





Autism in Adulthood:

Clinical Pearls from a Rapidly Emerging Field

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Presented at the Swedish National Conference on Neurodevelopmental Disabilities April 7, 2022



First 10 pictures of people in Google Image search for "autism" (April 2, 2022)

Autism Studies Published Over Time

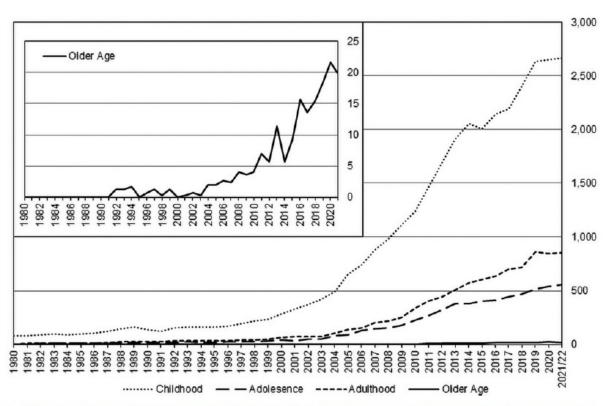


FIG. 3. The main graph illustrates the publication trends for the childhood, adolescent, adult, and older adult searches. The inset graph illustrates the number of older age search results over time with a reduced axis scale. The y-axes denote number of studies published.

Mason et al, Autism in Adulthood, 2022 online first





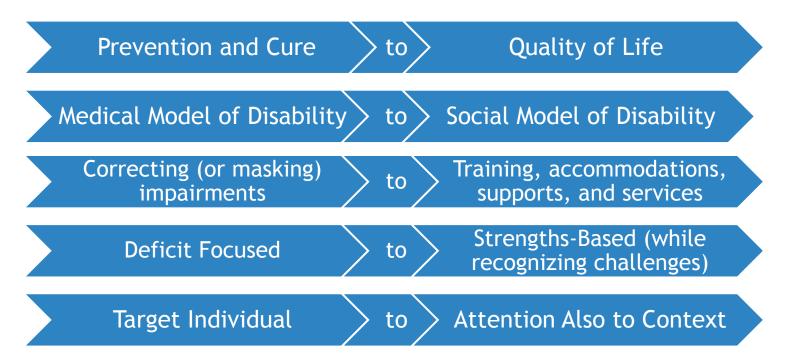
Autism Researchers, Clinicians, and Family Members Also Need to Transition...

Today's Talk



Approaches to Research and Practice

Transition to Adult Priorities / Values



No Lack of High Priority Topics...

- Stigma, discrimination, and acceptance
- Communication Access / AAC
- Sensory processing and autistic intelligence
- ► Education, employment, housing, community participation
- Sexuality, relationships, and caregiving
- Physical and mental health
- Identification and treatment of co-occurring conditions
- Healthcare and social services
- Biological, neurological, psychological, cognitive, emotional, behavioral, and social changes with aging
- Human and disability rights and advocacy
- Ethical issues in research, practice, or policy on autism
- Intersectionality with other marginalized identities

Strengths-Based Approaches

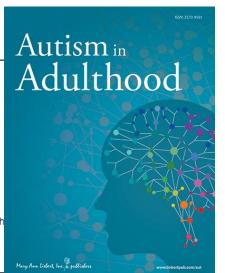
- What can the autistic person do? (Not just what they can't do.)
- That doesn't mean "sugar-coating" things or only looking at the positives.
- Strengths and challenges can co-exist (for everyone) and are in the context of societal and environmental barriers.
- Avoid stereo-typing autistic strengths. Think of strengths across the entire spectrum.
- Foster self-determination (with or without supports and shared decisions).
- Can potentially have concrete effects on practical skills, empowerment, self-impression, confidence, and employment.

For A More Detailed Discussion...

AUTISM IN ADULTHOOD Volume 3, Number 1, 2021 Mary Ann Liebert, Inc. DOI: 10.1089/aut.2020.0014

Avoiding Ableist Language: Suggestions for Autism Researchers

Kristen Bottema-Beutel, PhD,¹ Steven K. Kapp, PhD,² Jessica Nina Lester, Ph Noah J. Sasson, PhD,⁴ and Brittany N. Hand, PhD, OTR/L⁵



AUTISM IN ADULTHOOD Volume 1, Number 2, 2019 © Mary Ann Liebert, Inc. DOI: 10.1089/aut.2019.29002.aju

An Expert Discussion on Strengths-Based Approaches in Autism

Moderator: Anna Urbanowicz, PhD¹
Co-Moderator: Christina Nicolaidis, MD, MPH²
Participants: Jacquiline den Houting, PhD,³ Stephen M. Shore, EdD,⁴ I
Sonya Girdler, PhD,⁶ and Ralph James Savarese, Ph

AUTISM IN ADULTHOOD Volume 3, Number 1, 2021 © Mary Ann Liebert, Inc. DOI: 10.1089/aut.2020.29014.njw

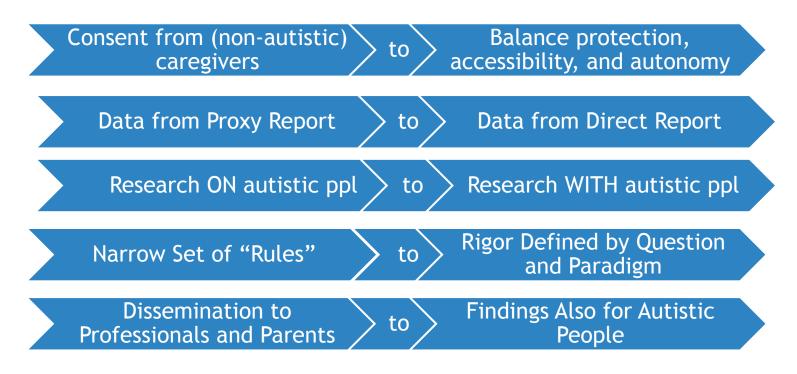
Toward a Neuroqueer Future: An Interview with Nick Walker

Nick Walker, PhD, and Dora M. Raymaker, PhD²

Clinical Implications

- ▶ Think about your approach to autistic patients:
 - ► Are you inadvertently pathologizing or dehumanizing them? Are you using an illness model?
 - Are you thinking of the impairment as residing solely in the person or are you paying attention to context?
 - Are you making unhelpful distinctions between "low functioning" and "high functioning" patients (which can harm all of them)?
 - What can you do to build on strengths and foster selfdetermination while appreciating the need for supports?

Accompanying Transition in Methods / Approaches



to

Participatory Research Approaches

- ► Have existed (outside of autism) since the mid-20th Century
- Response to problems of traditional research
- ► Many flavors (CBPR, PAR, co-production, etc.)
- Aim is to increase rigor and impact of research
- > Approaches to research can be used with any methods
- Rapidly growing popularity in autism research



Participatory Research Approaches

Including (non-academic*) community members on the research team





Equal Power Sharing (e.g., CBPR / some PAR)



Authentic Inclusion (e.g., PCOR / Co-Production)

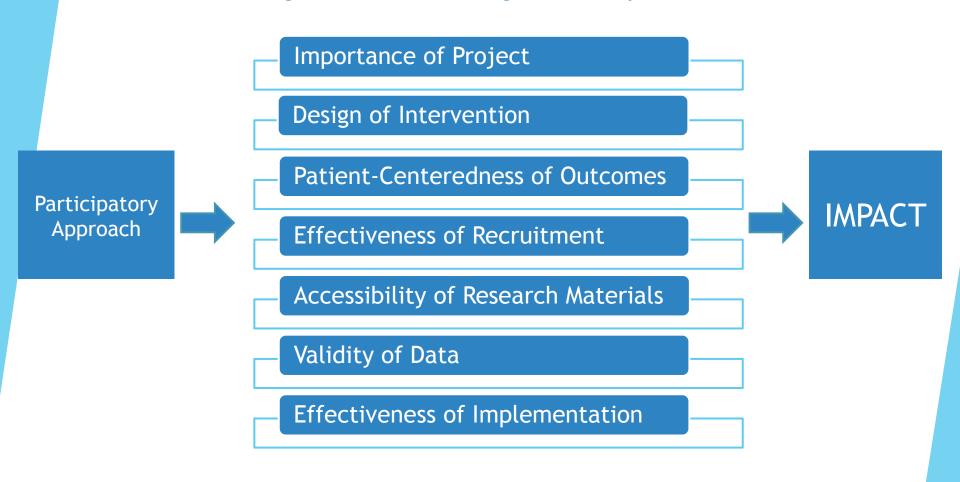


Consultation (e.g., Advisory Boards / Delphi Panels)

(And BTW, just getting data from study participants doesn't count.)

* In addition to efforts to increase diversity in academia

Meant to Strengthen Scientific Rigor and Impact





- Co-Founded in 2006 by Christina Nicolaidis and Dora Raymaker
- Autistic and non-autistic academic scientists
- Community partners: autistic adults and other stakeholders
- Community Based Participatory Research (CBPR)
 - Academics and community members serve as equal partners in all phases.

Academic Autism Spectrum Partnership in Research and Education

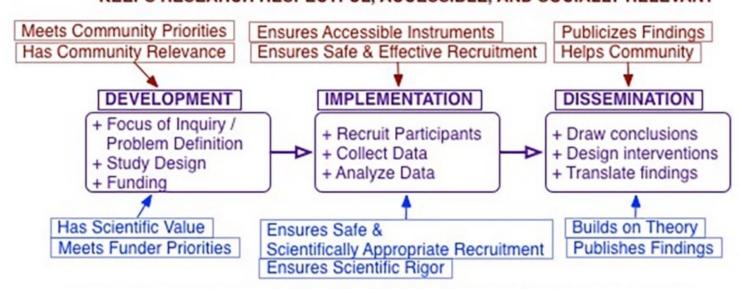


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Community Based Participatory Research



Community KEEPS RESEARCH RESPECTFUL, ACCESSIBLE, AND SOCIALLY RELEVANT



KEEPS RESEARCH SCIENTIFICALLY SOUND AND ACADEMICALLY RELEVANT

Academics

Nicolaidis et al, (2011) Progress in Community Health Partnerships

AASPIRE Research Projects







Outcomes



Mental Health



Employment







Violence and Abuse

Now....

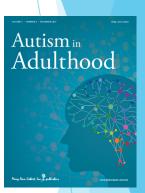


















Building brighter futures through autism research



The Risk of Building Too Fast...





And the need to build a strong foundation

AASPIRE Guidelines



AUTISM IN ADULTHOOD Volume 1, Number 2, 2019 © Mary Ann Liebert, Inc. DOI: 10.1089/aut2018.0020

Original Article



Christina Nicolaidis^{1,2}, Dora Raymaker^{1,3}, Steven K Kapp^{3,4}, Amelia Baggs³, E Ashkenazy³, Katherine McDonald⁵, Michael Weiner^{6,7,8}, Joelle Maslak³, Morrigan Hunter³ and Andrea Joyce³

Guidelines, Webinars, and Sample Materials at:

www.aaspire.org/collaborat ion-toolkit



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DOI: 10.117/1362361319830523
journals.sagepub.com/home/aut

\$SAGE

Development of the AASPIRE Web Accessibility Guidelines for Autistic Web Users

Dora M. Raymaker, PhD, 1.2 Steven K. Kapp, PhD, 2.3 Katherine E. McDonald, PhD, 2.4 Michael Weiner, MD, MPH, 2.5 Elesia Ashkenazy, BA, 2 and Christina Nicolaidis, MD, MPH, 1.2.6

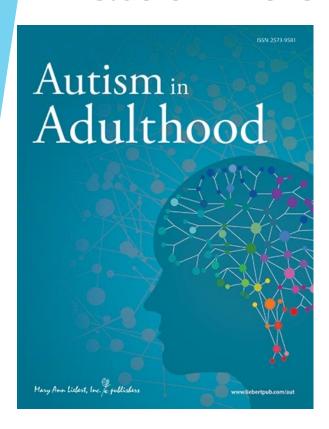
AUTISM IN ADULTHOOD Volume 2, Number 1, 2020 Mary Ann Liebert, Inc. DOI: 10.1089/aut.2019.0074 Advances in Measurement Methods

Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability:

Lessons Learned and Recommendations

Christina Nicolaidis, MD, MPH,¹⁻⁴ Dora M. Raymaker, PhD,^{1,3,4} Katherine E. McDonald, PhD,^{3,5} Emily M. Lund, PhD, CRC,^{4,6} Sandra Leotti, PhD,^{1,4,7} Steven K. Kapp, PhD,^{3,8} Marsha Katz, MS ED,^{4,9} Leanne M. Beers, PhD,⁴ Clarissa Kripke, MD,^{3,10} Joelle Maslak, BA,³ Morrigan Hunter, MA,³ and Kelly Y. Zhen^{1,3}

Inclusion in the Literature



- Focuses on most pressing issues affecting autistic adults.
- Editor-in-Chief Christina Nicolaidis
- Associate Editor Dora Raymaker
- ▶ 10 autistic adults on editorial board (and many family members and clinicians)
- Anti-ableist Language Policy
- Each manuscript gets traditional scientific peerreviews AND review by autistic adult
- Insights section for personal perspectives of autistic adults
- Approximately 1/3 of articles have included autistic authors so far

www.liebertpub.com/aut

- Marked OVER-USE of proxy reporting!!!
- ▶ But, lack of validated instruments for use with autistic adults
- Autistic people consistently note lack of accessibility of "standardized" instruments -> significant threat to validity
- Common concerns:
 - Difficult or imprecise language / response options with vague terms
 - Insufficient context or instructions
 - Varying answers in different situations
 - ▶ Difficult to separate from autism or incompletely captures construct
 - Offensive and ableist language or concepts
- Participatory process for adapting or creating accessible instruments
 Nicolaidis et al. (2020) Au

Nicolaidis et al. (2020), Autism in Adulthood. 2(1):61-76. Nicolaidis et al. (2021), Autism. 25(3):786-799



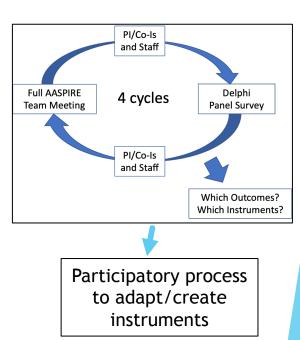
AASPIRE Outcomes Project

- What are most important outcomes to measure when evaluating services for autistic adults?
 - ▶ How can we best measure them?
- Created AutPROM Toolbox a set of accessible patient-reported outcome measures for use with autistic adults
 - Large prospective cohort study to test toolbox in settings where services are likely to be delivered (and follow outcomes)
 - Will make measures widely available to researchers and service providers

AutPROM Toolbox Outcome Measures



- Overall Health
- Mental Health (including measures of Depression, Anxiety, Emotional Wellbeing, and Autistic Burnout)
- Self Determination / Freedom to Make Choices
- Barriers to Communication
- Community Participation
- Employment Satisfaction
- Social Support
- Quality and Satisfaction with Healthcare Services
- Quality and Satisfaction with Social Services



Survey also includes demographics and disability characteristics, experiences of discrimination, and a module on gender identity, sexual orientation, and LGBTQIA+ stigma.

Population Characteristics

- Lots of challenges many unknowns.
- Cohort effects (and many misunderstandings)
- ▶ No clear systematic sampling frame -
 - Different recruitment strategies yield totally different populations
- Likely still underdiagnosing women and racial/ethnic minorities
- Possibly very high prevalence of LGBTQIA+ (especially trans and non-binary)

Clinical Implications

- ▶ If doing research: consider a participatory approach
 - ▶ But don't underestimate how much work it is (or just pretend to do it)
- If using research findings: be weary of studies that have not appropriately included autistic adults as coresearchers or fully addresses accessibility.
- If using scales or screeners in practice: do not assume measures for general populations or parents are valid or reliable with autistic adults. Check for accessibility and respectfulness.
- ▶ Don't assume that "systematic samples" are representative of the whole population

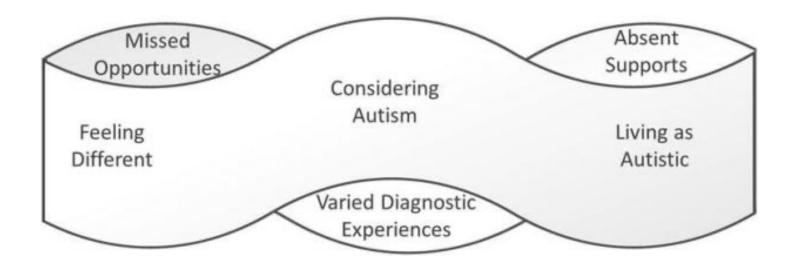
Mental Health

Adult Diagnosis Can Be Tricky

- Most instruments / diagnostic schedules developed with children in mind
- ▶ Not as well validated in adults
- Systematic review of questionnaires and diagnostic measures noted many limitations
 - Recommend combination of structured questionnaires
- Largely crafted based on how others perceive autistic child not how autistic person experiences autism.

Wigham et al (2019) Autism, 23(2): 287-305. Jones (2022, online first) Autism in Adulthood

The Experience of Seeking an Autism Diagnosis as an Adult



Known Co-Occurring Mental Health Issues, Developments, and Challenges

- ▶ High rates of anxiety, depression, and cPTSD,
- > 7-9x the odds of suicide
- ► Higher risk of experiencing violence and abuse
- Growing evidence for adapted mental health interventions (e.g. CBT)
- Limited workforce capacity (lack of autism training for many counselors seeing adults)
- Fragmented systems

Substance Use Disorders

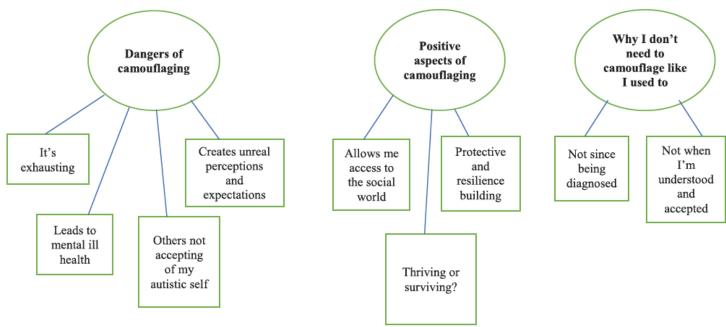
- ► Highly variable literature (but 11 of 26 studies rated as high quality)
- ► Risk often cited as lower than general population (when looking at all autistic people), but risk may be very high in some sub-populations
- Risk factors include: No ID, psychological distress, executive function deficits, family hx, low social support
- ▶ No adapted screening measures or treatments yet

Ressel et al (2020) Autism, 24(4): 899-918

Clinical Implications

- Recognize the potential benefits, and many barriers to adult diagnosis. Don't assume any self-diagnosed adult is faking it.
- Don't underestimate the impacts of co-occurring mental health conditions! Try to disentangle and treat.
- If possible, learn how to adapt interventions to be more accessible to autistic adults (but don't refuse to see them).
- Remember to try to prevent, identify, and treat substance use disorders, especially for autistic adolescents and adults without ID who have other risk factors. Easy to miss!!!

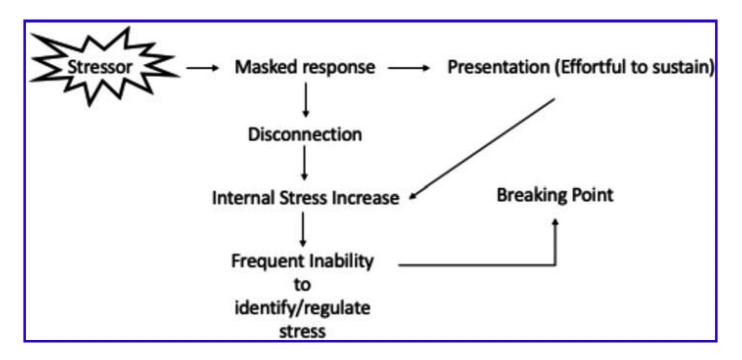
Autistic Adults' Experiences of Camouflaging and Its Perceived Impact



N=277 autistic adults

Bradley et al (2021) Autism in Adulthood, 3(4):320-329.

Conceptual Analysis of Autistic Masking: the Narrative of Stigma and the Illusion of Choice



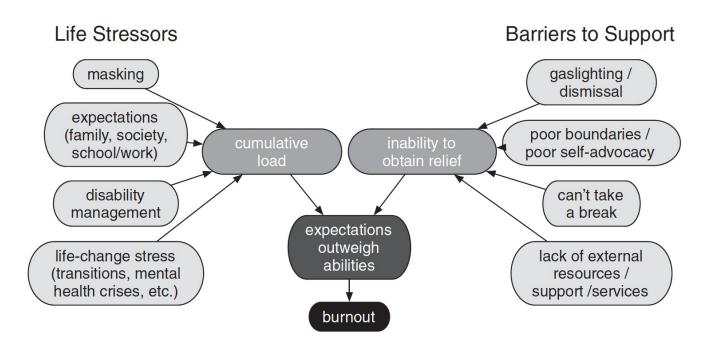




- Well-recognized by autistic community, but previously completely absent from the academic and clinical literature
- Qualitative study (19 public internet sources and 19 interviews)
- Pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus.
- ► Felt to be due to chronic life stress and a mismatch of expectations and abilities without adequate supports.
- ▶ Differs from workplace burnout and depression.
- Possibly plays large role in poor life outcomes and suicide.
- Possibly helped by acceptance, supports, reduced load

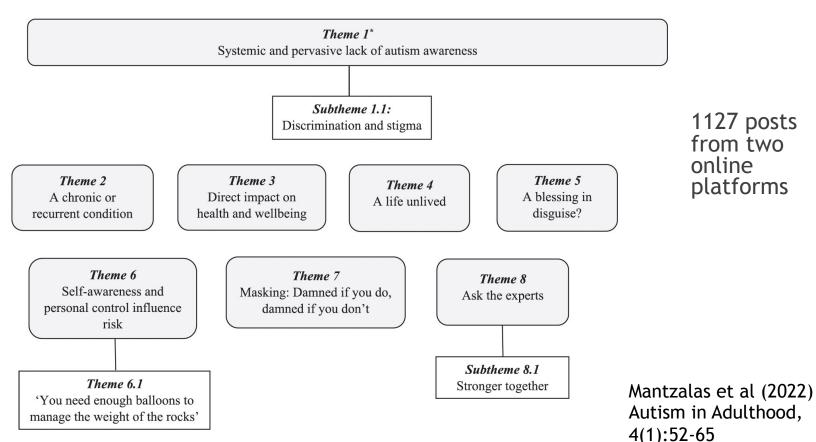
Autistic Burnout - Conceptual Model





Raymaker et al, (2020) Autism in Adulthood, 2(2):132-143

New Autistic Burnout Study



Clinical Implications

- Be extremely cautious of interventions that may increase masking.
- Consider autistic burnout as a potential cause for exhaustion, loss of skills, and increased sensitivities.
 - May be a large contributor to poor functional outcomes and high suicide rates
 - ► Help patients find way to decompress
- Actively work toward increasing acceptance.
 - It isn't just politically correct lack of acceptance is a major driver of poor mental health and other life outcomes

Part 3

Physical Health and General Healthcare

Associated Physical Health Conditions

- Reduced life expectancy
- Epilepsy
- Gastroesophageal reflux disease, constipation, dysphagia
- Feeding and nutrition problems
- ► Metabolic syndrome
- ?? What happens with aging ??

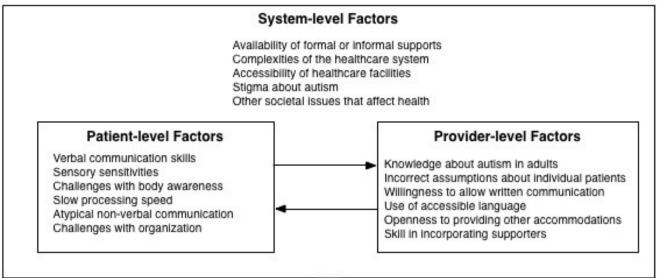


Healthcare Disparities

- Greater unmet healthcare needs
- Greater Emergency Department use, hospitalizations, mental healthcare use, and primary care use
- Lower use of Pap Smears and gynecologic examinations
- ► Lower satisfaction with patient-provider communication
- Lower healthcare self-efficacy
- Greater self-reported barriers to healthcare







39 Autistic Adults16 Supporters



Barriers to Healthcare (Systematic Review)

- Communication
- Sensory sensitivities
- Provider's degree of flexibility
- Slow processing speed
- Provider's negative attitudes
- Availability of supports
- Healthcare system complexity
- Emotional

- Challenges with organization
- Need for consistency
- Provider's lack of knowledge
- Negative prior experiences
- Stigma
- Socioeconomic factors
- ► Highly variable needs
- Problem didn't seem serious
- ► Too busy / other priorities
- Problem considered temporary

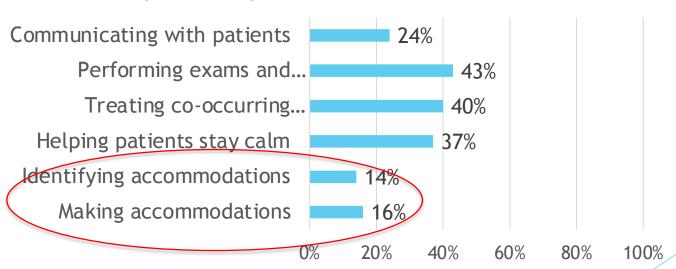
Adult Healthcare Workforce Training

- Consistent findings across studies document lack of training of GPs / PCPs on autism in adulthood
- Some may have knowledge about autism in children
 - ▶ But again, adults are not big kids
- Low priority topic
 - ➤ Small #s; young; much lower proportion of clinic day (compared to older adults)
- ▶ No adult equivalent of developmental pediatrician
 - ▶ Often no one to provide expertise, referrals, resources



Provider Self-Efficacy in Caring for Autistic Adults

Proportion of providers who felt confident in:



143 general practitioners in3 health systems in the US

www.autismandhealth.org



HOME • ABOUT • SITE MAP • PARTNERS • CONTACT

Theme: Light (default)

A A Search

 A A search

Search

AASPIRE Healthcare Toolkit

Primary Care Resources for Adults on the Autism Spectrum and their Primary Care Providers

This web site has information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on primary healthcare, or healthcare with a regular doctor.

The resources on this site are meant to improve the healthcare of autistic adults. They were made by the <u>Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE)</u> through a series of research studies funded by the <u>National Institute of Mental Health</u>. AASPIRE hopes that you will find these resources helpful.



Make a Personalized Accommodations Report for your healthcare provider.

This section also has information on:

- Healthcare
- Staying Healthy
- · Your Rights in Healthcare
- · Autism Information
- Medical Information
- · Checklists and Worksheets



This section has information on:

- · How Autism Can Affect Healthcare
- · Tips for Successful Office Visits
- · Legal and Ethical Considerations
- · Autism Information, Diagnosis, and Referrals
- Associated Conditions

Healthcare providers also might want share our <u>Autism Healthcare</u> <u>Accommodations Tool</u>, and other <u>checklists and worksheets</u> with their patients on the autism spectrum.

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Nicolaidis et al (2016) Journal of General Internal Medicine, 31(10), 1180-1189.







- Patient or supporter fills out a survey
- Computer uses answers to create a personalized and healthcare provider-friendly report of accommodations

Lots of Other Efforts and Pilot Programs

- Adult autism health checks in the UK (Newcastle group) and in Australia (CRC)
- Project ECHO Videoconference Training Programs for community based primary care providers (e.g., Autism Transition ECHO in US)
- Autism-Specific Clinics within Adult Primary Care (US)
- Possibly combining with other communication disabilities???
- Possible "Developmental Medicine" adult sub-specialty in the future??

All still early - lots more work to do!

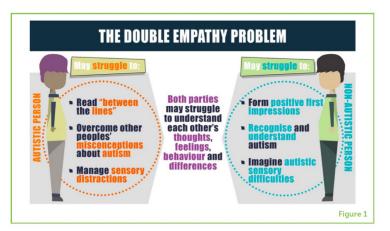
Clinical Implications

- Patients may not seek care when they need it work to decrease barriers
- High risk of missing preventive care, despite overall greater healthcare use
- Accommodations are key to providing care to adults -Learn how to make patient-specific accommodations.
 - ► Feel free to use healthcare toolkit (or adapt it)
- ▶ Need better approaches to training workforce
- Let's not wait until large cohort "suddenly" reaches middle age and needs more healthcare!

Relationships

Autistic Social Impairments vs. the Double Empathy Problem

- Challenges with social communication is characteristic of autism
- Strategies have largely focused on teach "social skills"
- ▶ But communication depends on **both** people
- Damian Milton coined the term "double empathy problem" in 2012 to focus on mismatch between communication styles between autistic and non-autistic people
- Growing literature focused on challenges non-autistic people have understanding or interacting with autistic people.



Neurotypical Perceptions of Autistic Adults

- Lots of studies showing that neurotypical adults rate videos of other neurotypical adults more highly than they do autistic adults (many variations).
- Variable findings about explicit (conscious) bias
 - > ? social desirability bias (and how low is the bar)?
- Evidence of implicit (unconscious) bias toward autistic adults.
- ► Trainings to help NTs Decrease Bias against Autistic People
 - ► Small effects in decreasing explicit bias / ratings, but not very effective for implicit bias.

Markers of Rapport in Autistic and Non-Autistic Interactions

> Study of autistic and non-autistic people passing story down chain.

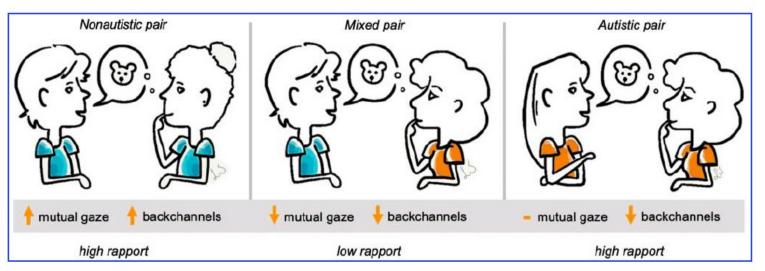


FIG. 2. Summary of results across pair types. Mutual gaze duration % and backchanneling rate are indicated as high in nonautistic pairs with upward arrows. In mixed and autistic pairs a downward arrow indicates lower use of a particular signal compared with nonautistic pairs, whereas a dash indicates no significant difference.

"This is Just How this Friendship Worked" - Experiences of Abuse

- Qualitative study of 43 autistic adults
- Cycles of victimization / poly-victimization
- Problems with trust (trust/distrust, self-blame)
- ► Challenges recognizing victimization (over/covert abuse, normalization, later realizations)
- Role of heightened compliance (desire to please, forced compliance, non-confrontational)

Pearson et al (2022 online first) Autism in Adulthood

Sensory Features, Sexuality, and Relationships

- Qualitative study of writings from autistic people
- Both sensory seeking/avoidant patterns across modalities (touch, sight, sound, smell, taste) affected sexual experiences and behaviors in + and ways.
 - ▶ Some patterns caused confusion, distress, frustration
 - Some people avoided activities due to sensitivities
 - Some seek out more intense sensations, felt intimacy promoted calming/self-regulation
- People wrote about strategies they used to enhance or enable sexual activity

Gray et al (2021) Autism in Adulthood, 3(3):238-246

Clinical Implications

- The burden of change does not have to be held completely by autistic people.
- It may take significantly more than superficial trainings of nonautistic people to reduce implicit bias or improve empathy of autistic people.
- Believe autistic people when they tell you people don't like them, they bully them, or they abuse them.
- Recognize that positive autistic-to-autistic interactions may not look like non-autistic ones.
- Actively talk to patients (with their permission) about sexuality, including how sensory issues may affect experiences and behaviors.

Part 5

Employment

Employment

- Long-known high rates of unemployment and underemployment
- Challenges both with obtaining and maintaining employment
- Programs often count "success" as obtaining any job even if not aligned with person's skills or interests
- Many questions remain:
 - ▶ Whether to disclose autism?
 - ▶ What helps people be successful in their jobs?
 - ▶ What would help improve employment outcomes?

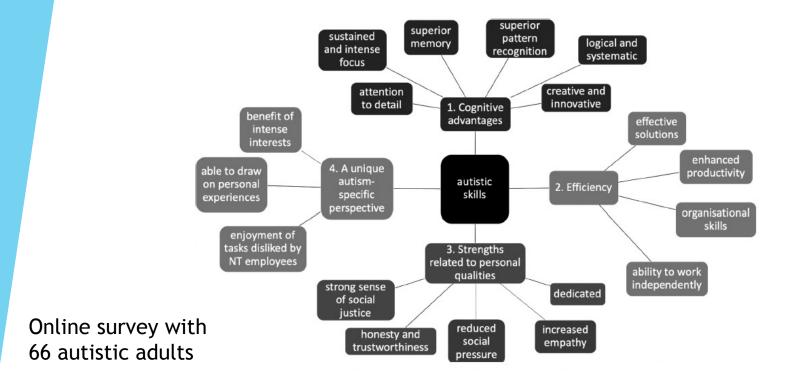
Simulated Hiring Decisions with and without Disclosure

- Non-autistic raters shown video clips of simulated job interviews.
 - ► Participants rated non-autistic candidates more favorably and hired them more often.
 - ► Telling participants that job candidates were autistic (whether or not they were) did not change ratings, but somewhat decreased "hiring" gap.
 - ► However, unclear how this would translate to real life.

Actual Disclosure in the Workplace

- Survey of 238 autistic adults in the UK with employment experience
- > 55% disclosed only to some people; 35% to everyone
- <30% disclosed on application or during interview</p>
- Mixed experiences (positive, neg, and neutral) after disclosure
- ► Top reasons to disclose: understanding, adjustments
- ▶ Top reasons not to disclose: fear of neg perceptions /bullying

Strengths and Abilities in the Workplace



Cope and Remington (2022), Autism in Adulthood, 4(1):22-31.





- 45 autistic employees
- supervisors
- 8 key informants



Figure 1. Model of Findings: Experiences and Facilitators that Interact with Dimensions of Success.

Clinical Implications

- ▶ We know employment can be a challenge
 - ▶ But there are successes and success should still be judged by the person.
- ▶ Build on strengths and interests.
- Recognize that disclosure can be a very positive or negative experience. Help create safe disclosure practices.
- Work to create more neurodiversity-friendly workplace cultures and structures; find ways to create flexibility (and bypass traditional Human Resources).

Take Home Points

Take Home Points

- Most autistic people will live most of their lives as adults.
- It's time for autism researchers, practitioners, and communities to transition to adulthood.
- ▶ We are still a very young, but rapidly growing field.
- ▶ Need better instruments, interventions, research.
- But there are still important implications.
 - Build toward an anti-ableist world that accepts, supports, and values autistic people for who they are.
 - Doing so doesn't mean ignoring that autism can also create significant disability and hardship, especially in a non-autistic world.
 - Include autistic people as partners (in research, education, practice, and life)
 - ▶ Value all autistic people regardless of their strengths and challenges.

Thank you to the AASPIRE partners, participants, and funders

- National Institute of Health
 - ► R01MH121407 (Outcomes), R34MH092503 (Toolkit Development), R34MH111536 (Toolkit Integrations), R21MH112038 (Employment), R01HD105655 (Pregnancy App) R21HD078830 (Pregnancy Qual), K23MH123934 (Suicide Prevention)
- The Centers for Disease Control (Partnering Project)
- Institutional
 - NIH via OCTRI (CTSA UL1 RR024140) for pilot-funding, KL2TR002370 (institutional training award for Dr. Raymaker); NIH BUILD EXITO support for pilot funds and research assistants; Portland State University and OHSU (Burnout), the Burton Blatt Institute (Wellbeing)
- Foundations:
 - Fulbright Foundation (Hospital) and the Medical Research Foundation (Employment measurement)