Autism and Skilled Employment

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Portland State University & AASPIRE
Introduction (Dora)

- 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 (Alannah)

- Portland State University undergraduate
- BUILD EXITO scholar
- Research intern for AASPIRE
- Major research interests: social equity, social determinants of health, environmental oppression
Academic Autism Spectrum Partnership in Research and Education (AASPIRE)

- Research group started in 2006 by Dora & Christina
- “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
AASPIRE cont.

• 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
Autism and Skilled Employment Background

- Employment is a high priority for the community, families, agencies, funders, broader communities
- Of autistic adults 18 – 64 receiving developmental disability services:

![Employment and Other Day Activities Table]

- But skilled?
Background cont.

• 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)
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 things that could inform an effective intervention

3. Develop a concrete, specific intervention plan
Study Design

- employees/job-seekers
- supervisors/supporters
- key informants

A few pairs

Thematic analysis, focused on what is happening and how the complex parts of the employment experience relate to each other

Learn what might help people to be more successful in finding and keeping skilled work, and being happy with their jobs
Sample and Recruitment

• Employees and supervisors:
  • Worked / looked for job in the U.S., ASD Dx, specialized training / seeking or have professional employment, 18+ OR supervised or supported an adult with and ASD Dx in professional setting
  • National sample
  • Word of mouth, social media, networking connections
  • PSU publicity

• Key Informants: Personal connections; purposively sampled to provide broad, systems-level information in a wide range of employment-related areas
Interview Guides

• Asked participants to tell their stories, guided the conversation with questions
• 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
Interviews

• Choice of email, telephone, video conference, text-based chat, in-person
• Conducted by Dora (autistic) & Lai (social work/employment support)

• Analysis:
  • Coded by Dora and Lai – researchers with different but relevant lived experience
  • Discussions full AASPIRE team, also serves as member checking
Employee Interviews
## Employee Demographics

<table>
<thead>
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<th>N</th>
<th>45</th>
<th>M.</th>
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<td></td>
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<tr>
<td>Female</td>
<td>21</td>
<td>47%</td>
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<tr>
<td>Male</td>
<td>18</td>
<td>40%</td>
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<td>6</td>
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<td></td>
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<tr>
<td>Asian</td>
<td>3</td>
<td>7%</td>
<td></td>
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<tr>
<td>Black/AA</td>
<td>2</td>
<td>4%</td>
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<tr>
<td>White</td>
<td>35</td>
<td>78%</td>
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<tr>
<td>Multiracial</td>
<td>4</td>
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<tr>
<td>Latino</td>
<td>1</td>
<td>2%</td>
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<td>AAA use</td>
<td>10</td>
<td>22%</td>
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<tr>
<td>Service use</td>
<td>19</td>
<td>42%</td>
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<td>Interview Mode</td>
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<tr>
<td>text chat</td>
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<td>7%</td>
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<tr>
<td>telephone</td>
<td>3</td>
<td>7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>video conference</td>
<td>5</td>
<td>11%</td>
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<tr>
<td>in-person</td>
<td>12</td>
<td>27%</td>
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</table>
Job Variety

- Art/Entertainment
- Law
- Health/Clinical work
- K-12 education
- College education
- Data processing
- Finance and insurance
- Government and public administration
- Utilities
- Engineering
- Information technology
- Hotel/food services
- Publishing
- Research
- Materials science
- Social work
- Trades
- Child services
- Athletics
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 and support systems

- 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."

"
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 important than job placement

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

- Importance 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 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."
Complexities of intersectionality

- Non-cisgender gender identities are *over-represented* in the autistic population
- LGB+ 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 for Service Providers & Others

• 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
Supervisor and Key Informant Interviews
Supervisor/Supporter Demographics

- N=11 (2 autistic)
- 4 pairs with employee interviews
- Majority female, white
- 3 job coaches; 8 job supervisors
<table>
<thead>
<tr>
<th>Role</th>
<th>Expertise / systems covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic researcher</td>
<td>High school transition programs, co-mentoring at transition, ecological models of employment, community outreach</td>
</tr>
<tr>
<td>Employment specialist (2)</td>
<td>Customized employment, employer outreach, VR and employment support connections, customized employment programs, disability and employment programs</td>
</tr>
<tr>
<td>Small business organizer</td>
<td>Small business needs, community outreach, employer outreach, business leader perspectives</td>
</tr>
<tr>
<td>Vocational rehabilitation</td>
<td>Vocational rehabilitation, job development, job coaching, integration with traditional systems</td>
</tr>
<tr>
<td>Policy / community leader</td>
<td>Employment policy, community-business internship programs</td>
</tr>
<tr>
<td>Disability service director</td>
<td>College internships, college transition programs, employee accommodations</td>
</tr>
<tr>
<td>Director specialist business</td>
<td>Providing specialty services to large tech corps, Dandelion Program (employee/employer training, support)</td>
</tr>
</tbody>
</table>
General Findings

Largely supported employee themes, from a different angle; in particular

- Job culture and “good fit”
- Understanding and working with history of trauma / mental health challenges
- Importance of disclosure, need to understand ASD in general and employees as individuals in particular
- Flexibility and creativity
- ASD as a strength (skills, creativity, dependability, “super-powers”)
- Importance of relationships; mentoring and friendships
Engaging Businesses and Employers

• Need to be creative and flexible
• Need to provide (ongoing) education
• Need to appeal to the “bottom line”
• Community connections and small business relationships can provide unique opportunities
Recommendations for More Inclusive, Successful Workplaces
Key Barriers and Facilitators to Success

- Traditional hiring processes present barriers; non-traditional or creative paths through internships, mentorships, personal relationships, skills demonstrations, and job carving facilitate.

- Pressure to mask autism presents barriers; accepting environments and job cultures that accommodate and allow autistic people to be themselves (including to disclose safely) facilitate.

- A history of failure compounds barriers; early successes facilitate ongoing success.

- Ridged workplaces present barriers; allowing the employee flexibility and control over their schedule, job tasks, and professional development facilitate.

- Other facilitators: clear expectations and feedback, mentors & trusted allies.
Tips from Successful Supervisors

• Be flexible
• Be clear about expectations and how communication will operate
• Give feedback, with compassion
• Provide mentoring, actively build trust, and create true peer friendships
Tips from Successful Supervisors

• Take a strengths-based approach
• Accommodate the employee’s individualized needs
• Create a culture of acceptance, and be mindful of good job fit
• Respect and appreciate your employee
Creating More Neurodiverse Workplaces

- Providing alternatives to traditional human resources hiring practices
- Challenging what “professionalism” looks like; being accepting of autistic difference
- Prioritizing, and crafting jobs to, skill and passion
- Accommodating needs
- Taking a trauma-informed approach
- Normalizing disability (not masking disability to make it appear normal)
Next Steps

• Finishing up the analysis of the research study

• Looking for partnerships and areas where we can build a new aspect to an existing program
  • Mentorships?
  • Internships?
  • Engaging companies that have skilled work available?

• Interested in thoughts from the community!
Thanks & Questions

• To the AASPIRE team, and to all of our research participants who shared their wisdom and experience with us

• Autism in Adulthood journal

• Contacts for us!
  • Dora draymake@pdx.edu | http://doraraymaker.com
  • Alannah malannah@pdx.edu

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