

PRIVACY AND CONFIDENTIALITY

Navigating complete anonymity: Engaging neurodiverse, justice-involved youth in a youth advisory board

Background context:

The focus of our project was to understand the experiences of neurodiverse youth involved in the youth justice system in Canada.

In order to design the project, a Youth Advisory Board (YAB) composed of neurodiverse youth involved in the justice system was developed. YAB members were recruited from a community organization that agreed to assist with the YAB. The YAB focused on obtaining feedback about the proposed project objectives, data collection methods, project logistics, analysis and knowledge mobilization outputs. The YAB's feedback was ultimately central to designing the project. However, the research team encountered various ethical dilemmas throughout the YAB process.

The main dilemmas encountered were maintaining confidentiality of YAB members consistent with the community organization's strict confidentiality protocols and also managing the relational/ethical aspects of the sessions.

The ethical challenge:

The community organization recruited YAB members and collaborated with the research team to facilitate the YAB. However, the organization had strict confidentiality protocols: no access to names/faces, and no direct communication with youth, other than during the YAB. As a result, the YAB took place over Zoom. While the research facilitators had cameras on, the YAB members had cameras off. This made it difficult to create a space where youth felt comfortable participating and for meaningful conversations to emerge. Additionally, it was challenging to ensure the sessions were engaging in an online format without seeing each other. Finally, case workers were present during the sessions, further complicating the relational dynamics of the sessions.

We therefore had two choices – work with the organization and adapt the YAB to ensure consistency with their confidentiality protocols, or, try to recruit YAB members without partnering with the organization. Ultimately we decided to continue working with the organization as we had previously encountered challenges when independently recruiting for the YAB due to organizational concerns rooted in adult-centric, protectionist discourses surrounding justice-involving youth.

Choices made:

To adhere to the community organization's confidentiality protocols and to manage relational/ethical aspects of the sessions, we made a number of ethical and relational decisions.

At the start of every session, we explained informed consent so the youth could make choices accordingly based on their comfort levels. Since YAB members were not allowed to share their real names, they selected a preferred name which was used during the sessions.

Given we could not see the young people (and they could not see one another), various modes of participation were integrated into the sessions to foster relationships and prompt discussions. For instance, prior to the first session, the research team dropped off toolkits to the organization for each youth to use in person throughout the sessions. The toolkits included resources such as whiteboards, markers and snacks. We found these were useful for participants that preferred to hand-write or draw out their ideas instead of sharing verbally/online. We also made use of on-line tools such as, Menti Meter, Jam Board, Zoom chat and Zoom audio, enabling youth to share their ideas via various online outputs (eg: online drawing, typing, speaking). These mechanisms were useful for participants that preferred to share their ideas online and enabled the participants to choose what they were most comfortable with. In particular, Jam Board seemed to be the most popular online option as participants could use shapes, colours, they could type one-word responses or longer sentences without having to verbally articulate their ideas. Some participants liked using Jam Board to express their ideas and would then unpack them verbally. These online mechanisms were also useful for the researchers because they served as centralized spaces that visually captured the data, and oftentimes we would return to the Jam Boards so participants could build upon their previous responses.

Games were also integrated to help build rapport (eg: ice breakers, mock interviews, etc) which were useful in allowing the researchers to strengthen their

relationships with the participants and build relationships amongst the group. For instance, we asked participants to pretend to interview one another and think about how it made them feel, what worked well, what they liked and how they could improve the interview process. This enabled the participants to provide feedback on how we could meaningfully design our interview process for the project.

Some consequences of the above decisions included occasional technical issues (eg: difficulty hearing the youth) and impersonal discussions at times due to relational constraints which may have diminished the potential for deeper discussions and relationships. It was also challenging to gauge youth engagement with cameras off. At times, the case workers tried to encourage participation and their presence may have impacted what youth shared.

Next time, the research team would consider one-on-one sessions with youth to allow for more in-depth discussions/stronger connections.

Reflexive questions / considerations:

- How might the presence of caseworkers in the room be managed so that the research participation (or non participation) of youth is not impacted?
- The fact that the youth were justice involved and participated in the YAB, while also involved with an agency can raise questions about consent. For example, is it possible that youth felt obligated to take part in the YAB? What can researchers do to manage inherent power imbalances and ensure that participation in the research is truly the choice of young people?
- Why was offering youth different modes of participation so important in this case? Are there any other methods of participation that the researchers might have considered?
- How can researchers navigate the ethical tensions between prioritizing youths' best interests, fostering trusting relationships, and adhering to the rules and protocols of community organizations?

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Related References:

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