



The Arc's Chapter Webinar Series Presents...

# Intersections of Disability and Rurality: Elevating Family Voices

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# Housekeeping Items

- All participants are muted during presentation
- There will be time at the end for Q&A, but you may ask questions using the chatbox function at any time
- If you are having any technical issues, please send us a chat and we will do our best to assist you
- Please fill out survey at the end of webinar to let us know of future topics you'd like to learn more about

# Agenda


- About the presenter
- Language & terms
- Autism
- Intersectionality
- Study & findings
- Participant experiences
- Implications

# About Jessica

- PhD Candidate Indiana University School of Social Work
- LCSW since 2010
- Research interests
- Son with Autism, daughter with ADHD
- Jessica is also neurodivergent



# Language & Key Terms

- Rural
  - Intersectionality Theory
  - Disability
  - Autism
- 
- Disability/Different abilities/Neurodiversity
  - Person-first vs. Identity-first language
    - Has Autism vs. Autistic, Has a disability vs. Disabled
  - Ask people what language and terminology they prefer and use that!

# Autism 1 in 44 (CDC)

## Possible strengths:

General: attention to detail, deep focus, fact retention, special interests, visual or unique learning, expertise, analytical, great with finding patterns, novel approaches, creativity, resilience, accepting of others, integrity and honesty, love for animals

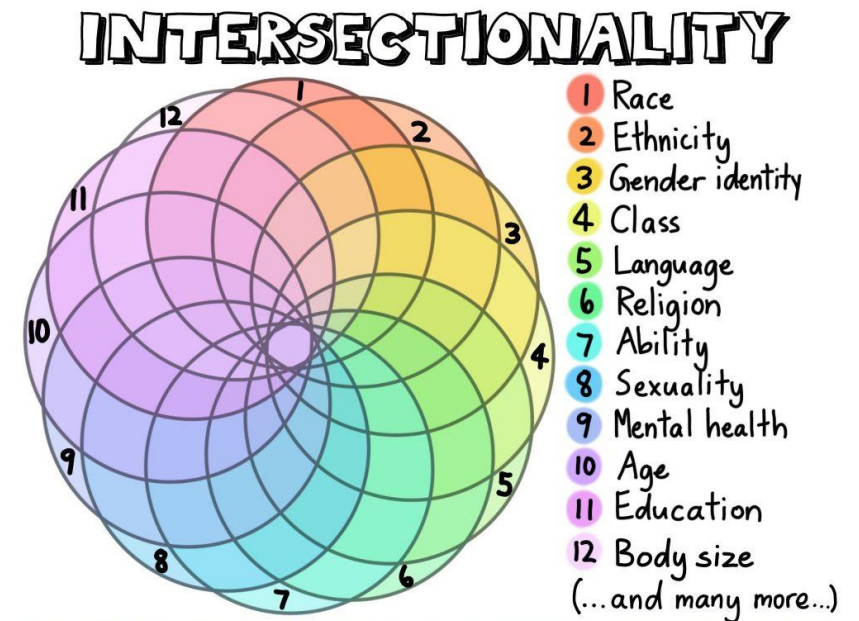
Affective empathy Vs. Cognitive empathy

## Possible challenges:

- Executive Functioning
- Social skills/social exhaustion
- Theory of mind
- Literal interpretation
- Formal speech, unusual social overtures
- Eye contact challenges
- Sensory issues
- Fixations, obsessive thoughts
- Focus on details, may miss big picture
- Difficulty with transitions
- Rigid thought processes
- Easily overwhelmed/overloaded

# Intersectionality Theory

## Understanding the Complexity of Experiences among People with Disabilities



Intersectionality is a lens through which you can see where power comes and collides, where it locks and intersects. It is the acknowledgement that everyone has their own unique experiences of discrimination and privilege.

- Kimberlé Crenshaw -

@sylviaaduckworth



# Intersectionality Theory

- Crenshaw (2017): Layers of identity and vulnerability
- In our studies, primary layers of gender, disability, and socioeconomic status.
- Intersectionality theory is helpful as it:
  - Encourages us to see beyond one aspect of identity
  - Considers overlapping or new combinations of identity
  - Looks to the person in addition to systemic layers for solutions
  - Considers increased level of vulnerability and risk





# Disability & Oppression



- The challenges people with disabilities face are compounded by inequality surrounding race, gender, economic status, etc.
- People with disabilities typically live below the **poverty** line and are 40% more likely to be unemployed.
- **Women with disabilities** are 10 times more likely to experience violence.
- **Black people with disabilities** make up nearly one-half of police killings.

# Study

- Qualitative research
- Gaps in research
- Rurality, caregiving, caregivers with disability, autism, Covid-19
- Theoretical framework
- Positionality

# Participants

Demographic	N	%
Gender		
Female	10	71
Male	4	29
Race/Ethnicity		
Asian	0	0
Black	2	14
Latinex	1	7
White	10	79
Other	1	7
Age		
18-30	5	36
31-40	4	29
41-50	3	21
50-60	2	14
61+	0	0

# Themes

- Six primary themes
  - Caregiver disability identified late
  - Lack of supports for adults with disabilities
  - “I don’t’ fit anywhere” (isolation)
  - Difficulty navigating social security benefits
  - Impact of Covid-19 pandemic
  - Blessings and challenges of raising a child with autism

# Participant Experiences

***Disability identified late:*** in my generation... they didn't diagnose anybody... They didn't have a lot of compassion for differences. You just had to deal. And you just had to be thrown in with everybody. It was a sink-or-swim kind of situation. Now that I've parented my kids and I see them, I think I have a lot of the same things that they have. And I later found out I'm autistic. But I'm like my daughter in that I mask it really well and I hold it all in, which causes mental health stuff. It causes depression and it causes anxiety. And when you're holding it in so tightly all day long, every single day, that smacks of anxiety, right?

***Lack of supports:*** There's really no support group, you know. Not where I live. Now it's a small town also. We have a group like one town over that's for parents of kids with special needs but not for adults with a disability. It's just expected that we know what to do. How to raise our kids. Track everything and make it work. There's just this expectation we can do all that which we could with maybe some help. But we never had the help. That goes back to it was identified way too late...and I don't have any idea who else is out there, other adults like me. I guess I could find an online thing I guess you know I can go get medication or therapy for my anxiety but not many people understand other parts of it, how hard it is.

# Participant experiences

***“I don’t really fit in anywhere”:*** *I don’t identify totally with the parents who have kids with autism, but I also don’t totally identify with some of these autistic young adults who have no kids who don’t know what it’s like to have a child with autism.*

***Difficulty navigating the social security process:*** *I just felt like a lot of it wasn’t clear. The language it just didn’t make any sense. And I would try and try to call. Just a bunch of automated stuff no matter what I tried. And I called multiple lines and tried all the options and could barely ever get a live person.*

# Participant Experiences

***Impact of Covid-19 pandemic:*** *I think I need caregiving help and it's even harder since Covid. I think it would be very helpful for me. And I can't acquire it because it's too expensive. Yeah. I think the government should see us disabled people, and help us in any way. Because my god I don't know how we're supposed to do it. I don't know how they think we would do it.*

***Blessings and challenges of raising a child with autism:*** *She just totally lights up. Like it's like an intense happy where she smiles so big I think it would hurt her face (laughs). I wish I felt things like that. I wish I felt intensely happy like that. It's just amazing. She jumps and flaps her arms and her whole face lights up and I can't help but light up too because it's just so purely happy you can't help but feel it.*



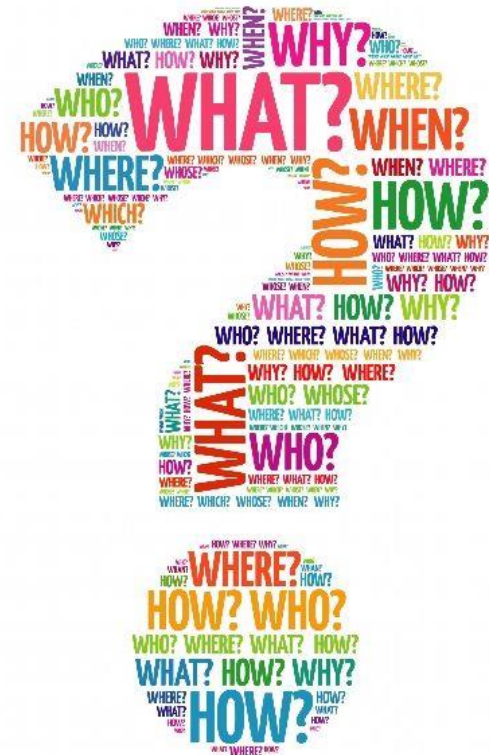


# Implications & Limitations

- Limitation: Small sample size, narrow study focus
- Implications
  - Improved and earlier diagnosis of developmental disability
  - Increased supports for parents with developmental disability
  - Increased supports for parents of children with autism
  - Improve SSA application process, more accessible
  - Policy, system, and research implications

# Questions? Experiences?

I welcome your input!



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