Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

USING AUTISTIC ADULTS' PERSPECTIVES TO IMPROVE SUPPORTS FOR EMPLOYMENT SUCCESS

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Background

- About Ian
  - Autistic adult
  - **Currently:** Social Policy PhD student
  - **Previously:** service recipient, vocational rehabilitation consumer

- Interest in employment
  - Developed from first-hand experience
  - Felt like research, media representations weren't capturing reality for a lot of autistic people
  - Wanted to figure out how to facilitate better outcomes

Purpose of Project

- Collect data on autistic adults' **experience finding, getting, and keeping (competitive) employment**

- Investigate autistic adults' **perceptions of challenges/barriers** to employment

- Understand **what helps autistic adults feel satisfied and successful** in employment

Three Questions to Think About

1) Do these findings match your experience or understanding?

2) Do these findings suggest other recommendations for policy/practice?

3) What's the best way to disseminate findings/recommendations? Who should hear them, and how should we share them?

The Autism & Employment Experiences Survey

Survey created based on

- Literature, interviews, discussion
- Involved autistic adults, service providers, family, other supporters

Responses from 611 individuals, collected during two time periods:

- August-October 2019 (496 respondents)
- January – July 2020 (115 respondents)

Sample recruited from:

- Community and support groups
- Contacts at service agencies, employment programs
- Personal connections

Sample Characteristics

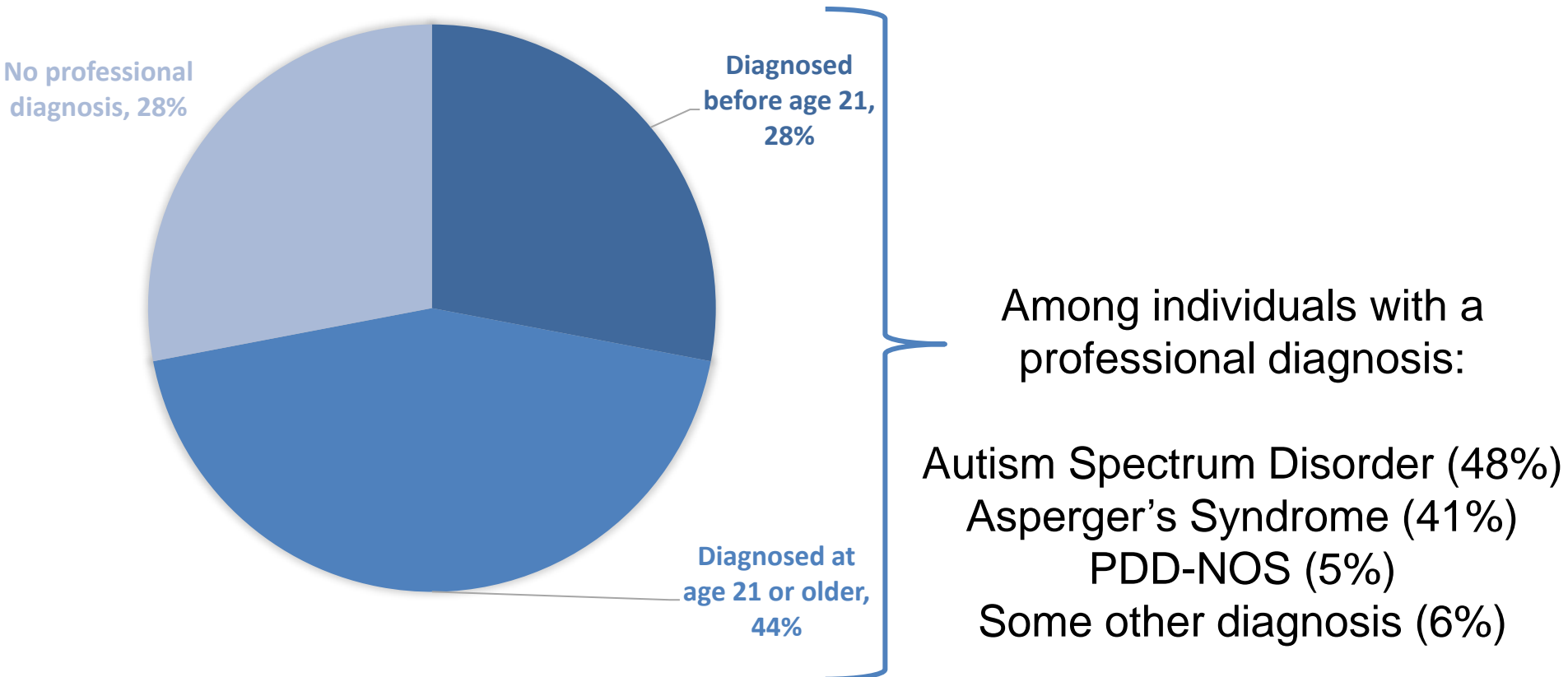| Age		
	18-24	19%
	25-30	27%
	31-40	27%
	41-50	18%
	Over 50	9%
Gender		
	Female	48%
	Male	23%
	Nonbinary or genderqueer	20%
	Other gender identity	7%
	No response	2%

16% identify as POC or bi- or multi- racial

Most commonly
- Asian/Asian-American
- Hispanic/Latinx

19% identify as transgender

Sample Characteristics

AGE AT DIAGNOSIS

No professional diagnosis, 28%

Diagnosed before age 21, 28%

Diagnosed at age 21 or older, 44%

Among individuals with a professional diagnosis:

Autism Spectrum Disorder (48%)
Asperger's Syndrome (41%)
PDD-NOS (5%)
Some other diagnosis (6%)

Sample Characteristics

Relationship status	
Single	44%
Married or cohabitating	41%
In a relationship (not cohabitating)	10%
Separated, divorced, or widowed	4%
No response	1%
Highest level of education completed	
Less than a college degree	32%
2-year degree or post-HS certification	10%
4-year degree	35%
Graduate degree	24%

Some differences are associated with age; for example:
- more older respondents than expected are married
- more younger respondents than expected have not completed college

Sample Characteristics

92% report **at least one condition or disability that commonly co-occurs with autism**

- Anxiety (77%)
- Depression (64%)
- Auditory processing disorder or delay (38%)
- Sleep disorder/disturbance (37%)
- GI issues (35%)
- ADD/ADHD (35%)

35% report **at least one other disability or condition** not commonly associated with autism

Employment History

- 93% of respondents had had **at least one paid job**

- 53% had **gone 6 months or more without employment** (when not in school) at least once since first began working

    - 60% of those not currently employed had not had a job for over a year

- 33% had **either never held a job for a year or more or only had one** job which they held for a year or more

Employment Status

CURRENT EMPLOYMENT STATUS

Pie chart:
- No response 8%
- Adequately employed 28%
- Underemployed 30%
- Not employed 34%
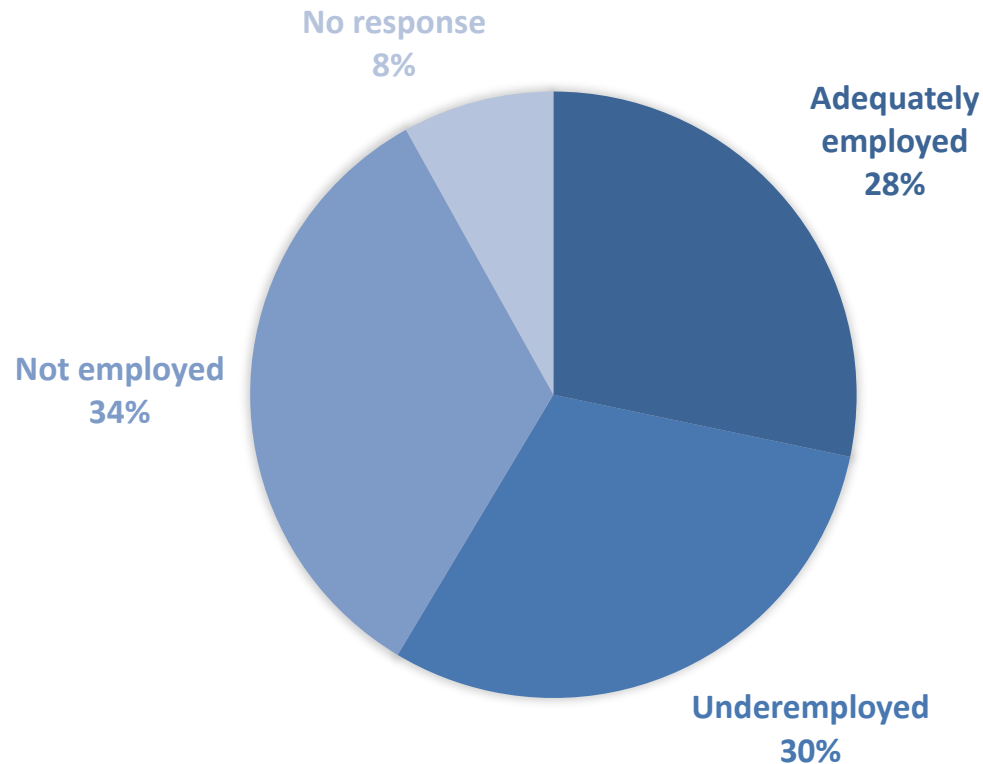
Underemployment: working fewer hours than desired, doing work that does not use skills or education, or being paid less than others doing similar work

Of those who were currently employed:

51% full time (35+ hours per week)

30% part time (34 hours or less per week)

14% self-employed

12% more than one job

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Disclosure & Accommodations

Of people who have applied to a job in the time that they have known they are autistic:

- 37% **never disclose** their autism **when they are applying** to or interviewing for jobs
- 22% **think disclosing** that they are autistic **makes it harder to get jobs**

Of people who knew they were autistic when they last applied to a job:

- 16% **needed accommodations** for an interview, **but did not request them**
- 25% **did not request accommodations** because they were **not sure if they needed them**

Perceived Barriers

Top selections for **things that make it hard to *get or keep* a job**:

- Social difficulties (80%)
- Communication difficulties (70%)
- Sensory issues (60%)
- Difficulty with planning, organization, or other executive function challenges (57%)
- Feeling isolated from coworkers (55%)

However, only 48% endorsed being autistic as something that made it hard for them to get or keep a job

Perceived Barriers are Influenced by Identity

Respondents who identify as POC, bi-, or multi-racial indicated that racial prejudice was a barrier to employment

- 32% for POC overall
- 50% for Black respondents

Compared to 7% overall

Respondents who identify as transgender indicated that prejudice towards LGBTQ+ people was a barrier to employment

- 52% for transgender respondents

Compared to 10% for respondents who do not identify as transgender

Perceived Barriers

Top selections for **things that *created challenges* for people *in a workplace setting***:

- Difficulty understanding unspoken social expectations (81%)
- Anxiety or depression (79%)
- Difficulty understanding indirect requests or communication (77%)
- Sensory issues due to the physical environment (77%)
- Feeling misunderstood (74%)

Priorities When Looking for Employment

Top selections for **things that were important to people when** *looking for or choosing* **a job**:

- Feeling supported by manager(s) or supervisor(s) (87%)
- Value and meaning of the work (84%)
- Distance from home/length of commute (82%)
- Company/organization morals or ethics (77%)
- Work/life balance (77%)

Least common selections:
- Company/organization size (24%)
- Having a mentor or coach at the job (36%)
- Company/organization has publicly supported neurodiversity (36%)

Priorities for Feeling Satisfied with Employment

Top selections for **things that were important to people to *feel satisfied with* a job**:

- Feeling valued as an employee (90%)
- Work/life balance (82%)
- Supportive manager (80%)
- Opportunities to pursue areas of own interest (74%)
- Getting to solve problems (74%)

Least common selections:

- Public recognition or awards (13%)
- Opportunities to advance within the company/organization or earn promotions (39%)
- A set schedule (43%)

Proposed Improvements

Top selections for **things that would *improve autism employment programs***:

- Work with autistic-led and self-advocacy groups (81%)
- Involve more autistic people in designing programs (80%)
- Hire autistic people to provide training to employers (77%)
- Survey autistic people about what supports and accommodations they need (77%)
- Hire for a wider range of jobs (75%)

Key Takeaways

- Employment status alone does not always reflect people's experiences or struggles

- Job match matters

    - Interests, skills, values, etc.

- Need for employer training

    - Feeling supported by manager(s) important for satisfaction, resolving challenges/barriers

- Autistic people are complicated, just like all people

    - Lots of variety in needs, experiences, and preferences

What Can Policymakers and Agency Leaders Do?

- Consider the whole person
  - Identity, context, co-occurring conditions, etc.
  - Establish partnerships/collaboration with other services
- Think about autistic perspectives
  - Autistic people want to feel valued and included
  - Recognize and respect agency, autonomy
- Ensure employers/managers have support *they* need to be supportive
  - Lots of potential to influence job satisfaction
- Be thoughtful about how outcomes are defined
  - What else can/should be evaluated beyond employment status?

Three Questions to Discuss

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