Narratives of Autism and Skilled Employment: Implications for Research and Service Delivery Regarding Intersectional Diversity and Inclusion in Professional Settings

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Introduction

- Research Assistant Professor, PSU Regional Research Institute for Human Services
- Intervention research with disability communities / populations; community based participatory research approach, systems scientist
- Co-director Academic Autism Spectrum Partnership in Research and Education (aaspire.org)
- Autistic and disability rights advocate, “got woke” in the LGBTQ+ movement late 80’s
- Science for social change!
Introduction

- Professor, Public Health, Syracuse University
- IRB Chair
- Community Psychologist
- Academic member of AASPIRE
- Research on respectful, inclusive research with adults with intellectual disability and action research addressing disparities among people with disabilities
- Science as social change
Introduction

- Portland State University undergrad
- BUILD Exito scholar
- Research intern for AASPIRE
- Research interests:
  - social equity, social determinants of health
  - environmental health, with a focus on LGBTQ youth and people with disabilities
Academic Autism Spectrum Partnership in Research and Education (AASPIRE)

- Research group started in 2006 by Dora & Christina (Katie’s been with us almost that long!)
- “Autism Journal Club” used to lure me into a social interaction
- Lots of complaints:
  - Not relevant / useful to autistic people
  - Issues with research design
  - Stigmatizing questions, language, dissemination
  - Potential harm to autistic people
- …just like other marginalized populations
Academic Autism Spectrum Partnership in Research and Education (AASPIRE)

- Stop complaining and do something!
- Team made up of academic researchers, autistic individuals, family members, healthcare providers, and disability services professionals.
- In partnership with PSU, OHSU, Autistic Self Advocacy Network, Autism Society of Oregon, Syracuse University, Indiana University, and members of the Autistic community at large.
Community Based Participatory Research

- Emancipatory approach to research developed in public health
- Community members are co-researchers in every phase of the research
- Lived experience and community knowledge is respected on the same level as academic expertise
- AASPIRE community partners involved at all stages of this project
Why Autism and Skilled Employment?

- Employment is a high priority for the community – wanted to do since 2006!
- Employment is also a high priority for families, agencies, funders, broader communities
- Of autistic adults 18 – 64 receiving developmental disability services:
  - Had a paid job in the community: 14%
  - Were in unpaid, activities in facilities: 42%
  - Had no work or activity: 27%

But skilled?
Autism and Skilled Employment

- Skilled / professional: requires specialized training or certification beyond what can be taught in the first weeks on the job
- Most autism or disability programs focus on entry level positions
- Less is known about skilled settings; may need different strategies?
- High rate of education; low rate of employment (2012 study of autistic youth showed 44% had post-secondary education but only 55% of them had any paid employment)
- Some autistic people may be better suited to skilled jobs???
- A community priority / frustration
Aims

A qualitative study that aims to use a community based participatory research (CBPR) approach to

1. **Understand the experiences of employees on the autism spectrum, at least half of whom have had a self-identified successful skilled job**, and their supervisors or supporters
2. Identify areas of systemic leverage in or around skilled settings that could inform an effective intervention
3. Develop a concrete, specific intervention plan
4. Build increased competence in ASD and employment for our CBPR team
Study Design

INTERVIEWS
- ~50 employees/job-seekers
- ~25 supervisors/supporters
- ~10 key informants

ANALYSIS
Thematic analysis, concentrating on understanding components, relationships, dynamics

MODELING & PLANNING
1. Causal Loop Diagram of system
2. Identify leverage
3. Identify intervention ideas
4. Interview 10 potential recipients
5. Finalize into R34 proposal

YEAR 1

YEAR 2
Sample, Setting, Recruitment

- Worked / looked for job in the U.S., ASD Dx, specialized training / seeking or have professional employment, 18+
- National sample
- Word of mouth, social media, networking connections
- PSU publicity
Interview Guides

- Semi-structured, story-telling focused interviews
- Employment / career history or support history, including successes, failures, work-arounds, influences, autism, and intersectionality
- Ideas around success & advice for employees and supervisors
- Wrap-up – what would you change, what services do you wish for, most important message
Interview and Analysis

- Invited from screener (online or over the telephone)
- Choice of email, telephone, video conference, text-based chat, in-person
- Conducted by Dora (autistic) & Lai (social work/employment support)
- Thematic analysis at a semantic level using a critical paradigm
  - Double-coding (Dora & Lai)
  - Discussions with co-investigators and staff with raw data access
  - Discussions full AASPIRE team, also serves as member checking
### Results: Demographics

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<td>10(22%)</td>
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<td><strong>Service use</strong></td>
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Job Variety!

- communications x2
- software engineer x2
- data entry / administrative / writing x2
- disability studies
- IT x2
- RN
- Caregiver / teacher
- web design / graphic design
- systems administrator, college professor, lab tech, vet tech, zoo keeper, body piercer
- Architectural Illustration, teaching, fine Art
- Social Work counselor, Exceptional Child Services Program Developer
- Manufacturing, construction
- librarian
- Public health (RA, PM, QA)
- Historical Society, Grant Writing, Library Services
- Photographer, human relations, probation, parole, human services
- immigration paralegal
- Graphic design, printing, and related work; owns small print shop
- records manager at a law firm
- Contract Special Investigator
- started own non-profit

- mathematics instructor
- Accounting clerk, purchasing coordinator
- Statistician/Demographer, Mathematical Statistician, Consultant
- Manager, social worker
- Gymnastics coach and judge, classroom teacher
- Paraeducator, substitute teacher
- Technical Writer
- Hairdresser, leatherworker, makeup artist
- Correctional Officer, Child and Adolescent Treatment Specialist
- Caregiver, Case Manager, Technical Aide/Braillist
- Electronics Engineer, Semiconductor research scientist, robotics engineer
- museum education
- policy analyst; legal intern / law clerk
- engineer (electrical), engineer (general hardware/facilities) x2
- pharmacy technician
high stakes of autism disclosure

- reason a job worked
- OR reason a job didn’t work
- even for the same person in the same field

"Recognize that the employee may be taking a massive personal risk in making their disclosure, and that they must have calculated that the extra measure of vulnerability prompted by disclosure was worth it."
unconventional paths into jobs

- Bypassing human resources
- Strategic use of interests and skills, finding niches

“[editor] showed me...some of the basics of using like graphic design software....and it was really the earliest early days of that stuff publishing, and somehow he and this other guy talked to student congress and they gave them like ten thousand dollars...to buy this computer system, which was like gonna be a publishing system....so I learned like really early on...how to use this stuff when even professional graphic designers didn't know what to do with any of it and they're just floundering, so that gave me a step into that kind of world.”
disconnects with service & support systems (asd / skilled)

- Understand skilled employment but not ASD or vice-versa

"I was a highly qualified candidate for WRP positions, but I never received any offers …. I later found out the government agencies mostly use disability hiring programs such as WRP…to hire employees for unskilled positions….This is a problem, since those on the autism spectrum often do much better with positions involving analytical thinking than positions involving unskilled labor."

“…my VR job developer found…a call center position that I think was probably an easy fit for her. Unfortunately, this job was incredibly stressful for me and my then VR counselor suggested I take Xanax during the day while at work. I eventually gave my notice as this was not the right fit for someone with my condition.”
autistic burnout and mental health management

- Large risk / fear
- Loss of work / inability to regain work

“As far as keeping a skilled job goes – I would say that the most important thing is to monitor yourself for signs of burnout and act sooner, rather than later, to thwart it.... I would suspect that burnout is by far the biggest contributor to lack of long-term success.”

“I wish I actually hadn’t interned every summer while I was in college....I think working nonstop was a contributing factor in my burnout.”
discrimination and bullying

- In work settings
- Throughout life, often from early age, has pervasive impacts on employment

"Every time I've disclosed I suddenly become like a lower person to that manager. Just because I'm autistic doesn't mean I want to be a low-wage grunt forever. It doesn't mean you have to talk to me like I'm not an adult or your peer. Acknowledge my differences and needs, but treat me like just another coworker. "
Impact of intersectionality

- “I’ve already got (race / gender / sexuality / autism) against me, I can’t risk anyone knowing I’m (gay / trans / autistic) too”
- Many participants identified as transsexual and/or LGBTQ+
- Multiple marginalization complicates employment

"[After coming out trans] ...I was told...that I was ‘fired for being gay.’ I also acknowledge that my privilege as a white-passing person has also helped me....I feel if I had the double-whammy of being a trans woman and a person of color, I would have almost no chance of getting a job. As it is, I have only a few strikes against me in the ‘not-employable identities’ column. I do worry that when I get married I may face more discrimination, as I plan to take my partner’s last name which is noticeably a Latinx name."
autistic “superpowers” facilitate success

“From the people I’ve chosen to share [my diagnosis] with it’s usually a positive response...like they know me and from seeing how I work with kids [with disabilities] they’re like, oh that would explain why you’re able to really zero in on that and you have this good rapport with that kid who’s hard to reach, and I'm like oh yeah I guess so [laughs] using my superpowers [laughs]”

“In the course of my education, anatomy, physiology, pathology, and symptom pattern recognition...became a special interest. This meant I could focus my autistic superpowers on succeeding at work.”
success is more than job placement

- Professional growth
- Work/life balance
- Financial independence
- Sense of community
- Feeling valued
- Meaningful work
- An accepting (e.g., neurodiverse) work culture
Complexities of Intersectionality

- Non-cisgender gender identities are over-represented in the autistic population
- LGBTQ+ identities may be as well
- Racial and ethnic minorities are under-represented in the autistic population
- Risk factors for bullying, discrimination, mental health conditions, burnout, and social isolation may be even more pronounced for autistic people who are multiply marginalized
Implications of Intersectionality
Findings for Employment

- Programs need to address intersectional identities and multiple marginalization
- Focus on autism or disability alone in interventions may be overly simplistic and marginalizing
- Discussions about disclosure strategies and resources need to take the possible disclosure of multiple identities into account
- Un-siloing employment research and diversity programs that address other vectors of marginalization may benefit the field
- Autistic people, employers, and support agencies/systems need to be aware of the additional burden of multiple marginalization in the workplace and in life
Where to from here? Musing toward intervention

- **When** - Still in training? First looking for work? Struggling to get work for a long time?
- **Where** - Disability service systems? Small communities? Partnership with a program?
- **What** - Mentors and networking? Hiring practices? Workplace culture?
- **How broad** - In geography? In types of work? In inventing something new versus looking to existing models?
- **How can we keep the burden from all falling on the autistic employees and job-seekers?**
Considerations for You

- Consider the insights and knowledge from lived experience autistic people have, including as members of your research team.
- Take a chance on hiring us in your labs and on your projects, be the unconventional path to a career 😊
- Provide vocational mentoring.
- Be mindful of that, just like the general population, we experience multiple identities, and these will influence our interactions with the world as well as the efficacy of programs and interventions.
Thank you to the AASPIRE Team, participants & you!

- Still would like one or two supervisors and one or two employees who identify as Latino/Latina
  - [http://aaspire.org/employment](http://aaspire.org/employment) has links to recruitment fliers
- Autism in Adulthood journal
- Contacts for us!
  - Dora draymake@pdx.edu | [http://doraraymaker.com](http://doraraymaker.com)
  - Katie kemcdona@syr.edu | [https://falk.syr.edu/people/mcdonald-katherine/](https://falk.syr.edu/people/mcdonald-katherine/)
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