Autism and Aging
Available Research and Suggested Supports

Presenter(s)
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Who We Are

Dr. Elizabeth Scheel-Keita:
- Professor of Sociology, PhD in Social Ecology, specializing in criminology, disability, family & gendered violence, and deviance.
- Autistic raising two autistic children, one adult and one teenager.
- Will be using Identity First language vs. Person First language as this is the preference of the autistic community.

Dr. Bridget Conlon-Mayfield:
- Associate Professor of Sociology

Abbreviations to know
- ND=Neurodiverse, includes autistics, adhd, etc.
- NN=Neuronormative
- STIM=Self-Stimulating Behavior
- SPIN=Special Interest
What is Autism?

**See Handout #1**

**DSM V: A Developmental Disorder based on how other people observe and experience the autistic person**

- **Persistent deficits in social communication** and social interaction
- **Restricted, repetitive patterns of behavior**
  - Inflexible, fixated, sameness
  - Sensory challenges
  - Behavior challenges
- With or without intellectual impairment
- With or without language impairment
- There are no subtypes, all prior dx are now Autism Spectrum Disorder
- Levels are not about functioning, but about support needed.

**A Neurological Difference that is equally valid to neuronormative ways of being and is disabling because world is set up for neuronormative people.**

- **Differences in social communication and social interaction**
  - May prefer parallel activities
  - May use AAC to communicate
  - Loves to communicate about special interests (SPIN)
  - Behavior is communication
- **Passionate about things they are interested and research them intensely.**
- **Sensory differences**
- **Feels things more intensely**
- Autism does not equal their co-morbid
- Support needed varies even within same day

**Center**
Center Autistic voices on their internal experiences of autism and their fears, hopes, and experiences with aging.

**Move**
Move past stereotypes and myths about autism.

**Introduce**
Introduce common co-morbid that might complicate care.

**Review**
Review the research on autism and aging.

**Provide**
Provide ideas for supporting Autistics in a variety of settings as they age.

**Warning**
Content Warning: Mentions of suicide and trauma
AUTISM SIGNS IN ADULTS THAT MAY HAVE BEEN MISSED AS KIDS

SOCIAL SIGNS
- May feel, like you become whoever you’re around most.
- May constantly rehearse conversations or interactions.
- May feel as though you are always on a stage.
- May have a few close friends not many acquaintances.
- May see the world literally and in black and white.
- May struggle with other people breaking rules.

BEHAVIORAL SIGNS
- May often fidget, chew, tap, or other repetitive behaviors.
- May get more or less upset at something than is “appropriate.”
- May be very involved in specific hobbies or interests.
- May struggle to adjust when plans change without warning.
- May have routines that don’t seem to have a real purpose.
- May struggle in situations that are unfamiliar.

SENSORY SIGNS
- May be a very picky eater with few preferred foods.
- May struggle with noises, touching, or sensory input.
- May seek out squeezing, rubbing when overwhelmed or upset.
- May chew, rub or tap certain materials obsessively.
- May struggle to process visual or auditory information.
- May struggle to settle body down enough for restful sleep.

COMMUNICATION SIGNS
- May experience pain or discomfort during eye contact.
- May struggle to keep track of a fast conversation.
- May take jokes very literally, and not understand teasing.
- May miss sarcasm or subtleties while others are speaking.
- May prefer to communicate over text or email.
- May not understand why blunt honesty is seen as rude.

AUTISTIC STRENGTHS

1. Visual skills: visual learning, depth perception
2. Attention to detail: thorough & accurate
3. Creativity: unique way of thinking, novel solutions to problems
4. Integrity: honest & trustworthy
5. Empathy: excellent social skills, high IQ
6. Memory: excellent memory and memory
7. Unconventional skills: unique cognitive abilities
8. Analytical: problem-solving skills
9. Deep focus: concentration & responsiveness to structure
10. Critical thinking: sound logic, behavioral

11. Proactivity: self-assurance, self-confidence
12. Kindness: sensitive, issues of difference

13. And so many more...

10 Positive Things About Autism by the girl with the curly hair

1. Autistic people are usually highly dedicated to, and interested in, their interests
2. Autistic people may be very creative and direct
3. Autistic people may have very good attention to detail. Their work is likely to be thorough and accurate
4. Autistic might be more likely to be in control of their emotions and more interested in new things and environments
5. Autistic people are likely to be very adaptable and committed. They will stick to plans and follow through with things
6. Autistic people may have exceptionally good awareness of themselves and others
7. Autistic people may be very sensitive to sounds, smells, sights, etc., as well as their own and other people’s feelings
8. Autistic people are likely to think about the future their own short-term
9. Autistic people are likely to be more accepting and understanding of difference and may challenge norms
10. Autistic people have a different way of thinking about things which can lead to creative ideas and remarkable achievements

Always remember that everyone is different. These are general findings and may not be true for everyone. Find out more about Autism & Embracing Diversity at www.Thats4WitsTheCurlyHair.co.uk
Perceptions of Autistics

- Autistic people are constantly told they are “too _____”
  - Too much, too intense, too real, too honest/blunt, too open/trusting, too serious
  - Too sensitive, too crazy/weird, too dramatic, too negative,
  - Too hyper, too slow, too clumsy, too loud, too messy, too impulsive
  - Too smart, too detailed, too perfectionistic, too rigid, think too much

- They lack empathy
  - They may not know how to express it in a neuronormative way, but they do have empathy
  - They may be confused by picking up on other people’s emotions

- They have disordered communication vs. different communication

- They are violent (more likely than neuronormative to be victimized, but not to be perpetrators of violence)
  - Aggression is almost always due to sensory dysregulation or emotional distress or the fight/flight response

Why is the Research Sparse?

- Relatively recent diagnosis
- Shifts in the diagnostic criteria from DSM-IV vs. DSM-V
- If people have survived to adulthood, they may have never been diagnosed
- Initially considered an issue in children
- Communication differences may limit study availability
  - E.g. people who do not speak (Riccio 2020)
Study Design and Measurement Issues

• Dickter et al. – Neurotypical adults had negative implicit bias, but positive explicit bias
  • More autistic behaviors (self-report) led to less negative bias
• Ee et al. – Semi-structured interview about loneliness
  • Based on De Jong-Gierveld’s model of loneliness
  • Autistic adults were more lonely
  • “Social skills and dissatisfaction with social support were associated with greater loneliness among autistic and non-autistic groups”
• Online interaction is a key “collaborative resource” that helps create empowered identities

What Does the Research Say So Far?

• Many are very isolated
  • Stigmatizing effect of early symptoms
  • Effect of stigma on family relationships
  • Communication differences may not be well-understood, especially speaking
• They have learned to mask, for better or worse
• But they also are more expressive about some symptoms
• They have more health problems, both physical and mental
• This could contribute to early mortality
• Likely a reciprocal relationship between health and isolation
The Role of Gender?

- Women have been studied far less than men
  - Partially because the measures underestimate rates in women
- Little is known about women’s friendships between autistic and non-autistic (Sedgewick et al.)
  - A lot of similarities between autistic and non-autistic
  - Greater problems with social inference skills
  - More negative social situations
  - More social and sexual vulnerability
  - But feel better about adult relationships than adolescence

The Roles of Stigma and Isolation

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Autism and COVID

- Autistic people are more likely to be affected by the changes related to COVID
  - Isolation, chronic health problems, access to care, unemployment, etc.
  - Acutely aware of uncertainty
- But has also forced people into trying a lot of accommodations
  - Some may feel used to social isolation
  - But some is not by choice
  - Autistic people may have something to teach about coping with isolation
  - Don’t just go back to the way things were before

Den Houting, Jac (2020)

“In this time of uncertainty, I hope that you will also find space to be kind to yourself, and others. Remember that it is okay to not be okay during this time. While you take care of yourself and your loved ones, I encourage you to also consider what you may be able to do to support the autistic community and other vulnerable populations, both during this crisis and when we eventually emerge on the other side.

In return, the autistic community may be able to teach you a thing or two about coping with isolation. Together, let us take this opportunity to create a more connected, considerate world. A world that will allow those of us who live in the margins to step out of isolation, perhaps for the first time.”
Possible Future Research Avenues

- Relationships between Health, Stigma, Aging, Isolation
- Intersectionality
- Connection between research and policy
- Warner et al. 2019 – Workshop developed 11 research goals to improve physical and mental health
  - Newcastle University and Autistica
  - Experts from Europe, Australia, and US – 2-day workshop
- Possible theoretical models?

11 Considerations for Mental and Physical Health

- Tailoring measures
- International collaborative effort to find key indicators to compare between autistic and non-autistic
- Studying self-advocacy strategies and barriers to self-advocacy
- Greater understanding of factors that influence personal wellbeing
- Reviewing evidence of accommodations and service design for autism-friendly health services
- Creation of online health care “toolkit” to improve primary care
- Developing a personalized annual health check
- Evaluating cardiovascular and gut problems in older autistic adults
- Empowering with knowledge about genetics and biology
- Considering knowledge priorities regarding sexual development
- Investigating experiences in residential facilities
Autistics Want You To Know

Parallel activity vs. interactive activities

Express empathy by sharing stories of ourselves
- Look for others to do the same
- Do not like rehearsed or canned responses

Fluid Functionality
- What they are capable of doing one day, might not be capable of doing another day.

Explicit communication, not Minnesota nice or metaphors or sub-text.

More stressed, tired, and overwhelmed – less likely to mask and produce neuronormative responses

Autism does not equal our co-morbid. Distinct disorders even if overlapping

Forcing us to comply with neuronormative standards may appear better and bothers others less, it can increase trauma, anxiety & depression and self-hatred

Non-speaking is not the same as not communicating.
- Behavior is communication.
- Augmented and Alternative Communication is acceptable & should be encouraged

Autistic Concerns About Aging

- Loss of hard-fought for autonomy if forced into facility or guardian takes over or they can no longer drive (many gained autonomy later than typical)
- Financial future due to intermittent, under and unemployment
- Navigating health care decisions, health insurance/MA, community resources, Power of Attorney, Health Care Directives, Trusts, Wills and Waivers and other decisions seniors have to face due to EF issues
- Loss of cognitive skills when they already struggle with EF skills
- Pre-existing mental health and chronic illness dx can lead to overlooking changes due to aging, so aging not ever explained by doctors (everything becomes “autism”)
- Losing their support system if they lose family/friends or are forced into care
- Not having official dx and not being understood in health care and housing situations.
- Being ridiculed or forced to stop acting autistic such as STIMs being considered disruptive and having restraints or ABA used again when most Autistics consider these very traumatic.
- Loss of structure when jobs end or children move out so they might forget to do basic self-care or mental health conditions might worsen
- Strong Likelihood of late diagnosis, mis-diagnosis, or late-in-life, self-diagnosis-- especially in females.
Additional Concerns About Aging

- Communication with housing and medical staff is complicated by interoceptive differences & missing major health concern due to difficulty recognizing cues in the body and not being able to tell people when they have a toothache or something else not obvious.
- Communication issues due to discrimination in health care
  - “How traumatized we are from medical personnel from a lifetime of being told we are hypochondriacs when we actually had medical issues (sic), sometimes life-threatening issues. Some of us have PTSD from being denied help during crises.”
- Additional communication difficulties due to loss of hearing, vision, memory, strokes or other things that impact speaking
- Sensory needs not respected in care facilities or by caregivers who don’t know them well.
- Worried about being placed in nursing facilities or group homes due to need for alone time, down time, peaceful time. Being around people all day would be exhausting.
- Lack of information on how autism impacts aging and particularly how it impacts AFAB Autistics going through perimenopause/menopause
- Managing self-care when they become more fatigued with aging
- Dealing with being a senior when they didn’t expect to live this long
Common Co-morbids that Might Impact Care

- 50%+Autistic People have four or more conditions, but the instruments we use to diagnose them may not work as well with autistic people
  - Speech and Language Disorders
  - Gut Issues: Celiac/IBS/Crohn’s/Chronic Constipation as many as 85%
  - Sensory Processing Disorder: Under-register or Over-register sensory input; can impact all senses
  - Other Psychiatric Disorders 85%: Anxiety & Depression & Bipolar 27%, PTSD & C-PTSD ADHD, Suicide (1-35%)/Suicidal Ideation (11-66%)
  - Epilepsy & Seizure Disorders 25% to 40%
  - Sleep Disorders 50% to 80%
  - Feeding & Eating Challenges/Disorders & non-healthy weight status
  - Allergies, specifically food and inhalant & Mast Cell Syndrome 50% higher than non-autistic population
  - Intellectual disabilities
  - Auto-immune illnesses, Ehlers-Danlos Syndrome/Hypermobility Syndrome, Dysautonomia
  - Genetic Conditions such Mitochondrial Dysfunction & Fragile X

Health Issues in Autistic Seniors

- 2.5 x more likely to die early
  - Out of 22 physical health conditions, Autistic adults more likely to have 19 of them.
    - Example: Heart disease 37% compared to 23% NN; Diabetes 7.6% v. 4.3%
  - Out of 9 mental health conditions, Autistic adults more likely to have 8.
    - Due to abuse/exploitation/bullying, isolation, stigma, lack of belonging
  - Lack of support over lifetime related to self-care & medical treatment
  - Loss of parents & caretakers leads to no support & social isolation
    - Can be placed in care of unfamiliar people or group homes/nursing facilities away from their community & supports so easier to overlook their needs
  - May be assigned a guardian and a loss of autonomy=stress
  - Autistic traits such as same foods & sedentary lifestyles can lead to poor health outcomes
  - Executive function skills, particularly those related to organization and planning can lead to missed appointments & not following recommended care
  - Lifetime of stigma & discrimination=more social isolation, trauma, & stress
  - Experiencing the world intensely leads to repeated burnout, trauma & stress
  - Trauma leads to behavior problems, mental illness, long stays in psychiatric facilities
  - Autism shares genetic roots with many cancers, Parkinson’s, and many mental health conditions
    - Parkinson’s 200 more likely in Autistics 40+ compared to 40-60 NN
Impact of Autistic Brain in Aging

• Both autistics and people who are aging have differences in the frontal lobe and with network connectivity. This means that autistics may be impacted more heavily as their brain ages with more significant declines in cognitive brain function.

Autistic masking can make people appear more “functional” and needing less supports.

It can also lead to Autistic Burnout

It can cause therapists, health care providers, and family/friends to overlook or minimize the very real support needs.

Lack of support leads to the cumulative negative impacts on physical and mental health evidenced in the research.

Aging provides both a pathway to stop masking as adults more fully embrace their identity as Autistic AND it can create complications that make it less likely that an Autistic can mask, making them appear or feel “more Autistic” (displaying more symptoms associated with autism).
Autistic Burnout, Regression vs. Autistic Aging

**Autistic Burnout (often referred to as regression by professionals and caregivers)**

- Typically, due to the demands of life exceed a person’s resources and are highly likely when major life events happen, including health status changes
- Not permanent, just a temporary response to overwhelm
- May lead to more meltdowns or shutdowns, sensory dysregulation and emotional dysregulation
- Requires more support

**Autistic Aging**

- Due to getting older and changes in demands
- Loss of skills may be more permanent
- Typically requires more support
- In longitudinal study on autism & aging, 78% of individuals were rated as “poor” in health outcomes at the older ages with intellectual disability as factor
Support Best Practices

• Begin with understanding
• Embrace differences
• Include the Autistic Community in designing supports
• Build genuine relationships, not focus on behavior
• Provide individualized adaptations
• Build inclusion into your programs, centers and care practices
• Reduce stigma
• Learn Autistic communication styles
• Reduce barriers to treatments from the individual to the organizational to the societal level

Embrace the Unusual

• Don’t assume negative intentions for autistic behaviors or differences
• Understand that there are higher percentages of Gay, Lesbian, Bisexual, Trans, Non-Binary, Asexual, and other variants of sexuality and gender among autistic people
• Recognize that Self-Stimulatory Behaviors (STIMS) are soothing and useful at keeping Autistic people regulated (rocking, flapping, chewing, twirling, hanging upside down)
• Eye contact can be physically and/or psychically painful. Don’t force.
• Allergy symptoms can be associated with impending meltdown or sensory dysregulation or anxiety. Antihistamines can help more than allergies & treat allergies consistently.
Aids for Communication

- **Social Scripts**: All of us might ask others to tell us what to say in novel situations/interactions, but autistic people can benefit greatly from this as it can reduce anxiety about social interactions.

- **AAC tools** such as text to speech devices or speech to text software, letter pointing, ASL, and writing can all be useful for different people.
  - Even valuable for those people who are mostly still speaking orally
  - Many autistics can become non-speaking when under stress and oral language issues in older adults may be exacerbated among autistics

- **Don’t simplify language because you assume autism=intellectual disability and normal offense we do to elderly (speak loud, etc.) will upset/offend autistics even more as many deal with this from childhood**

- **Consider using Visuals & Context Clues**
Modifying Sensory Challenges Can Make a World of Difference

- Food issues: issues could be looks, taste, texture, temperature, combined foods, etc.
- Keeping an IV in or tape on skin or even lotion could be a challenge as they can’t block out sensation and it is more painful than what is expected.
- Florescent lighting or too much sunlight can cause migraines or dysregulation and even allergies and seizures.
- Overhead speakers can cause major dysregulation due to audio processing issues, sensory & frustration at lack of ability to discern words.
- Temperature of rooms in care facilities or lower income housing can cause sensory dysregulation.
- Often just unable to block out things like traffic, dust particles in air, copy machine noises from across the building, the beeping of machines, etc.
- Blackout curtain or wearing sunglasses outside or light that can be dimmed.

Aids for reducing Anxiety among Autistics

- Social Stories: Not to teach “correct” or neuronormative behavior, but as a way to help people learn what to expect.
- Describe what you are doing and why before you do it.
- Reduce sensory overload/external stimuli
- Reduce demands/expectations
- Assume positive intent & that behavior has meaning for them, seek root causes of new behaviors not just ABA
- Presume competency
- Ask before touching or approaching in their bubble (and realize their bubble may be much larger than neuronormative people)
- Get consent for all treatments, crossing boundaries, etc. even when it is inconvenient
- Prepare person for all changes in routine, expectations for the day, and people
- Never invalidate their experience with anxiety or fears even if you have zero understanding of why that would be anxiety producing for anyone and you’ve never heard of it before
- Accept their coping strategies they’ve developed, including STIMS, even if you don’t know how it is related to their fears.
Adaptive Tools that might be Useful

- Weighted lap pad or blanket
- AAC tools
- Social Stories
- Opportunities to share SPINS and continue to participate in communities around those areas of interest
- Comfort objects and fidgets for sensory & emotional regulation
- Navigation tools for health care access, community resource access, and other systems designed to support Autistics

I Want You To Know About... Autistic Shutdown

- Safety first! Help them to a quiet space with minimal stimuli.
- Be sensory sensitive! Many are not tailored to their needs.
- Eliminate all expectations! They are currently overwhelmed.
- Reduce interaction, giving them space & time.

Autistic Shutdown is NOT: Stubbornness | Lack of respect | Disorder

Autistic Shutdown IS: Voluntary | Painful | Exhausting

Please be patient & compassionate.

Maybe your client isn’t “non-compliant.” Maybe:
- They’re not feeling safe with you.
- They’re not feeling safe in general.
- You’re not hearing their concerns.
- The modality you’re using is more harmful than helpful.
- There’s no flexibility to your approach.
- You haven’t earned your client’s trust.
- You’re addressing the wrong thing.
- You’re re-enacting oppression.
- You’re not the best fit for them.
Strategies when a person is appearing to be difficult or non-compliant

1. Person is not being difficult on purpose, but that they are having a difficulty.
2. All behavior is communication; so what is the person trying to say?
3. Don’t accept neuronormative attributions of behavior for autistic people.
   Things like “seeking attention” or “temper tantrum to not getting their way” and other ideas about why people behave the way they do are often not a good fit for autistic reasoning.
4. Resistance to authority and need for control are hallmarks of anxious responses, pathological demand avoidance, social justice orientations, experiences with trauma and oppression, and inflexible thinking...all common among autistic people.
5. Reduce demands.
6. Reduce transitions and unexpected changes.
7. Reduce sensory input except those they find soothing.
8. Allow them to keep objects or movements that may seem odd to you but provide comfort to them.
9. Don’t stifle repetitive movements or behaviors unless they are harming the person or someone else.
10. Simplify/Reduce the number of steps someone has to complete in order to complete a task.
   For example, don’t wrap utensils in napkins or plastic so I have to take off the wrapping to eat; don’t require that I have to uncover everything and find places to set the lids and wrappers while I eat. Make everything easily accessible with minimal steps.
11. Make sure to explain each step. What are you doing and why are you doing it and what do you need from me? Be explicit.
12. Give more time to transition between what they are doing and what you want them to do

Make sure you are actually listening to them and not assuming their meaning.

Strategies for congregate care settings

Build inclusive environments where odd behaviors and mannerisms are accepted and welcome.

Build inclusive environments where different forms of communication are not automatically seen as rude or behaviors.

Have a variety of Assistive Communication available.

Opportunities for down time

Emphasize person centered care.

Tailor support to the individual.

Make sure there is enough structure and routine to make life as predictable as possible.

Use visual schedules and visual supports.

Help them stay connected to their community & supports.
Don’t wait until you have a diagnosed autistic to implement some of these strategies. Many people benefit when you design and program for all types of disabilities and differences.

Be Mindful. Don’t just add an Autistic person, try to make them conform or offer them an adaptation and declare yourself inclusive. This is the mistake schools & workplaces are making. Exclusion & bullying are still primary experiences of autistics in schools and workplaces.

Inclusion isn’t add and stir. Inclusion is appreciation of differences. How do you build appreciation for all differences among your staff? Among your residents? Among your programming? Built into your policies? Built into your timetables and staffing guidelines?

Build relationships based on mutual respect.

Do provide accommodations even if you don’t understand it or if you know another autistic person who doesn’t need that accommodation and definitely do not apply 1 size fits all solutions to problems that arise.

Example: Can autistic elders contact your service or program via email or the internet or do they have to call? Maybe you think the elderly prefer phones, but this may not be true of autistic seniors.

The Disability Community has a rallying cry that is useful to remember when planning, educating, designing & working with the Autistic community:

“For me, inclusion is about a community where everyone is recognized for their differences and everyone is recognized as belonging – not only in our schools, but in our communities.”

- Dr. Joseph Petner, Educator

“Maximize Joy and Connection, Minimize Fear”

Sharon Florentine

“Nothing About Us Without Us”
References


References

References

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