016 from Current Exemplary Literature (CEL), 2016

to the present. From page 17: “Inclusion of Autism advocates in the research process We must consider the voices of autistic individuals who are aging to be included in the research activities that we engage in -- not just as participants (the sample) responding to the interview or survey, but also as an integral part of “team science” (where possible) in the discovery process (e.g., authors and co-authors) and advisory boards (e.g., community programs) and policy groups. This reflects Wenn Lawson’s connection to “Nothing about us without us” – and to the participatory research work of Christina Nicolaidis.”

<https://autismcanada.org/wp-content/uploads/2018/03/The-Odyssey-of-Autism-Aging.pdf>

An older analysis mentions no women other than Temple Grandin, as recently as 2013.

<https://pdfs.semanticscholar.org/1a1a/b13cd033c486ab3f94c7d8c57c637297ce47.pdf>

Zener, Dori, “Helping autistic women thrive” in *Advances in Autism*, July 3 2019 (C Jenkins edited this article). INVEST (Identify Needs, Educate, Strengthen and Thrive) is a strengths-based neurodiversity therapeutic approach. Dori is co-moderator of Asperfemme Toronto (Asperfemme was co-founded in 2011 by Christine Jenkins in Ottawa.)

YouTube clips:

Recent presentations:

Hamdani et al. Rotterdam presentation 2018 Understanding the Health Care Experiences of Girls and Women on the Autism Spectrum (study in progress that I advised on)

<https://insar.confex.com/insar/2018/videogateway.cgi/id/942?recordingid=942>

All the presentations in Rotterdam: <https://insar.confex.com/insar/2018/webprogram/Session3969.html>

Several presentations of interest to older females. See Harwood and Grant, Moseley, and Freeth.

<https://youtu.be/DzllVigwm5k> 56:40 *When my Autism Broke: Shedding a Light on the Menopause in Autistic People*. Rachel Moseley: “There hasn’t been a single study (until now) on how autistic people cope.” Focus group of 8 individuals revealed cracks in the mask.

Discover Conference 2019, Panel—Virginia Bovell is especially good. https://youtu.be/ciby20Cg_jQ

Wenn Lawson at Autism Europe 2016 <https://www.youtube.com/watch?v=oeoAbkdcqVI>

Role models

Hannah Gadsby: “Three ideas. Three contradictions! Or not.” TED talk, June 2019

<https://youtu.be/87qLWFZManA> 18:33

Hedy Lamarr. PBS NewsHour March 2018. News report on the documentary “Bombshell: the Hedy Lamarr story.” https://youtu.be/_rlXHNeQD-s 07:34

[Acting and performing appeal to autistics because you can script what you do, and no one contradicts. Other women we strongly suspect are Frances Farmer and Marilyn Monroe; Daryl Hannah disclosed a few years ago.]

Greta Thunberg interviewed in Swedish. Start around 03:50 where she says she gets the strength to be different from her Asperger's. 12:07 <https://youtu.be/YrZ93Nbo34E> Skavlan Jan. 21, 2019

60 Minutes Australia interview in English (she is more monotone as it is her second language.) May 21, 2019 02:01 <https://youtu.be/bJ7aSc-5Yo0> Also <https://www.bbc.com/news/uk-48017083>

Books and articles

Hendrickx, Sarah. Women and Girls with Autism Spectrum Disorder. Chapter 15 "Ageing with Autism". Jessica Kingsley Publishers, London, 2015. Foreword by Judith Gould.

Lawson, Wenn. Older Adults and Autism Spectrum Conditions, an Introduction and Guide. Jessica Kingsley Publishers, London, 2015. Foreword by Carol Povey of the NAS.

Simone, Rudy. Aspergirls, especially Chapter 5 on Internalization of Blame and Chapter 20 on Getting Older on the Spectrum. Jessica Kingsley Publishers, London, 2010.

Wright, SD (ed.) Autism Spectrum Disorder in Mid and Later Life. London: Jessica Kingsley Publishers, 2016 Contributions by Judy Endow, Temple Grandin and Cos Michael.

NAS: Boehm, A (2013) Getting on? Growing Older with Autism. National Autistic Society.

Materials from the Springboard Clinic in Toronto (executive functioning/AD(H)D

<http://www.springboardclinic.com/the-book/online-course>

<https://www.theglobeandmail.com/life/home-and-design/article-designing-for-dementia-long-term-memory-care-from-the-ground-up/> August 11, 2019 Matthew Hague

<https://www.citylab.com/life/2015/09/why-seniors-are-forming-villages-to-age-in-place/405583/>

Beacon Hill Village co-housing model, Chris Bentley, September 17, 2015

There are a number of options short of institutional living, finding a mature student to live in, or a homestay (warn them "I won't be socializing with you every day." You don't need to disclose your labels.

Green Lyndsay. *You COULD live a Long Time: Are You Ready?* Green discusses the need to be proactive, making ever younger contacts, having a will and powers of attorney, giving stuff away. "Who will speak for us when we can't speak for ourselves."

Late diagnosis and missed diagnosis

<https://theconversation.com/autism-screening-tool-may-not-detect-the-condition-in-some-women-96488>

Poster by Autism Research Lab, University of Sheffield <http://www.autismresearchlab.group.shef.ac.uk/>

<https://c57057.sgvps.net:2096/cpsess1265664552/3rdparty/roundcube/?task=mail&action=get&mb ox=INBOX&uid=7&part=2&frame=1&extwin=1>

Poster: Autism and Ageing: Study of 10 Women and 25 Men: Sex Differences in Behavioral and Neural Cognitive Control and Associations with Symptoms in Older Adults with Autism Spectrum Disorder, Arizona State University Contact Melissa Walsh Melissa.stoeckmann@gmail.com

Health care

The need to train General Practitioners: <https://theconversation.com/gps-urgently-need-training-on-autism-77301>

Hamdani, Lunsy, Kasse et al. Future models of peer support y.hamdani@utoronto.ca

<http://www.researchautism.net/publicfiles/pdf/Cos%20Michael%2025.11.15.pdf> Cos Michael, Autism and Ageing consultant, slides from 2015

Michael, Cos. "Why we need research on autism and ageing", May 2016

<https://journals.sagepub.com/doi/full/10.1177/1362361316647224>
