Making the Shift: Roadmap for Youth Homelessness Data Infrastructure

5: Youth Focus Groups

PolicyWise for Children & Families

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Acknowledgments

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Key Messages

We conducted group discussions with youth with lived/living experience of homelessness to learn their thoughts on information collection, use, and sharing when seeking housing supports. These are the key messages we heard:

1. **Make intake positive.** When youth use services, information collection can be an emotional process. Limit questions to those that are critical for immediate needs to reduce youth burden. Special attention is required when asking sensitive questions, such as on ethnicity and gender identity, as youth fear negative treatment on disclosure.

2. **Build informed processes.** Youth should not have the fear of loss of services when they don't consent to provide information. Consent process should be "informed" by clearly explaining how information will be used and shared. Read out the consent form.

3. **Use information to support journeys.** Consider the long potential path for youth when collecting information. This may involve a return to supports. For example, youth would like briefer information collection on return to services and a regular update of information. They also want their information to be removed once housing conditions stabilize.

4. **Allow youth choice.** Provide youth with autonomy on decisions on what they share and who their information can/cannot be shared with. Make sure consent is really a choice.

5. **Target a more inclusive definition of youth homelessness.** While the current definition of youth homelessness is comprehensive, youth would like it to be even more inclusive. For example, include cases where youth live with their guardians but feel a "lack of physical and emotional safety." Inclusivity empowers youth and helps create a more complete count of youth homelessness to better plan for supports.

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Introduction

This project is funded by Making the Shift: Youth Homelessness Social Innovation Lab. Making the Shift is co-led by the Canadian Observatory on Homelessness and A Way Home Canada. It is funded through the Networks of Centres of Excellence. Working in collaboration with researchers, policymakers, practitioners, and advocates, the Lab conducts, funds, and mobilizes cutting-edge research and prototypes promising program models in communities across Canada to prevent and end youth homelessness.

This project's goal is to create a roadmap for data infrastructure to support the prevention of youth homelessness in Canada. Data infrastructure refers to the collection and storage of information; people's skills, mindsets, and capacity around information; the rules for who can access the information and in what ways; and how the information can be used. Project activities include: 1) project steering, such as convening advisory team meetings to inform project actions; 2) learning to understand key related data infrastructure, promising practices and processes, other Making the Shift project learnings, community service provider related practices, youth with lived experience relevant practices, and Indigenous community relevant practices; 3) engagement with stakeholders to co-decide the best path for a roadmap; and 4) the co-creation of the roadmap with stakeholders.

This document shares learnings from focus group discussions with youth with lived/living experience of homelessness/housing instability. The discussions aimed to understand what youth think about: 1) their experience with information collection when they sought housing and related supports; and 2) sharing of information they provide when accessing services.

Methods

Ethics approval was provided by the University of Alberta Research Ethics Board and the McGill University Institutional Review Board.

We conducted three focus groups with youth with lived/living experience in two provinces (Alberta and Ontario). Focus group discussions were conducted in September 2023. All methods were co-designed in partnership with an engagement facilitator with lived experience of youth homelessness.

Step 1: Discussion guide preparation

We created semi-structured discussion guides to facilitate conversations. Discussions focused on youth's thoughts on information collection and sharing, based on their experience accessing housing supports. Our youth engagement facilitator reviewed and revised drafted questions, to improve accessibility and relate questions to youth experience (See Appendix 1 for discussion questions).

Step 2: Participant recruitment

We recruited 21 youth participants through introductions from youth-supporting organizations with existing connections to us and partners who had connections with youth-supporting organizations across the country. Prior to recruitment, we explained the aim and the purpose of the focus group, the eligibility criteria for participants, the duration of a discussion, and compensation. Eligibility for the focus group was: 1) being aged between 18 and 30 years old; and 2) having experiences of homelessness or housing precarity from 2019, to connect experiences with modern practices.

Step 3: Focus groups

After receiving written consent from participants, we conducted 2-hour focus group discussions in English. The discussion was recorded with the consent of participants. We transcribed audio recordings and removed identifiable information. At each session, one youth support worker was present to provide support to youth participants if necessary, supporting trauma informed care. Youth were paid $50 and provided food and beverages for their participation.

Step 4: Data analysis

We coded focus group transcripts using NVivo12 Plus. We created an initial code list based on the discussion questions. As we deductively assigned pre-defined codes to transcribed data, we also inductively created and added codes to capture other topics and themes that arose. We iteratively reviewed and organized codes across the data to best reflect what was shared. An independent reviewer with in-depth knowledge of the project examined the coding and theme list, and themes were revised. As a final, critical step, our youth engagement facilitator reviewed our work to help revise, validate, and interpret the themes.

Findings

Participant background

We held three focus groups with 21 youth that crossed two provinces (Alberta, Ontario). Participants ages were: 18 to 20 years-old (12 youth), 21 to 25 years-old (8), and 26 to 30 years-old (1). Their self-identified gender was: male (12), female (1), prefer not to answer/no response given (8). Their ethnic backgrounds[1] was: white (5), black (7), Indigenous (10), other (1), and do not know (1).

Key themes

1. Make Intake Positive for Youth

Youth generally described the intake process as involving many questions and signatures. They called the process *"the worst nightmare of homework"*. Reflecting on the lengthy intake process, youth suggested to: **1) reduce the number of questions to only essential questions;** and **2) train frontline staff so that youth can feel respected** "*as a real person, like a human being, instead of a statistic."*

Many youths reported that **information collection at intake was an emotionally difficult process**. One youth recalled, *"[The Staff] was asking me lots of questions and I was really nervous when I answered them."* **Many felt nervous and fearful, feeling that *"maybe we wouldn't have place to stay"* unless they answered all the questions.**

Others were frustrated by being asked the same questions when calling the organization again.

"And then you have to tell them again. And the next time you call, it's like a revolving door. They don't retain the information. Or maybe they do, but they make you say it over and over again."

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[1] Participants chose all categories that applied to them.

Some expressed fears around identification when being asked for their ID:

"Participant: I think the first thing [they] asked me for was like identification
Facilitator: Like the actual physical ID?
Participant: Like you need to prove it, and if you can't prove it within a certain time you can't be in the shelter
Facilitator: So if you can't prove who you are within a certain time, you can't access the shelter?
Participant: I don't know if they asked everybody that, but yeah."

Youth sometimes found questions uncomfortable and awkward. For example, they felt awkward answering about: "Relationships with family including siblings," "Where they were coming from," and "Where they slept the last night." Also, they feel that **questions about sensitive information cannot be simply reduced to yes or no questions,** such as on substance use, family situation, and mental health challenges.

One black youth did **not feel comfortable being asked about their ethnicity because of biases which may lead to undesirable treatment**. *"If like you say, oh, you know, I'm white, and then they're gonna proceed to deal with you a certain way. You say, I'm black, African, you know, you're gonna proceed to deal with you a certain way. You say, I'm Native, I'm a First Nation, you know, they're gonna proceed to deal, all three of those answers are gonna get different treatment."*

Youth stressed the importance of **allowing questions to make them comfortable in the intake process.** *"I think the thing that should definitely be put more in place is like it being stressed that you can ask questions about the questions and stuff like that. Like, it's okay. You don't have to answer this or this. It's okay you can ask about these questions. I feel like that should be stressed more."*

2. Build Transparent, Informed Processes

Information use can have implications on youth. One female participant shared an example of **how certain information was used against her**. She shared that when she was younger, her daughter was taken away due to sharing about her mental health challenges. *"They used my depression against me…they didn't let me talk…they wouldn't listen to me."*

Youth shared varied experiences of the consent processes when their information was collected. One youth recalled that they were told *"even if you did say yes at any point, …you could also withdraw your consent in case you don't want that in the system anymore."* A few others stated that they were not fully informed about how the information would be used and feel that *"people don't ask for consent enough"*. In addition, they did not feel that they could say no to certain questions as it would affect their services offered. "*Because you need a shelter, right, you're desperate to get a shelter. So, if you need the service, you can't say no"*.

Youth responses varied on their thoughts on information sharing between organizations. Many showed a **positive response to the idea of their information being used for better service delivery and prevention of homelessness**. On the other hand, some expressed that it could be *"scary"* and *"worrisome"* if their information was shared without knowing how the information is used and by whom. In contrast, one youth thought *"privacy isn't really a big concern anymore"* now that personal information can be shared via apps anyway.

One youth mentioned that **sharing is complex, as what they share is built on trust**:

"I don't even think the most relevant thing is what the questions are, but who's getting the answers. Yeah, like who's reviewing the answers. That way, you can be confident if you're telling someone you trust, and you're telling someone you don't trust. Or if someone you don't know, then you're going to be way less confident."

Building on this perspective, youth asked 1) for a **clear explanation of how their information will be used and by whom**; **2) to be asked for consent as often as possible**; and **3) to have consent forms read out to them and time allotted to ask questions.**

3. Use Data to Support Youth Journeys

Youth discussed that **data needed to be setup to support their journeys over time**. Some youth who returned to services had to go through a lengthy intake process. They preferred to have a **briefer intake option for those who previously accessed services, consisting of the update and verification of stored information**. Youth suggested to create *"a package that is ready to be sent to a program upon request…"* so that youth can pull up their previous profile if they access services in the future. At the same time, since different people are involved each time and things change, specific details may need to be added and updated when they return.

Along these lines, many youths iterated **the need to update collected information over time** since the information can become less relevant or accurate, particularly those collected when they were minors. *"I feel like definitely if you have something on your file from when you're a minor, it should be redacted, I feel. And maybe they should just follow up instead and ask if these are relevant issues now that you're an adult instead of keeping it on your file for so long."* Youth discussed that **individuals are responsible for updating their information by informing** the service provider when a change happens in their information and condition. On the other hand, **the service provider should periodically check-in to make sure everything is still accurate**.

Youth discussed that once they **reach a point where housing support is no longer needed, collected information should no longer be made available.** Thinking about the future, a youth participant mentioned, *"If I had kids, I wouldn't want them to know I was here."* Another youth participant stated, *"I feel like just because some time has passed doesn't mean that…the consent is invalid."* **Youth showed varied responses on how long their information should be kept**, since *"it depends on the person's personal history."*

4. Allow Youth to Make Choices

Youth stressed **the need to recognize their agency to make choices in terms of what information can be shared and with whom**. For instance, they proposed **a list of people to share with and those to not share with**.

"Participant: there should definitely be like a blacklist of some, of some sort of like, absolutely do not share my information with my parents, or something like that. Like a list that is there that you can be like, Okay, you can't share my information with these people.
Facilitator: How do you feel about that green list that was mentioned about like, you can share with these people, these specific details?
Participant: I think that that's just as important of like, well, here's somebody safe that I feel comfortable you sharing this information to."

People who youth were comfortable sharing with varied among: the staff/social worker who they interact with and manages programs; a school counsellor; or teachers. On the other hand, they often

did not feel comfortable having their information shared with parents and relatives, the authorities (e.g., police), and the public.

Although there are tensions around minors' understanding of their rights and information collection and storage, **youth feared that adults speaking on their behalf can result in undesired outcomes**. *"I feel like consent when you're a minor is a very touchy subject because I don't believe it's legally binding, at least to my knowledge. But if you get a parent involved as well, that's not necessarily the best either because they're speaking for somebody else."* This may be further complicated in the case where negative/abusive relationships exist with the adult.

Some youth requested **respect of youth autonomy for decision-making and independence regardless of age**. *"Like, just how you can do certain things like in school, some schools you can do like independent learning. Like I feel like it's the same for that. You should be able to switch over …if you don't have a good relationship with your parents or you're on your own. You should be able to go and switch it over so it's you signing those forms kind of thing. I don't think there should be like a certain age, it's just kind of your situation that's what it should be based on."*

5. Youth Want an Inclusive Definition of Youth Homelessness

Definitions are critical as they frame data collection that affect how youth are supported and which programs are funded. When supplied with Canada's youth homelessness definition which "refers to the situation and experience of young people between the ages of 13 and 24 who are living independently of parents and/or caregivers, but do not have the means or ability to acquire a stable, safe or consistent residence," **many saw the definition as wide enough to include different situations youth faced when seeking housing support**.

The current definition considers "risk of homelessness", which refers to "who are not homeless, but whose current economic and/or housing situation is precarious". However, as one youth described, to them **homelessness is** *"a person who does not have a safe place to call home."* Some youth pointed out the **lack of the concept of a** *"feeling of safety, either physically or emotionally"* **in the current definition**.

A couple other ideas to reflect the reality of youth lived experiences were proposed:

*"Youth 1: lack of financial means to support their own daily needs including housing and meals. Youth 2: independent living from parent should be completely removed. Because while, yes, that is what's typically thought of as homelessness, like, doesn't have a house to stay in…***You can still be living with, like somebody that it's just like hard to escape from their domestic situations and stuff like that, where that definition would no longer apply to them.***"*

Discrepancies from the age range in the definition and how services were delivered were pointed out. Many proposed **increasing the age range and/or categorizing age groups** to meet the complex needs and unique situations of each individual youth and transitioning young adult to avoid their falling through cracks in the system.

"Participant: [---] Like it might be difficult like making that transition, like aging out of like something that's 13 to 24, turning 25 and instantly being in this bigger pool of people, like 25. Session Leader: that's exactly what happens right now. Participant: such a big pool and you're given less opportunities."

Conclusion

Discussions with young people with lived and living experience of homelessness shed light on relational dimensions of information collection, use, and sharing when youth seek housing support. When disclosing their personal information, they must navigate power-structures within the system and difficult emotions, such as fear and frustration.

While youth support the idea of using anonymized information for the purpose of helping prevent others from experiencing homelessness, they would like to be fully informed about how their information will be used so that they can make the decision to consent to its use. Clear communication and transparent processes for consent for information use and sharing are needed for ethical use of collected information. As a last note, youth asked for more inclusive definitions of youth homelessness that address their varied situations. This is important as how we define youth homelessness affects how we collect data to know its scope and address it.

Appendix

Appendix A: Discussion questions

Data Collection & Housing Services
Many of our questions today will be asking about how you feel about your personal information being collected and its connection to accessing housing supports. I will provide some definitions as we move along to help the conversation flow. Remember that you can share as much or as little as you'd like for each question.

1) Please share a bit about your experiences when first accessing and/or using housing supports (for example: Accessing an emergency shelter, signing up for a service).
    a) What information were you asked for when you first came in or began to access the service? (for example: Name, Date of Birth)
    b) Is there anything you were asked to share that you weren't comfortable sharing?
    c) Were you informed about how your information would be used after it was collected?
    d) Did you feel like you could say 'no' to giving this information without affecting the services you got?

2) Personal information (for example: Gender or immigration status) is often stored in databases compiled by those who fund services, like the Government of Canada for example. Information that is collected from you has the potential to be used to help make services for youth experiencing homelessness better. For example, some data being collected might be able to predict if a young person was at risk of becoming homeless before it even happens. When this data is used, it is usually grouped and presented in reports with graphs and stats, without your names.

    a) How do you feel about your information being used this way?
    b) What, if anything, needs to be in place to make youth feel better about how their data is being collected and used?

Consent & Privacy
Consent occurs when someone voluntarily agrees for something to happen or to do something for someone else. It is also ongoing in that you can change your mind and say no later. Consent is a huge part of ethically collecting people's personal information. For consent to be valid, the person should be able to understand what they are agreeing to do and feel like they can say no without any problems with services collected.

3) How often and at what point should youth accessing housing services (e.g., Shelter) be asked for their consent to share their personal information with other service providers? For example, some services may make you sign a new agreement each year while others require it when changes are being made to the original agreement.

4) Oftentimes we hear that youth are sick of being asked the same questions over and over as they seek to get support. If your information were to be shared with other organizations, you would not have to repeat answering the same questions so often. Are you comfortable with the idea of your information being shared with different organizations in this way? Why, or why not?

    a) What would make you more comfortable with sharing your information across organizations?

5) Who should be able to easily access these records? Who should not be? Why?

    a) How long should consent to share information for housing services be valid for? For this question, it might be helpful to think about someone's journey from being unhoused to having housing stability.

Definitions

Many services provide definitions and descriptions to tailor their services to specific populations (for example: Refugees and women). These definitions and terms also have the power to include or exclude people from accessing certain supports. For example, some homelessness services may be for a specific gender group or age group.

6) Canada says Youth Homelessness is "situations and experiences of young people between the ages of 13-24 who are living independently of parents and/or caregivers, but do not have the means or ability to acquire stable, safe or consistent residence."

    a) Is this definition sufficient? What, if anything, is it missing?
    b) How can this definition be improved?

Closing

7) Do you have any final thoughts or feelings you'd like to share about collecting personal information, information sharing, data usage and/or consent you'd like to add before we wrap up?