OurVOICESMatter

karis Disability Services

Our Voices, Our Stories, Engaging Everybody: A photovoice project

Project Team

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*"**H**old **O**n **P**ain **E**nds"*

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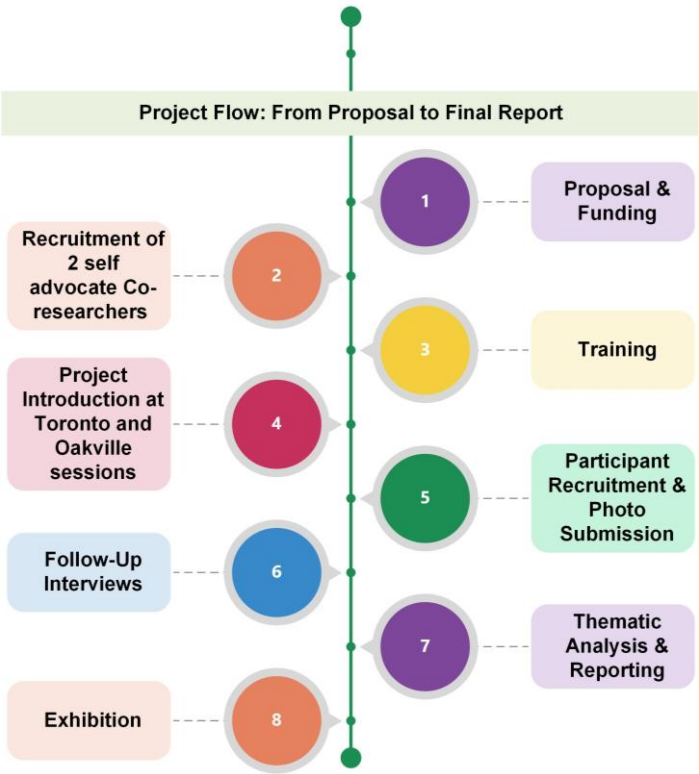
- We would also like to acknowledge the members of the OVM Council Wayne, Dzidra, Casey and others for their encouragement and ongoing support throughout this project, and, most importantly, all the Photovoice participants who registered, generously shared their time and insights, and made this initiative possible.

How We Did It



About the Photovoice Method

Photovoice is a method where people use photos to show their experiences and what matters to them. They take pictures of their daily lives, challenges, or important issues and then talk about what the photos mean. *(Wang & Burris, 1994).*

For those who found it difficult to take photos themselves, staff members provided support, ensuring the images still reflected each participant's own perspective and experiences at the engagement sessions.

Purpose

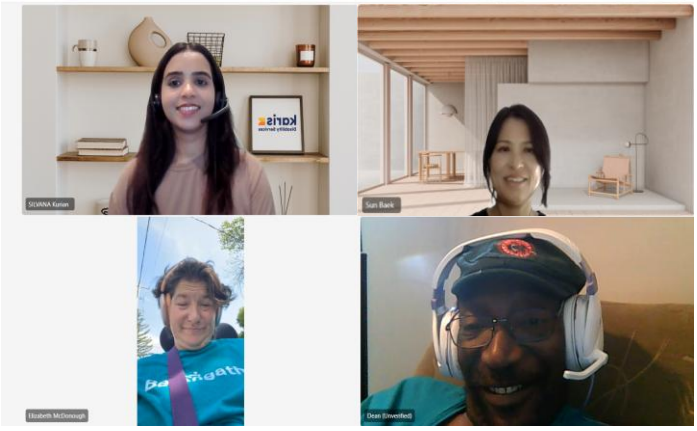
This research explores the experiences and perspectives of people with disabilities who attended the Karis engagement sessions, using the Photovoice research method. Inspired by the improvements identified through the Participatory Advocacy Research Network Camp (October 2024), the project aims to understand how attendees experienced the sessions, particularly whether they felt respected, included, and valued.

The study also examines the impact of including self-advocates and people with disabilities in planning and co-presenting roles at the engagement sessions, and how this involvement shaped the overall experience for service users. Finally, the project will identify practical ways to improve future conferences, so they better meet the needs of people with disabilities and promote inclusion.

How We Did It

Project Team

The project team included two self-advocate co-researchers and two Karis staff members from the Quality, Research, and Practice Initiatives Department. This equal representation between self-advocates and staff follows participatory research best practices. The self-advocates were engaged as independent contractors and were selected from participants in the October 2024 Participatory Advocacy Research Network Camp, as this project was inspired by Karis's involvement in that event.



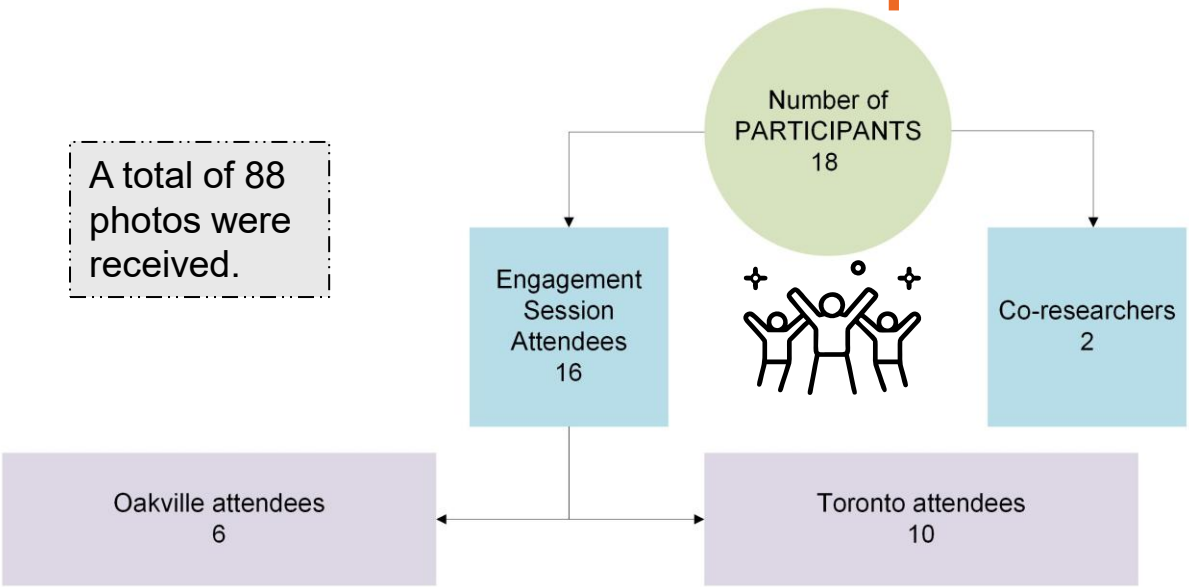
Project Timeline and Preparation

From May to September 2025, the research team met online via Microsoft Teams once or twice a week for one-hour sessions. During these meetings, the team:

- Reviewed the Photovoice methodology.
- Covered research ethics, privacy, and confidentiality.
- Prepared materials such as consent forms, project information sheets, and recruitment presentations for the engagement sessions in Toronto and Oakville
- Attended Toronto and Oakville sessions and recruited participants.
- Conducted follow-up interviews with the participants (in-person and online)
- Reviewed methodology of thematic analysis.
- Conducted thematic analysis of photos and interview transcripts.
- Prepared Reports and materials for the final exhibition

Our Research Participants

A total of 88 photos were received.



Co-Researchers also as Participants

In participatory action research, it is important to include people with lived experience in all aspects of the project. In our study, the co-researchers also took part in the Photovoice project as participants. This approach ensures that the research reflects the real experiences of people with disabilities and that their voices are at the center of the project.

Follow-Up Meetings After Photo Submission

After the photos were submitted, staff researchers met with participants to discuss their photos and experiences. Eleven meetings were held in person, five were held online, one was conducted by phone, and feedback from one participant was collected via email.

Participants also received a $25 Tim Hortons gift card to thank them for their time, participation, and contribution.

Findings from the project

Follow-up meetings with 18 participants provided rich insights into the engagement session. Using photos from the event as prompts, participants shared their experiences, highlighting what they valued, enjoyed, and felt could be improved for future sessions.

Five prominent themes emerged: **Collaboration, Positive Emotional Experience, Social Connection and Belonging, Meaningful Activities, and Advocacy**. Other themes included feedback on food and some general feedback.

Theme	Number of Comments	Description
Collaboration	23	Participants collaborated through co-presenting, working together with leadership or others at the session.
Emotional Experience	23	Participants felt a variety of positive emotions at the session.
Meaningful Activities	18	Participants found the activities enjoyable and helpful.
Social Connection & Belonging	17	People experienced connecting with people and being part of something.
Advocacy	9	People had opportunities to advocate for themselves and make differences.
Feedback on meal and snacks	8	Most participants enjoyed the food, describing it as tasty.
General Feedback	7	Participants described the session as enjoyable, providing a learning experience and a pleasant break from routine.
Recommendation	20	A range of suggestions was provided to improve future events for people we support.

Theme 1: Collaboration

Participants described a strong sense of working together with peers, staff, and leadership throughout the session. Collaboration was valued both in formal opportunities such as co-presenting and co-designing with leaders and staff, and in informal interaction that fostered mutual support, encouragement and connection.

Working together and sharing feedback and ideas helped people feel respected and connected.

Co-designing & Working together (mentioned by 8 participants)

Directly engaging with leaders gave people meaningful opportunities to share their thoughts and form relationships

Collaboration with Leadership (6 participants)

Collaboration

Co-presenting (5 participants)

Presenting together with staff or leaders gave participants pride, enjoyment, and a shared voice.

Support from staff (4 participants)

Support from staff helped people join in, feel confident, and stay involved.

"I enjoyed and was proud of co-presenting."
"I loved leadership."
"Nice to see my friends and the groups working together."
"Staff helped with speech."
"I enjoyed working with leadership."

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Theme 2: Emotional Experience

Participants reported a range of positive emotions, from fun to pride and hope, shaped by both activities and the inclusive environment.

Fun
Mentioned by 7 participants

Fun was frequently mentioned, whether through social connection or engaging activities.

Happy
5 participants

Many expressed they felt happy during the session.

Pride
3 participants

Participants felt valued, and proud, especially after contributing as a co-presenter.

Mixed Positive Emotions
4 participants

A blend of excitement, comfort, pride, and importance, even alongside nervousness.

Optimism
2 participants

Some expressed hope for the organization's future.

Love
2 participants

Some participants used the term 'love' to describe their overall experience at the event suggesting a positive response in the context of a welcoming environment.

"It was a lot of fun"

"I felt good about myself"

"Fun, not nervous, felt great, comfortable, happy, felt in the spotlight."

Theme 3: Meaningful Activities

Participants shared positive feedback about various interactive activities during the session, highlighting their role in fostering engagement and satisfaction. This theme is divided into several subthemes reflecting the types of activities and general impressions shared by participants.

Meaningful Activities

Writing Activities (4 participants)

Participants appreciated the opportunity to write or draw during the session.

General Feedback on Activities (7 participants)

Participants shared positive overall impressions of the activities, describing them as helpful, fun, and engaging.

Engagement Session Activity (7 Participants)

Participants highlighted specific engagement activities designed to promote interaction and hands-on involvement.

Wall Activity (4 participants)

This activity involved posting questions and comments on a shared wall, creating an interactive space for participants to express thoughts and engage with others.

Sorting Activity (3 participants)

Participants reported enjoying the hands-on sorting tasks, which appeared to support engagement and active involvement.

Although many participants recalled participating in the sorting activity, they were often unable to remember the specific contents of the cards or the rationale behind the task.

"Good to ask questions like on the wall"

"Enjoyed sorting cards and papers."

"had the opportunity to draw or write."

Theme 4: Social Connection & Belonging

During the session, participants experienced a strong sense of connection both through reconnecting with peers within Karis and forming new relationships. These moments of interaction created conversations and helped people feel welcomed and valued.

Participants felt like they were part of something. They enjoyed being together and felt included.

Belonging

(mentioned by 4 participants)

Reconnecting with friends

(3 participants)

Making New connections

(10 participants)

Participants liked seeing friends, peers within Karis. Being with familiar friends made them feel happy and comfortable.

Participants had a chance to meet new people during the session and having engaging conversations with them.

"Great to see my friends there."
"Engaging in the conversation and listening"
" Felt like being part of something"

Theme 5: Advocacy

Nine participants described opportunities during the session to advocate for themselves and contribute to making a difference. Many spoke about sharing important personal goals, expressing their ideas, and feeling heard in meaningful ways.

Self-Advocacy and Sharing
(Mentioned by 6 participants)

Participants valued the opportunity to talk about what matters to them, including their personal goals and key topics such as housing and independence.

Making a Difference
(3 participants)

Several participants enjoyed advocacy work and wanted to help the organization make a difference.

"I shared everything I wanted to share"
"I like to help Karis, making differences"
"I enjoyed advocacy work"
"I shared about future goals"

Theme 6: Feedback on meal & snack

Eight participants talked about their experience with food. Six described it positively, highlighting the good quality and enjoyment of mealtimes. Two offered suggestions for improvement, which will be included in the Recommendation section of this report.

"I enjoyed lunch.
"Having lunch was nice"
"Food was good"

Theme 7: General Feedback

Seven participants offered general reflections on the engagement session, describing it as enjoyable experience. Several appreciated the opportunity to step away from their usual routines and welcomed the change to learn new things in a supportive and friendly environment.

"Nice to get away from here."
"It was a learning experience."
"Like a picnic."
"I wouldn't change anything as the program was good."

What Participants Recommend

Making the events "FUN" (5 participants)

Many participants expressed a desire for more fun and engaging activities. Suggestions included incorporating games, karaoke, dancing, and outdoor events to increase enjoyment and participation.

From a research perspective, it is important to consider the feasibility of implementing such suggestions while also reflecting on the extent to which participants may have misunderstood the primary purpose of the event.

Creating More Opportunities (5 participants)

Participants hoped for increased opportunities to engage actively through co-hosting, co-design, and more frequent sessions. They also hope for wider participation of service users in upcoming events.

Improvement for Activities (3 participants)

Some participants suggested offering a greater variety of activities, including individual activities and avoiding crowding during tasks like the wall activity.

"More Games"
"More outside events like BBQ"
"I want to do co-hosting again!"
"More activities for people to choose from"

What Participants Recommend

Improvement for Conference Hall Layout (2 participants)

Several participants recommended changes to the physical setup (e.g., Toronto session layout) to allow for more comfortable seating arrangements, including more personal space and opportunities to sit alone if preferred.

Recommendations on Food (2 participants)

Suggestions around food included offering healthier options such as fruits and vegetables, adding more options for people with dietary restrictions like dairy-free and gluten-free, providing more beverage choices like sparkling water and less pop.

Additional Suggestions (3 participants)

Other feedback touched on logistical and session structure improvements, including concerns about travel distance, more writing or drawing materials, and more scheduled breaks after each session

"The tables were too crowded, spread people out for the next time"
"Have more heathy food like fruits and vegetables"
"More questions about food preferences during registration"
"More blank papers or pads for people to write or doodle on"
"Too far, a long trip"

Session Recommendation for Leadership / Engagement Organizing Team

Most participants shared that they had a positive experience at the engagement session. They enjoyed making new connections and reconnecting with friends. Many self-advocates said that co-hosting with leadership and staff was a valuable experience and something they felt proud of. During reflection, participants were more likely to remember activities they were involved in. Some participants were able to recall and discuss their involvement in activities such as the wall exercise and sorting tasks. However, many had difficulty remembering the rationale behind these activities, including the purpose and specific components involved.

To make future sessions more accessible, **alongside the recommendations service users shared**, it may help to:

- **Use simpler words and larger fonts.** An open randomized controlled trial found that simplified ("easy read") text combined with mediation significantly improved comprehension for adults with intellectual disabilities compared to complex text with mediation, highlighting the importance of both simplification and support (Buell et al., 2020).
- **Provide more one-to-one support so that everyone's voice can be heard.** Inclusive research finds that using a supporter or communication partner increases participation by people with higher support needs (Hall et al., 2025) and helps interpret abstract language and technology during sessions, making one-to-one support an evidence-based accommodation (Öhrvall et al., 2024).
- **Offer more options for individual activities, recognizing that service users have varied abilities and needs.** Research on reading development in children with intellectual disabilities shows that both decoding and oral language skills predict comprehension outcomes, but additional supports are often needed to scaffold engagement and understanding (van Wingerden et al., 2017). This highlights the importance of tailoring activities to individual strengths and support needs.
- **Offering more practice sessions and preparing well in advance** could help them feel ready and confident to present alongside leadership. One self-advocate co-host had difficulty remembering their role during the session. A qualitative study of peer-led self-advocacy groups found that social engagement and peer supports fostered agency, leadership, and confidence among people with intellectual disability (Bellon et al., 2025)

Limitations of the Project

- **Challenges with follow-up:** Scheduling one-on-one interviews after photo submissions was challenging due to logistical constraints (reaching staff, scheduling conflicts, availability etc.)
- **Recall and feedback issues:** Some participants had difficulty remembering the event and providing feedback, highlighting the importance of conducting follow-ups promptly. For future sessions, staff should be reminded about the need for quick responses, and the research team should also prioritize prompt follow-ups, recognizing that people have different capacities for recalling events.
- **Cognitive variability:** In this project, the research team provided plenty of time and support (visuals, breaking down questions etc.), which helped many participants share their views. However, the ability to provide feedback varied depending on the cognitive abilities (level of IDD) of the individuals supported, which should be considered in planning future sessions and research activities.
- **Limited training on photography:** Due to time constraints, participants did not receive training on photo-taking. As a result, staff were more actively involved in capturing photos. Offering training in future projects would likely yield more meaningful and participant-driven photographs. The photos submitted tended to overrepresent staff, likely reflecting the greater staff presence at the event. One of the emergent themes was that participants enjoyed collaboration with leadership and staff, which may also have contributed to this.
- **Access to photo-taking tools:** Several participants did not have access to personal devices such as cell phones. In the future, providing a variety of tools such as disposable cameras, tablets, or shared devices could make participation more accessible.

Reflection from Co-researchers

- **Accessible reporting:** Creating a report within the organization that is accessible, inclusive, and not overly formal can be challenging. Some sections of this report may not be fully accessible to all service users. However, a simpler version will be shared for the participants. For future projects, we could explore offering the report in multiple formats, such as visual, audio, and video, to make it more engaging and accessible for everyone.
- **Value of photovoice:** The photos served as powerful tools to elicit experiences, helping participants recall the event and supporting more meaningful conversations. They placed both interviewer and participant within a shared context without requiring lengthy explanations.
- **Flexibility in follow-ups:** Flexibility was essential when working with participants, as their needs varied. While scheduling follow-ups was challenging, offering multiple meeting formats (online, in-person, email, phone) helped make participation more accessible and feasible.
- **Benefits of co-research with self-advocates:** Collaborating with self-advocate researchers enriched the project by incorporating lived experiences and perspectives. For example, during report development, self-advocates helped make language more accessible by encouraging us to consider the viewpoint of the people we support.
- **Feedback from self-advocate co-researchers:** Self-advocates said they really enjoyed being part of this project. They shared that working as co-researchers helped them learn a lot and felt very valuable, even more positive than their experience at PARN camp. For future collaborations, they recommended checking in about the level of support they may need and offering task reminders, which they find very helpful. They also expressed interest in having more opportunities to be involved as co-researchers.

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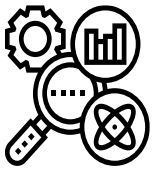
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