


Discovering autistic youth and young adults' experiences of workplace disclosure

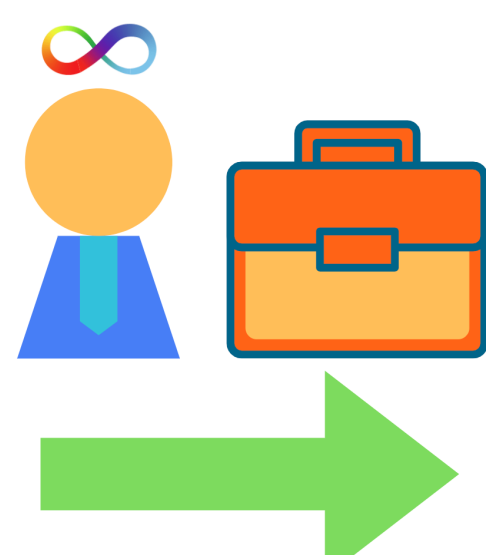
Shaelynn Hsu ^{1,2}, Vanessa Tomas ^{1,3}, and Sally Lindsay ^{1,3}

Background and Rationale

Deciding to disclose one's autism in the workplace is a complex process which incorporates a multitude of factors.

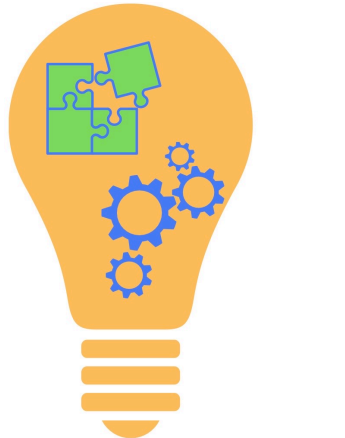


Most research focuses on older aged autistic adults.




Little is known about the disclosure experiences of autistic youth and young adults as they are newly transitioning to employment.


Objectives



1) To investigate the influence of internal and external factors on disclosure approaches and strategies.

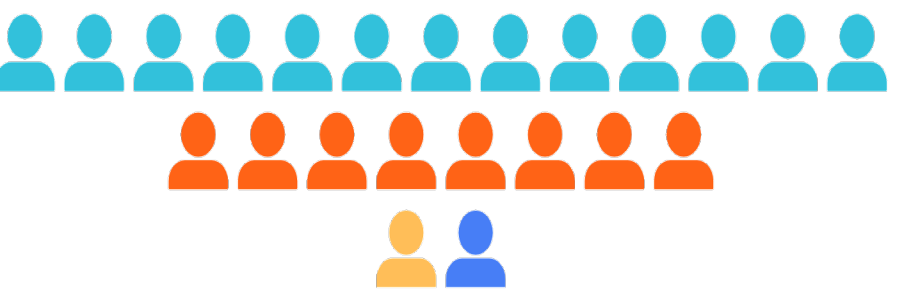


2) To understand how youth with autism navigate the process of disclosure.




3) To explore how youth with autism perceive and weigh the outcomes of disclosure.

Methods and Analysis




We conducted six virtual focus groups with 23 autistic youth and young adults (13 men, 8 women, 1 transman, 1 transwoman, age range 18-29).

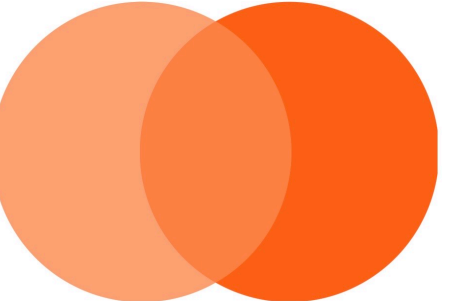
To analyze the data, we used an inductive thematic analysis led by two coders on NVivo:



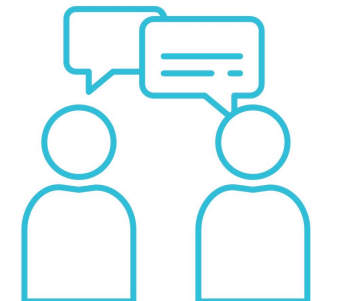
1) Collaboratively coded first two transcripts to create coding framework.



2) Independently coded next two transcripts.



3) Conducted coding comparison query to compare Kappa scores.




4) Coders discussed codes with Kappa scores <0.4 and came to a consensus. Steps were repeated for the last two transcripts.

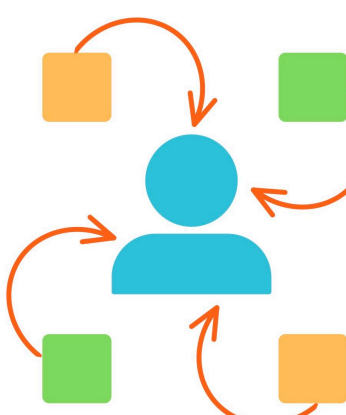
Workplace disclosure decision-making for autistic youth and young adults is influenced by several individualized factors, with external factors such as workplace environment, culture, and social determinants being the greatest influencer.




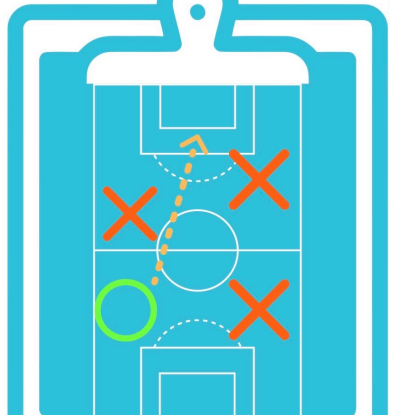


Results

We developed six overarching themes:


- 1) weighing benefits and risks
 

“you also may not want to tell because you may not want anybody to think that you can't do the job.” [Woman, 28]
- 2) external factors
 


“Um, I think with me it's just like, if someone notices like one of the coping mechanisms I'm using or something like that, I might bring it up – or, if it's directly relevant.” [Man, 29]
- 3) experiences of autism
 
- 4) contingent supports
 
- 5) disclosure roadmap
 
- 6) the game plan
 

Conclusion and Next Steps

The study revealed individualized, context-dependent disclosure experiences and influencers. Next steps for future research should prioritize, understand, and explore the impact of external factors (e.g., workplace culture) on the disclosure process and how to address these influencers.



Relevance to Holland Bloorview Clients and Families



- These findings shed light on youth's lived experiences, especially the challenges they encounter in disclosing their condition in employment.
- These findings offer Holland Bloorview clinicians (eg. occupational therapists and job coaches) the knowledge to develop employment tools and programs.
- Developed employment tools and programs may provide support to autistic clients with the workplace disclosure process.

Funding



1. Bloorview Research Institute, 2. York University, 3. University of Toronto