

Leaving Places: Autistic people's perspectives on "elopement"

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Land Acknowledgement

- ▶ We recognize that many Indigenous Nations have longstanding relationships with the territories upon which York University campuses are located that precede the establishment of York University. York University acknowledges its presence on the traditional territory of many Indigenous Nations. The area known as Tkaronto has been care taken by the Anishinabek Nation, the Haudenosaunee Confederacy, and the Huron-Wendat. It is now home to many First Nation, Inuit and Métis communities. We acknowledge the current treaty holders, the Mississaugas of the Credit First Nation. This territory is subject of the Dish with One Spoon Wampum Belt Covenant, an agreement to peaceably share and care for the Great Lakes region.
- ▶ see <https://www.federationhss.ca/sites/default/files/2023-02/Indigenous-protocols-Congress-2023.pdf>



What is “Elopement”?

- ▶ When Autistic* children or adults depart suddenly from supervised settings or relationships without permission or notice
- ▶ “Running away”, “wandering”, “going missing”
- ▶ Research frames elopement as a safety concern (eg. McIwain & Fournier, 2017)
- ▶ Research frames elopement as a “problem behaviour” to be “extinguished”, especially in educational contexts (eg. Boyle & Adamson, 2017; Lang et al., 2010; Stockhall & Dennis, 2016)
- ▶ Research also explores the perspectives of affected others, including parents (e.g., Anderson et al., 2012; 2020; Solomon & Lawlor, 2013) and first responders (Calton & Hall, 2021; Chown, 2010; Gardner et al., 2019)

*The use of identity-first and capitalized descriptions of “Autistic people” come from stated community preferences, with the acknowledgement that this preference is not universal (Brown, 2011)



Our Study: Centering Autistic Perspectives

- ▶ **Virtually no research has explored the experiences and knowledge of Autistic people about elopement** (see Solomon & Lawlor, 2018, as an exception)
 - ▶ Our study was suggested by an Autistic community member to address this gap
 - ▶ Participatory action framework, bringing together a university team and four Autistic community co-researchers who have relevant lived experience
 - ▶ Pilot survey was funded by a UW-SSHRC Explore Grant (2022-2023), and continued research will be funded by a SSHRC Insight Grant (2023-2028)
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Survey: Autistic People's Perspectives on Departure and Well-Being

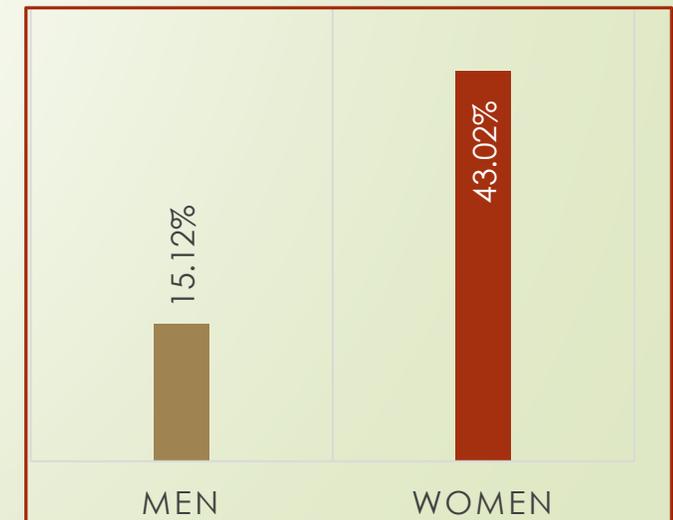
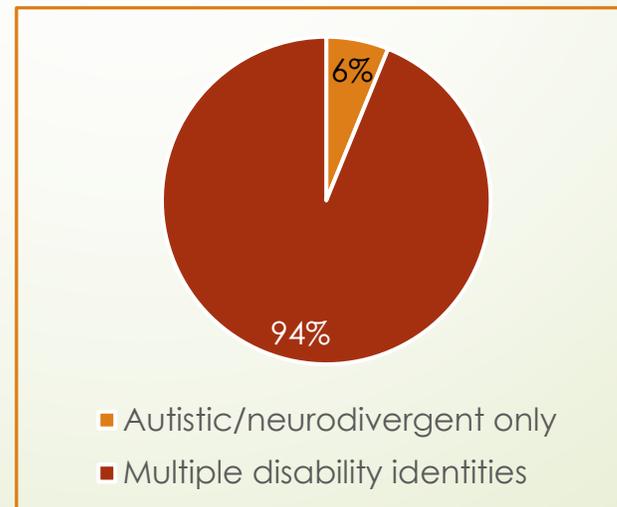
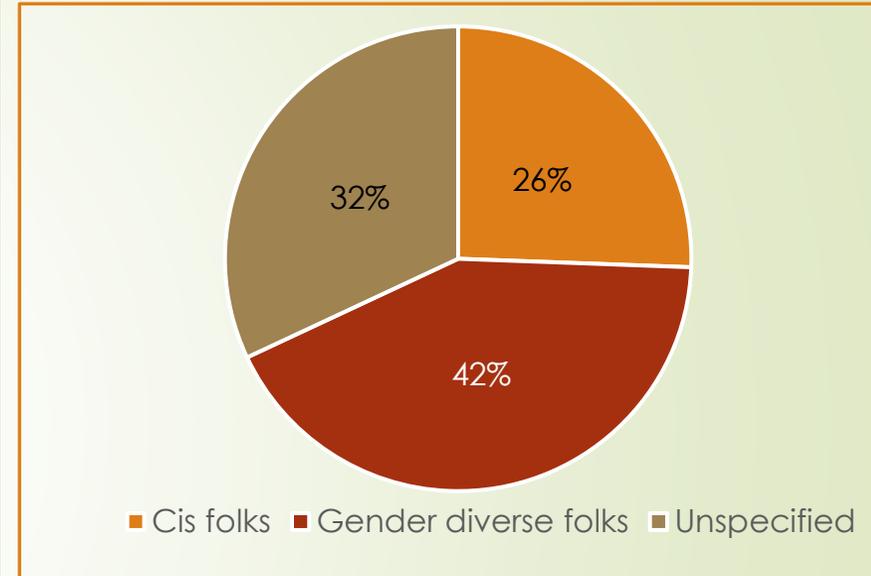
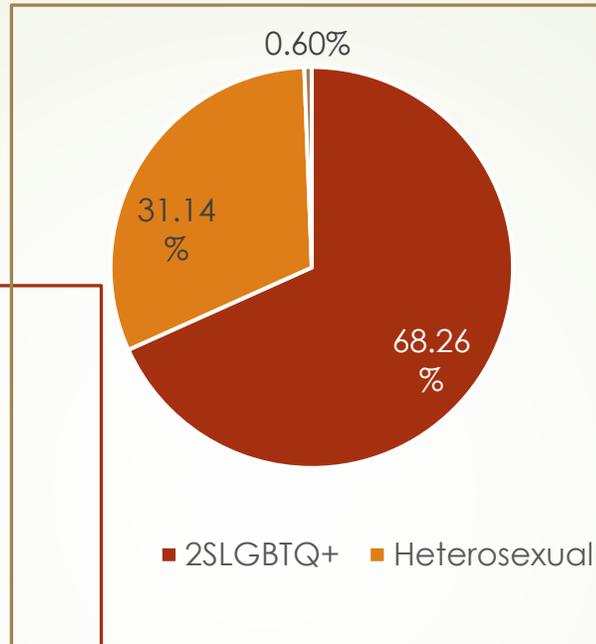
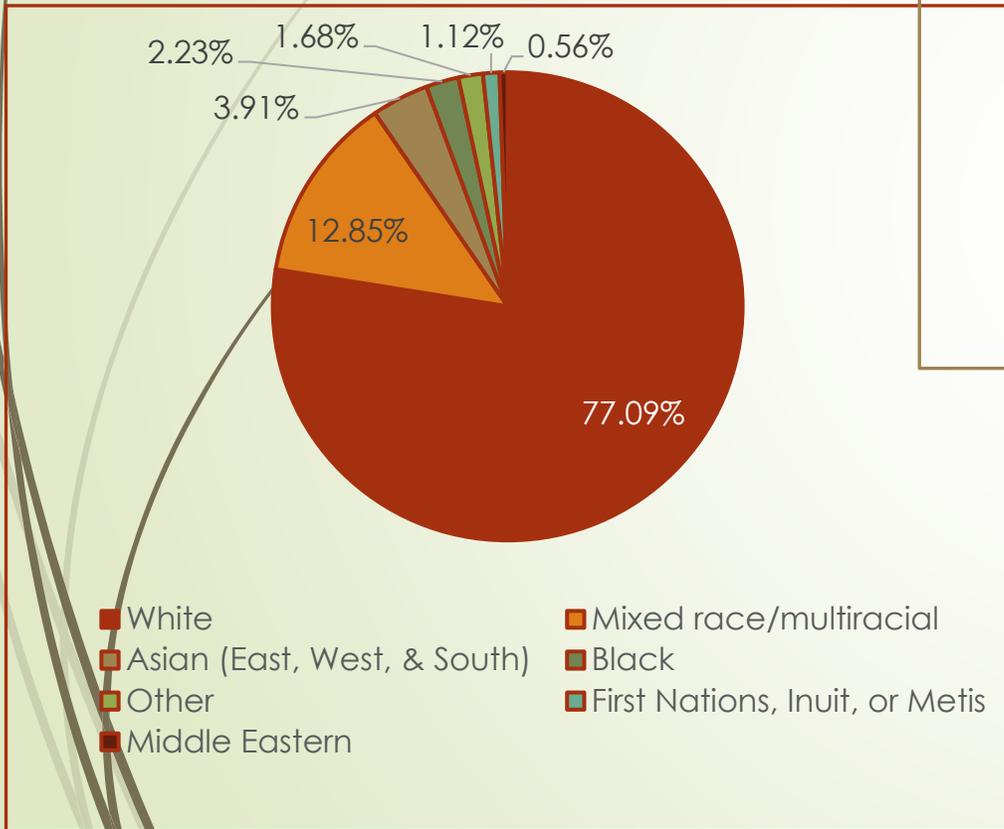
- ▶ Online survey was developed in collaboration with the co-researcher team
- ▶ Distributed via researchers' and co-researchers' social networks, social media, Autistics4Autistics (A4A) Ontario, & Autistic Self Advocacy Network (ASAN)
- ▶ Participants had to be at least 13 years of age, identify with autism, and have experience with elopement/leaving places (broadly defined)
- ▶ Questions about reasons for eloping, impact on well-being, and others' responses
- ▶ Final sample included 205 eligible respondents
- ▶ Survey was intended to be a pilot, but the number and richness of responses give us plenty to analyze



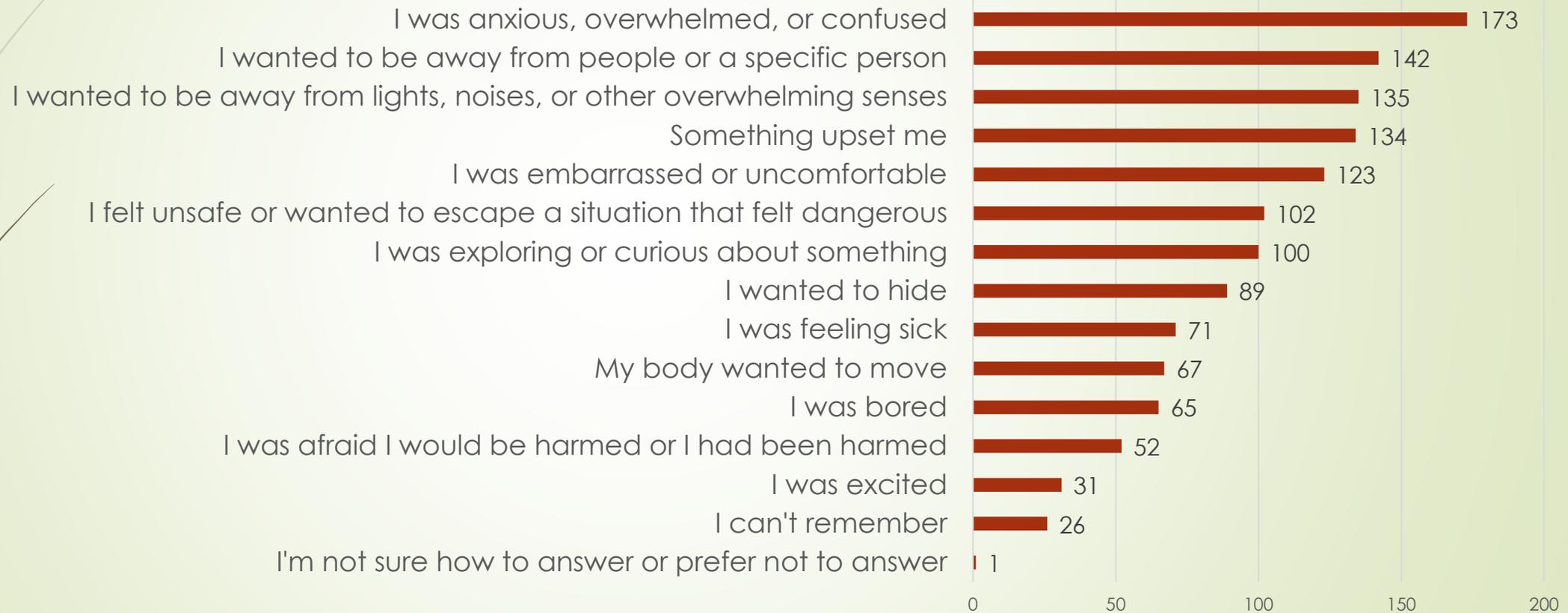
Survey Analysis: In Progress

- ▶ Primarily looking at descriptive statistics and broad trends at present
 - ▶ Many survey questions were “choose all that apply” in recognition of the complexity of people’s experiences
 - ▶ Several text-based questions were also included on the survey
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Survey demographics



Findings: Why Do People “Elope”?

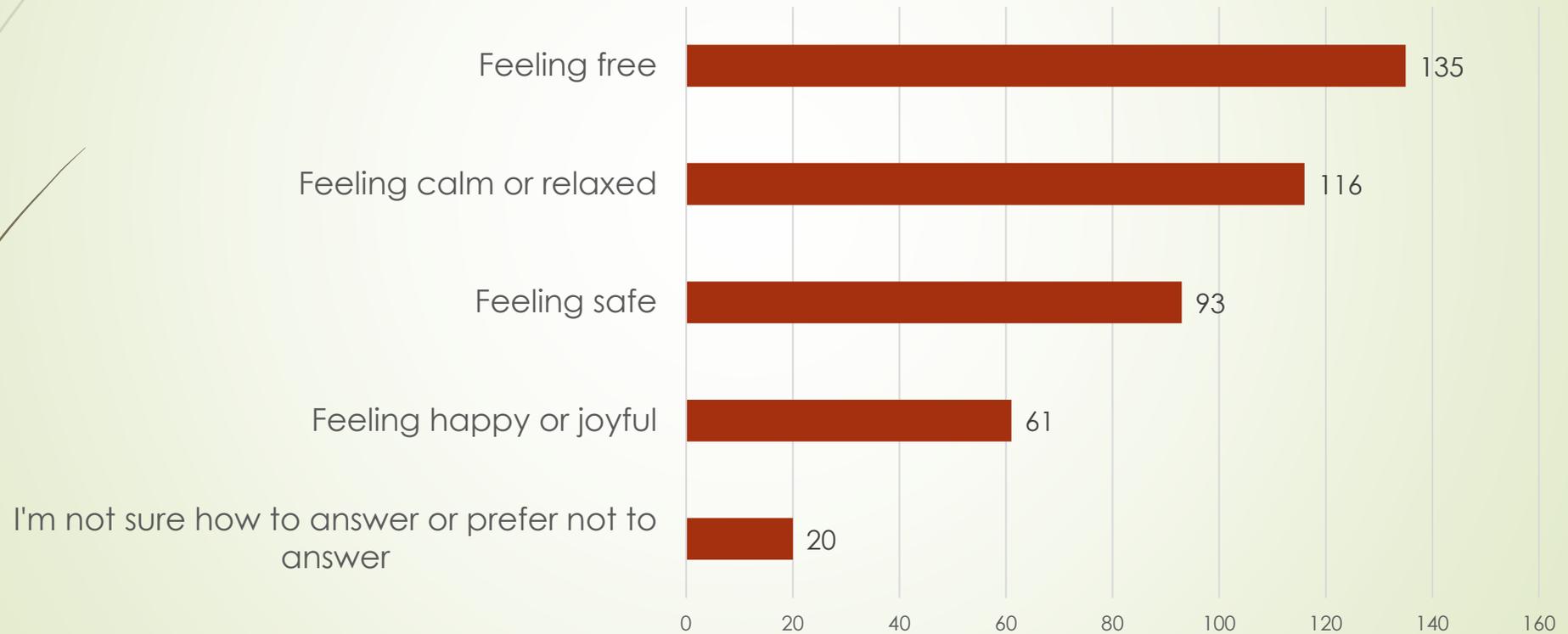




Findings: Why Do People “Elope”?

- ▶ Some respondents provided text responses that added greater depth or nuance to the presented survey options:
 - ▶ *Feeling like I'm invisible...being unheard/unsupported in times of stress...*
 - ▶ *Because I was being bullied. Because a teacher wouldn't listen to me or help me, so I ran off.*
- ▶ Others added entirely new reasons for leaving:
 - ▶ *Defy parent*
 - ▶ *I was sent to find something and didn't realize that I was expected to return if I couldn't find it, rather than continue looking.*
 - ▶ *I did not know how to leave politely in a neurotypical way so I just left.*

Findings: Positive Emotions Associated With Elopement





Findings: Positive Emotions Associated with Eloping

- ▶ Some respondents provided rich text responses describing the emotional impacts of leaving places
- ▶ In preliminary analysis, two common themes emerged from the text responses: **relief**, and **a sense of control**
 - ▶ *Feeling safe - but I didn't tick it above, because it's not a positive thing -- it's more just like relief?*
 - ▶ *Feeling in control of my life and decisions*
 - ▶ *I feel confident about exercising my agency*
 - ▶ *I was in control of my personhood & autonomy, & my body could "breathe"*



Findings: Negative Emotions Associated With Elopement

- ▶ The most common negative feeling was “Feeling anxious or overwhelmed” (130 respondents)
- ▶ While respondents did report negative emotions associated with elopement, when asked how they felt after leaving compared to how they had felt before, **55% indicated that “leaving usually makes me feel better” compared to only 3% who said “leaving usually makes me feel worse”**
- ▶ **Our results suggest that far from being an “irrational” problem behaviour, elopement can serve a variety of purposes and hold different meanings for people who leave places**



Findings: Elopement and Experiences of Violence

- ▶ While the nature of the survey questions makes it difficult to determine the frequency of violence in people's lives and the exact timing of violence relative to elopement, **survey results indicated that violence is not uncommonly a factor in elopement**
- ▶ Parental abuse was the most commonly reported form of violence (43 respondents, or 44% of the respondents who answered the question), followed by sexual harassment (39 respondents, or 40% of respondents)
- ▶ Importantly, participants also reported excessive use of force by police (14 respondents, or 14% of respondents)
- ▶ While preliminary, **these findings complicate the dominant narrative** of elopement as a behaviour that others should stop in order to prevent harm



Findings: Responses From Others

- ▶ Parents/guardians were most commonly reported as present during elopement (80%), followed by teachers (45%), additional family members (36%), and strangers (29%)*
- ▶ Others' responses ranged from harmful to helpful: when asked to rate others' responses on a scale of 1-10, **police officers and mental health practitioners were rated as the least helpful in their responses** (average score of 3), **while paramedics, strangers, and mobile crisis teams were rated most highly** (average scores of 6, 6, and 8)
- ▶ **Parents and teachers had an average rating of 4 out of 10**

* Question was "choose all that apply", so percentages add up to more than 100%



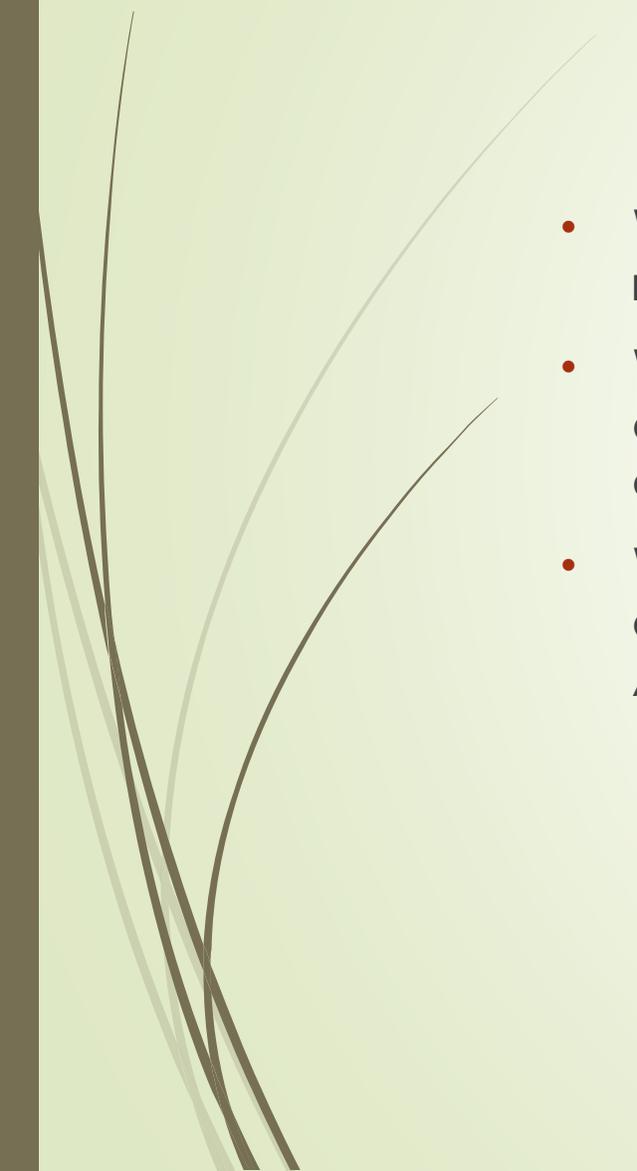
Findings: Implications



- ▶ Our findings indicate that **people elope for a variety of different reasons and a majority feel better after leaving a place**
- ▶ Our results also demonstrate that:
 - ▶ a) **elopement is not a specialist concern, as strangers are often present when someone elopes**
 - ▶ b) **the two groups of people most commonly reported as being present during elopement (parents and teachers) may not be responding in helpful ways**
 - ▶ c) **mental health providers, such as social workers, were rated as having mixed helpful/ harmful effects (average rating of 3)**
- ▶ Elopement is not just a consideration for specially trained frontline workers, or Autistic people's loved ones – **society as a whole should be prepared to respond to elopement in helpful ways**



Next Steps



- We received a SSHRC Insight Grant (2023-2028) to continue this research and expand our methodology
- We will be creating a larger team of Autistic co-researchers and collaborating with Autistic and non-Autistic scholars from a variety of backgrounds
- We will be conducting **interviews** and **photovoice** to deepen our understanding of elopement and its impact on well-being, from Autistic people's perspectives



Questions? Comments?

► **What implications do you see for your own work?**

► **Contact us:**

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► **Project website:**

<https://uwaterloo.ca/scholar/m23gibso/eloping-autistic-peoples-perspectives-departure-and-well-being>



References



- ▶ Anderson, C., Law, J., Daniels, A., Rice, C., Mandell, D., Hagopian, L., & Law, P. (2012). Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders. *Pediatrics*, 130(5): 870–877. doi:10.1542/peds.2012-0762.
- ▶ Boyle, M., & Adamson, R. (2017). Systematic review of functional analysis and treatment of elopement (2000–2015). *Behav Analysis Practice*, 10, 375–385. DOI: 10.1007/s40617-017-0191-y
- ▶ Calton, S., & Hall, G. (2021). Autistic adults and their experiences with police personnel: a qualitative inquiry. *Psychiatry, Psychology and Law*, 1–19.
- ▶ Chown, N. (2010). ‘Do you have any difficulties that I may not be aware of?’ A study of autism awareness and understanding in the UK police service. *International J. of Police Science and Management*, 12(2), 256–273. DOI: 10.1350/ijps.2010.12.2.174
- ▶ Gardner, L., Campbell, J., & Westdal, J. (2019). Brief Report: Descriptive analysis of law enforcement officers’ experiences with and knowledge of autism. *Journal of Autism and Developmental Disorders* (2019) 49:1278–1283.

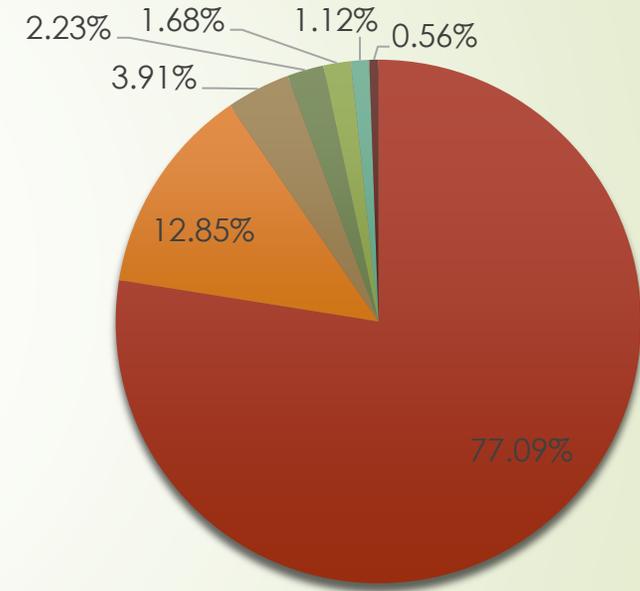


References

- ▶ Lang, R., Davis, T., O'Reilly, M., Machalicek, W., Rispoli, M., Sigafoos, J., Lancioni, G., & Register, A. (2010). Functional analysis and treatment of elopement across two school settings. *Journal of Applied Behaviour Analysis, 43*(1), 113-118. doi: 10.1901/jaba.2010.43-113
- ▶ McIlwain, L., & Fournier, W. (2017). Mortality & risk in ASD wandering/elopement 2011-2016. National Autism Association.
- ▶ Solomon, O., & Lawlor, M. (2018). Beyond V40.31: Narrative phenomenology of wandering in autism and dementia. *Cult Med Psychiatry, 42*(2): 206–243. doi:10.1007/s11013-017- 9562-7.
- ▶ Stockhall, N., & Dennis, L. (2016). Stop the running: Addressing elopement in young children with disabilities. *Young Exceptional Children, 19*(2), 3-13.

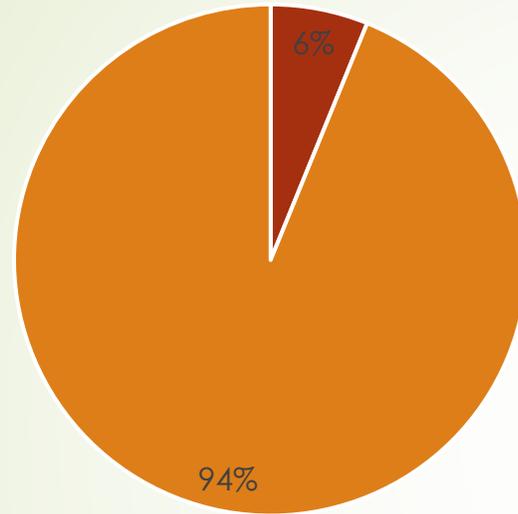
Survey Demographics: Racial Identity

Race	Respondents	Percentage
White	138	77.09%
Mixed race/multiracial	23	12.85%
Asian (East, West, & South)	7	3.91%
Black	4	2.23%
Other	3	1.68%
First Nations, Inuit, or Métis	2	1.12%
Middle Eastern	1	0.56%

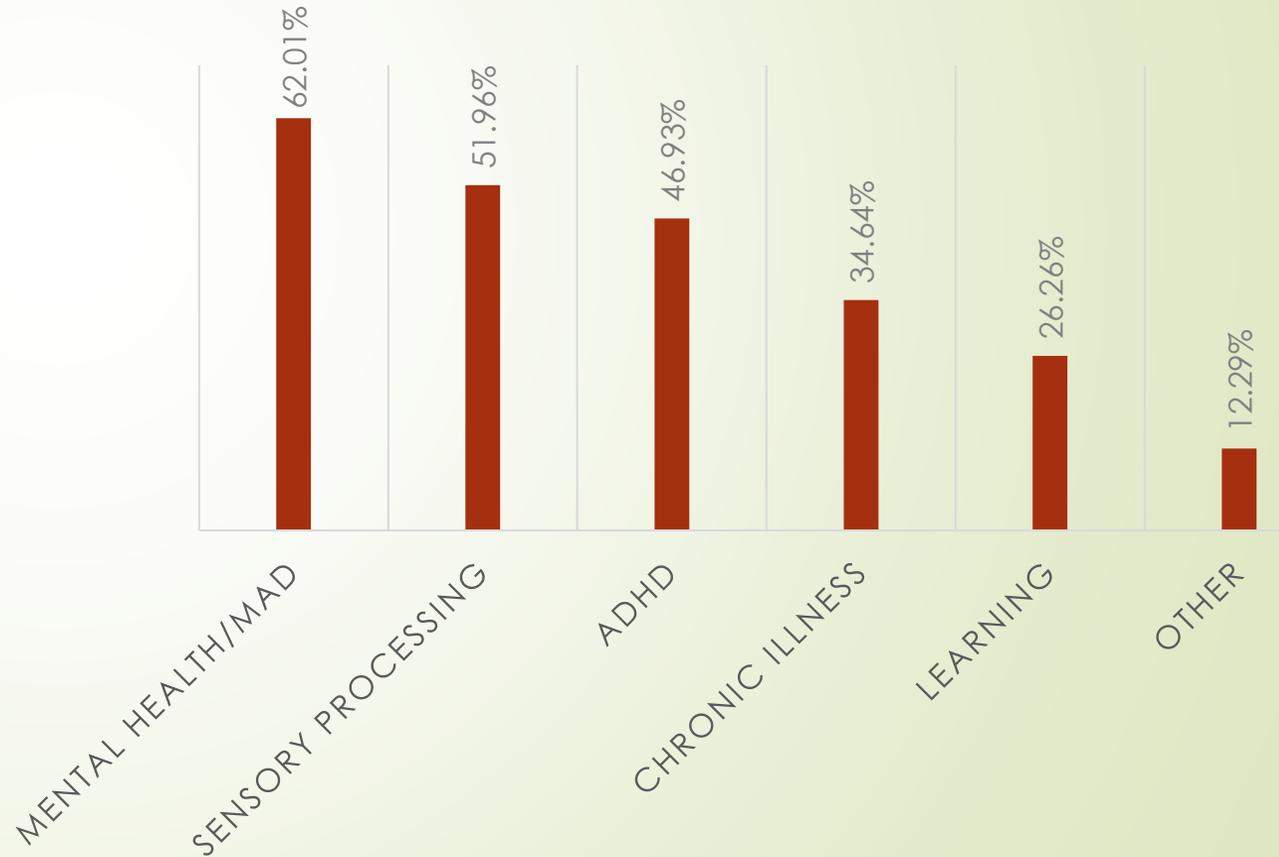


- White
- Mixed race/multiracial
- Asian (East, West, & South)
- Black
- Other
- First Nations, Inuit, or Metis
- Middle Eastern

Survey Demographics: Disability Identities



■ Autistic/neurodivergent only
■ Multiple disability identities



2SLGBTQ+ RESPONDENTS

