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RESEARCH ARTICLE

The *SibKit 2.0*, a tool created by siblings, for siblings

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Abstract: *Introduction*: Siblings of children and youth with disabilities are frequently overlooked in pediatric or mental health research. They are often excluded from conversations about their siblings' care and therefore experience a lack of mental health supports. This paper aims to describe the co-design and development of *SibKit 2.0*, a booklet built on *SibKit ABI*, designed to support siblings of children and youth with disabilities. *Methods*: The *SibKit 2.0* was co-designed by Holland Bloorview's sibling support team, health professionals, and families, including parents and 7 young siblings (ages 7-18). Participants reviewed the original *Sibkit ABI* and provided recommendations on content, format and design. Feedback was compiled and incorporated into the resource. *Findings*: Including young siblings as co-designers of the *SibKit 2.0* empowered this underrepresented group and improved its content, visual design, and accessibility. Families, clinicians, and community partners provided positive feedback highlighting the value and importance of this resource. To date, over 500 families have accessed the SibKits online. *Discussion*: Including siblings in the co-design process for *SibKit 2.0* provides them with a relevant resource they can use on their own or with a trusted adult, opening the floor for tough conversations and guiding them through future planning. *Conclusion*: Engaging siblings as co-designers enables the creation of a meaningful resource that reflects their realistic needs. It is important to utilize co-design strategies while developing resources, especially for underrepresented populations.

Keywords: Sibling caregivers, Lived experience, Young caregivers, Co-design, Mental health, Family-centred care.

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Introduction

Sibling relationships might be among the most important and long-lasting ones one develops from an early age. It provides opportunities for social-cognitive development, supports social learning, and facilitates problem resolution (McHale et al., 2014). It is also found that differential parental treatment may lead to negative sibling dynamics, with poor life adjustments starting in childhood.

Sibling relationships often become more complicated when one of the siblings has a disability. Lee et al. (2025) found that siblings of children with disabilities experience a wide range of negative emotions such as embarrassment, anxiety and guilt. They may learn to internalize their negative emotions during their upbringing, resulting in lower self-esteem and confusion about their identity. On the other hand, some siblings shared that being in this role taught them to be more empathetic and understanding of individuals' differences. Additionally, while navigating these challenges, siblings may learn to become their siblings' protectors/caregivers and may aim for academic excellence to please their parents (Lee at al., 2025). Many siblings also make career choices highly influenced by their lived experiences. These increased challenges could lead to negative health outcomes if insufficient support is provided.

Siblings of children and youth with disabilities are the forgotten caregivers and are not typically studied in pediatric healthcare or mental health research. They are often excluded from caregiver conversations and are not considered part of their siblings' care team and therefore experience a lack of mental health support (Giallo et al., 2012; Hurtado et al, 2025; Marquis et al., 2019; Martinez et al., 2022).

According to recent data, 34% of sibling caregivers provide care for a sibling with a disability, and 28% of those they care for are under 18 years old (Canadian Centre for Caregiving Excellence, 2024). For this paper, sibling caregivers will be defined as unpaid individuals who support their families because they have a sibling with physical, intellectual, or developmental disabilities. Support may include providing emotional and instrumental assistance to meet others' emotional and/or physical needs (Canadian Centre for Caregiving Excellence, 2024). They will be referred to as 'siblings' throughout the paper.

Sibling caregiving manifests in various ways as individuals learn to pick up responsibilities early in life. A recent study by Hanöz et al. (2024) found that typically developing individuals played instrumental caregiving roles for their siblings, such as assisting with self-care and education. They also took on roles that provided emotional support to the family, such as mediating conflicts and suggesting resolutions when disagreements arise.

Despite playing an essential role in the family, many siblings do not recognize themselves as caregivers. Instead, it is suggested that these individuals were often parentified and expected to act responsibly from a young age. As a result, their involvement is typically overlooked by adults or healthcare providers, whose recognition is usually directed towards parents.

The early parentification and lack of support in siblings' caregiving roles manifest in various ways and can negatively impact siblings' well-being. Giallo et al. (2012) identified that individuals have increased rates of emotional and behavioural problems. Similarly, Marquis et al. (2019) reported a significantly higher rate of mental health challenges in siblings of children who have a developmental disability. Additionally, these siblings are found to use the health care system more frequently than siblings of typically developing children.

The need for mental health support and resources for this population was made evident at Holland Bloorview through multiple requests from family members for ongoing sibling support. An annual workshop was created 30 years ago, providing resources to parents and guardians who wanted to support their sibling child, later transforming into a panel of siblings, from children to adults, sharing their lived experiences. This annual workshop was always well attended, with an average of 30-40 families. Despite the high participation rate, siblings and their families expressed a desire for ongoing support, beyond one event a year. The Sibling Support Program was awarded initial funding from the 'No

Boundaries' grant in 2018 and has continued to operate through funding from the Holland Bloorview Foundation.

Holland Bloorview's Sibling Support Program uses a participant-directed, play-based model to give siblings, ages 7 to 18, the opportunity to relax, unwind, and connect with peers who share lived experiences. It provides a safe space for them to initiate conversations about having a sibling with disability. The program is open to any child who has a sibling with a disability, complex medical need and/or dual diagnosis. It is one of the few across Canada that does not require families to be current or former clients to access services. Referrals to the sibling program can be made directly by families or by members of their care team, wherever they are receiving care.

The program has been running successfully for over five years, with more sessions added each year, now offered in both virtual and in-person formats. Akin to most initiatives and programs at Holland Bloorview, the Sibling Support Program is co-designed with its participants in mind. Decisions on program content, activities, and snack options are made with the sibling participants and their families. The final virtual session of the year includes a dedicated time window for feedback, during which participants can review the activities they liked, those that need more work, and what they would like to see more of in the future. Pre- and post-feedback are also collected after each session. Including participants in the planning of these sessions allows the program to grow with them, providing continuous support over time by following their lead. It also reinforces the idea that their voices and opinions have value, which is not always the case for sibling caregivers in healthcare.

In recent years, several programs have been developed to address gaps in sibling support. One such example is iSibWorks, a virtually delivered cognitive-behavioural group intervention for siblings of children with disabilities (Mallory et al., 2024). Despite all the progress made, siblings are still an afterthought in some healthcare settings, regardless of the higher rates of mental health challenges they experience. While the past decade has seen an expansion of programs for siblings, opportunities for siblings to participate as co-developers remain limited (Nguyen et al., 2023).

The creation of SibKit2.0 aims to address some of these gaps in sibling-centred mental health resources by providing a co-designed, accessible support tool for young sibling caregivers. Research suggests that siblings of children with disabilities experience more emotional and behavioural challenges, including higher rates of conduct problems such as fighting, arguing, and non-compliance, potentially due to heightened family stressors and limited coping resources (Giallo et al., 2011). In addition, a lack of knowledge about their sibling's condition can lead to poorer adaptation and adjustment (Kao et al., 2012). Studies also highlight the importance of providing siblings with opportunities to develop coping strategies, build positive relationships, and prepare for future caregiving roles (Nguyen et al., 2023). These findings support the need for resources that promote self-care, education, and future planning among sibling caregivers.

SibKit 2.0 followed the success of the *SibKit ABI*, a booklet for siblings and children of youth with pediatric acquired brain injury (ABI) created at Holland Bloorview. This booklet focuses on self-care, learning and understanding of new information, and resources for building positive relationships. Similar to the collaborative nature of our programs, the development of the *SibKit2.0* involved both Holland Bloorview's sibling support team, who are older siblings with lived experience, and younger siblings participating in the program. This paper highlights that including siblings as co-designers in pediatric support initiatives creates meaningful, inclusive, and family-centred mental health.

Methods

The *SibKit 2.0* was created by Holland Bloorview's sibling support team, who are also siblings with lived experience, and was developed with help from social workers and child life specialists. It was co-designed by seven young siblings (3 younger and 4 older siblings) whose siblings had various diagnoses, such as physical disabilities (1), neurodevelopmental disorders (5), and rare genetic conditions (1). All seven siblings were regular attendees of Holland Bloorview's monthly Sibling Support Program, which has been running for 8 years. Alongside the seven siblings, three mothers also participated in the review process alongside them. *SibKit 2.0* is a participatory codesign project that includes participants and staff with lived experience in its

creation. Since the toolkit was developed as part of a resource development initiative, research ethics board approval was not required.

Co-design is a participatory approach where clients and individuals with lived experience are actively engaged as collaborators throughout the development of an intervention or resource, rather than serving as passive participants (Carey et al., 2024; Nguyen et al., 2025). Grounded in principles of participatory action research and experience-based co-design, this approach emphasizes shared decision-making, iterative feedback, and the integration of lived experience with professional expertise (Mulvale et al., 2016; Mulvale et al., 2019). Co-design also requires structured processes to ensure meaningful engagement, clear communication, and accessibility for all participants (Micsinszki et al., 2022). By centering the perspectives of siblings and families, co-design aims to create interventions that are both contextually relevant and responsive to psychosocial needs, enhancing acceptability and impact.

The *SibKit ABI* was a booklet for siblings and children of youth with pediatric acquired brain injury (ABI) created at Holland Bloorview. This booklet was created with Holland Bloorview's inpatient population in mind by a multi-disciplinary team in 2019, focused on the needs of siblings of children with acquired brain injury. This tool continues to be used by families and clinicians and has proved to be an invaluable resource.

When creating *SibKit 2.0*, the priority was to continue co-designing resources and materials with siblings with lived experience. This version aims to meet the needs of a wider range of children and youth who have siblings with disabilities, medical complexities, or diagnoses.

The Sibling Support Program Coordinator (SSPC) identified 8 program siblings who were regular attendees and invited them to provide feedback on the current *SibKit ABI*. Each sibling participated in a Zoom session alongside their parent or guardian. Zoom calls were scheduled for one hour. Families were sent a digital copy of the *SibKit ABI* prior to the session, along with the discussion questions to review beforehand. As the coordinator of the regular monthly program, the interviewer was known to all interviewees. During the interview, the SSPC would screen share the *SibKit ABI* and ask the discussion questions as they scrolled through the tool.

Figure 1: *SibKit 2.0* discussion questions

1. Would you prefer to access the SibKit online or as a book?
2. Is there anything missing from the SibKit?
3. Is there anything that you would like to add to the SibKit? (ex. different sections, activities, etc.)
4. How do you feel about the amount of text/words in the SibKit? Is there too much/just enough/too little?
5. How do you feel about the number of pictures in the SibKit? Is there too much/just enough/too little?
6. Do you think other siblings would like this? If yes, why? If no, why not?
7. Which sections did you like?
8. Which sections didn't you like?
9. Is there anything you think we should take out of the SibKit?
10. Do you think this SibKit will help other siblings like you?

Each session was facilitated by the SSPC using pre-written discussion questions (Figure 1). Feedback and design choices were elicited through open-ended questions to facilitate conversation about the tool. The questions were age-appropriate for school-aged participants to avoid confusing or overly advanced language, covering everything from whether the tool should be available both online and in print to what they liked and did not like, and the ratio of text to photos. Some example questions included: "Would you prefer to access the SibKit online?", "Is there anything missing from the SibKit?", and "What do you want to see in the SibKit?"

A participatory, experience-based co-design approach was employed to actively involve siblings in developing *SibKit 2.0.* Following Nguyen et al. (2025), siblings served as research partners, contributing to needs identification, content development, and iterative feedback on prototypes. Building on Mulvale et al. (2016,

2019), we implemented structured processes to support engagement, address accessibility, and document participant contributions. Guided by Carey et al. (2024), interdisciplinary stakeholders (siblings, families, and siblings' support staff) perspectives were integrated to ensure relevance, while principles from Micsinszki et al. (2022) informed facilitation strategies, expectation-setting, and trust building. Participants' feedback on content, visual design, and accessibility of the *Sibkit ABI* was reviewed and incorporated into the resource, ensuring alignment with both lived experiences and best practices in participatory research.

In total, we completed reviews with seven siblings and eight parents, with one sibling missing their review due to illness. All the feedback was combined into one document.

Results

Lived experience in co-design

Co-design has always been crucial when working with families and partners. Everything that was created, from program sessions to resources, is designed with siblings, for siblings. Conducting these reviews with participants in the program was vital. Research has shown that, despite an increasing number of resources and programs for siblings, they are typically not involved in co-development or facilitation processes (Nguyen et al., 2023). It is therefore important for young siblings to advocate for themselves and future siblings by co-designing this resource. A clinician, who is also a sibling with lived experience, shared this same feeling when they saw the tool: "As a sib, I also wish there was a SibKit when I was navigating all of these questions years ago!"

Significance of *SibKit 2.0*

The *SibKit 2.0* includes interactive tools that help siblings understand different diagnoses, feel more included, work through feelings they may experience as siblings, and learn more about what the future holds. It can be used to open and guide new conversations at home between siblings and their parent or guardian. Creating a tool that covers such a broad range of topics has made this our most reliable and trusted resource to share with new families. This has been demonstrated through families' gratitude and relief when being introduced to the tool. Based on conversations with new families registering for the Sibling Support Program, it was found that families often register for sibling programs after a new diagnosis in their family or during another transitional time in their child's life. Having an in-house resource that can offer support as families navigate these unique and sometimes challenging times. It also provides parents with a starting point for helping their 'sibling' child navigate a new situation, whether on their own or with guidance from a parent or guardian. Specifically, this toolkit guides siblings in navigating complex feelings such as anger, surprise, confusion, sadness, and acceptance. The toolkit also helps siblings learn and build a circle of care and promotes self-care through activity worksheets.

We also received some mixed reviews. For instance, there was almost an even split on whether the tool should be an online or print resource. Many preferred physical copies to cut down on screen time, whereas one sibling noted the tool should be as reusable as possible because "you wouldn't keep buying the same book over and over again" (Sibling participant 2, Feb. 23, 2021), recognizing that this resource may grow with them. Given this feedback, we prioritized offering both physical and digital copies. This included making the digital copy available as a fillable PDF, ensuring the document is accessible to siblings over time and can be returned to when needed.

Feedback from partnering clinicians

With the support of a local sponsor, we were able to print 410 physical copies of the *SibKit 2.0* to keep at Holland Bloorview and distribute to families, external organizations, and partners. The copies at Holland Bloorview were split amongst the inpatient units, the outpatient playrooms, the Family Resource Centre, and the sibling program itself. The sponsor also printed 100 copies to distribute to their own clients, expanding reach even further. The digital copy was widely shared throughout the hospital, as it was easier to share with families who were not on-site or preferred the digital tool. The tool was well received across all teams at Holland Bloorview, with one clinician sharing:

> I took a look at the kit today online and it looks fantastic! I can't imagine all the hard work that went into designing it. I just wanted to acknowledge it looks great and very user friendly. Thanks for working on this project. I hope to be

able to share this new resource with clients as applicable.

This feedback from staff and clinicians underscores the value of co-design. Having buy-in from the clinical team provides families with more opportunities to access this resource.

Similarly, a local partner who had previously been using the digital copies requested physical copies to share with their families, years after it was released, and shared their thoughts via email once they received them: "They are beautiful! You can tell that so much time, care, and information went into them. I am super excited to share them with the [organization's] families." One of the many goals of *SibKit 2.0* was to broaden the scope of the previous *SibKit ABI*, including the siblings and families who could access it. Having the opportunity to share resources like the *SibKit 2.0* with external organizations directly contributes to this.

Including siblings who were active participants in the Sibling Support Program highlighted the importance of lived experience in co-design and the value of hearing directly from the population the tool is intended to serve.

Feedback from siblings and parents

During the review/collaboration sessions, the siblings demonstrated a high level of openness and responsiveness. Their contributions offered valuable insights into their experiences with the previous tool and their perspectives on desired features and improvements for a future iteration. These reflections provided important user-informed context to guide subsequent development. Parents and guardians were also encouraged to participate in the review process by providing feedback, ensuring that caregivers' perspectives were incorporated alongside the siblings'. The siblings and parents who contributed to this work were all grateful to take part in the process.

Many of the siblings had similar takeaways, such as: (1) keeping the 'Brain Mascot' character from the first SibKit, (2) including all previous activities, (3) adding more pictures and visuals, and (4) keeping text sections short with words that are simple and easy to understand. Other feedback included more information on self-care, a calendar or planner to track their own activities and their siblings', and having activities generated towards all ages rather than some for younger siblings and some for older siblings. A parent of one of the siblings who participated in the co-design process wanted additional copies to share with family and friends: "I love to share about [sibling] being a contributor because she is so proud." This comment highlights how valuable co-design is, from the perspective of a young sibling who feels pride in their contributions.

The parent and sibling collaborators were happy to participate in this work, but it was important to our team that they were appropriately acknowledged for their contributions to co-designing this resource. As seen on the back cover of the *SibKit 2.0*, all siblings and their parents are credited by name as 'Sibling/Parent Leader and Content Expert'.

Having staff and clinicians with lived experience makes engaging with siblings and their families less challenging, as they have a different understanding of family dynamics and the barriers that can impact participation.

Discussion

The creation of the *SibKit 2.0* introduced siblings and their families to a broad and expanded version of the *SibKit ABI*. It provided siblings with a living document they could go through on their own or with an adult they trust, which could open the floor for tough conversations and guide them in planning for the future. Including siblings in the co-design process for this tool ensured the creation of a resource directly with the population who could benefit from it. Through the co-design process, it was evident that siblings want an inclusive, interactive tool with activities geared towards siblings of all ages. They also want the tool to be as accessible as possible, available in both digital and print formats, with fillable fields in the digital copy so it can be reused over time. This tool has resonated with other partners and collaborators because of the intention behind each contribution. While we had siblings participate in co-design, the majority of the staff working on this tool were also siblings with lived experiences.

Overall, the general theme of their recommendations was geared towards inclusion and making this an accessible tool for all. Given their lived experience as siblings to children with different needs and abilities, this is not surprising, as they have likely witnessed exclusion firsthand.

Co-design is invaluable when developing resources for siblings and families. The voices of those with lived experience cannot be replaced or replicated. This is especially true for populations that are often overlooked or excluded from healthcare conversations, such as sibling caregivers. Including young siblings as co-designers of the *SibKit 2.0* empowered this underrepresented group and created a meaningful and relevant resource for other young caregivers. Understanding the target population brings a new level of collaboration that, while not required, creates a lasting impact on the work being completed.

While the co-design approach provided invaluable feedback and created an extremely applicable resource, it also required additional time, coordination, and flexibility between staff and families. As this toolkit targets young caregivers ages 7-18, it spans a wide age range and poses greater challenges for age-appropriate design and language. Additionally, perspectives of siblings of children with developmental disabilities might differ from those of siblings of children with acquired injuries, making it more difficult to create content relatable to all siblings. As a result, the *SibKit 2.0* aimed to address commonalities across siblings' experiences, such as well-being, self-care, and relationship-building, rather than focusing on providing diagnosis-specific information.

Mallory et al. (2024) examined the feasibility, acceptability, and preliminary psychosocial outcomes of *iSibWorks*, a virtually delivered cognitive-behavioural group intervention for siblings of children with disabilities. Consistent with the literature identifying siblings of children with disabilities as an often under-supported and excluded caregiving group in research (Hurtado et al., 2025; Lee et al., 2025), both the *SibKit 2.0* initiative and *the iSibWorks* intervention address pertinent gaps in sibling-related support. Findings from *iSibWorks* align with prior psychosocial intervention studies (Abdelaziz et al., 2024; Hastings & Beck, 2004), demonstrating that structured cognitive-behavioural and peer-based programs can foster emotional validation and coping skills. In contrast, *SibKit 2.0* advances the field through a participatory, co-designed model that positions siblings as contributors to intervention development rather than solely recipients of care. A participatory action co-design approach addresses the need for more inclusive, contextually grounded sibling interventions that better reflect lived experience.

Similarly, Nguyen et al. (2025) describe a participatory action research approach in which both youth and young adult siblings of individuals with disabilities are engaged as co-researchers to co-develop a toolkit to support advocacy and future-oriented conversations. Both the *Siblings TEAKit* and *SibKit 2.0* address a gap in the literature, recognizing siblings of individuals with disabilities as under-supported caregivers with distinct psychosocial needs (Lee et al., 2025). Both initiatives adopt participatory approaches that center siblings' lived experiences to promote empowerment and communication. However, they differ in scope and focus: *Siblings TEAKit* targets youth and young adult siblings, whereas *SibKit 2.0* engages younger siblings and emphasizes emotional expression, self-care, and understanding disability through a non-clinical resource. Together, these initiatives extend the literature by demonstrating how co-designed, sibling-led support can be tailored across developmental stages and contexts, and by highlighting that empowerment and dialogue are critical psychosocial outcomes that may not be fully captured by traditional clinical measures.

University Health Network (2024) describes the co-design of a toolkit to help healthcare providers recognize and support young carers (defined as individuals under 25 who provide ongoing caregiving) during clinical interactions. The toolkit integrates the perspectives of young carers, healthcare providers, and caregiving organizations to guide healthcare providers in engaging young carers effectively and connecting them to relevant supports. University Health Network (2024) and *SibKit 2.0* demonstrate growing recognition that underrepresented caregiving groups, such as young carers and siblings of individuals with disabilities, benefit from resources co-designed with lived experience to address unmet psychosocial needs. While Caven et al. (2025) target systemic change by equipping healthcare providers to better recognize and support young carers during clinical interactions, *SibKit 2.0* directly supports siblings through accessible psycho-educational and relational resources. Both initiatives contribute to the field by demonstrating how co-designed interventions can enhance psychosocial support at both the systemic and individual levels.

These initiatives, along with the *SibKit 2.0*, highlight a shift from professionally driven, outcome-focused programs toward participatory and accessible supports that recognize siblings as both caregivers and collaborators in care. Future versions of the *SibKit* can continue to engage sibling caregivers as co-developers while exploring age- and diagnosis-specific resources to address their specific needs.

As all the authors have lived experience as siblings and are Sibling Support Program Staff, there may be biases from personal opinions and beliefs regarding the scope of the work and its value. Other limitations include the population of siblings we worked with, all of whom were regular attendees of the Sibling Support Program at Holland Bloorview at the time. The group that participated in the review was also quite small (7 siblings and 8 parents).

Conclusion

Sibling relationships are potentially the longest relationships in a client's life. Including siblings as caregivers in the conversation is essential, especially when developing resources that directly impact their well-being. Including sibling caregivers as partners and collaborators in the co-design process for the *SibKit 2.0* emphasized the importance of the voice of those with lived experience. The value that lived experience brings cannot be replaced or replicated, as each sibling's experience is so unique and individual.

The siblings who reviewed and contributed to the creation of the *SibKit 2.0* offered suggestions based on their lived experiences as siblings, such as the inclusion of a calendar or planner to keep track of busy days, which are often filled with their siblings' appointments. They also wanted activities around self-care and managing their emotions. Since its release in 2021, feedback for the *SibKit 2.0* has been overwhelmingly positive, with parents and guardians expressing gratitude that a tool exists to help guide these conversations at home.

This paper aims to describe the co-design process used to meaningfully engage siblings in developing *Sibkit 2.0*. Engaging families in co-creating resources can present unique challenges, but this *SibKit 2.0* can serve as an example to demonstrate its benefits and value to all organizations. Without the voices of those with lived experience, these tools and resources lack authenticity and reliability.

Research on sibling caregivers remains limited but is slowly growing in the field. To expand on these findings, future studies can examine the *SibKit 2.0* tool itself, its impact on conversations at home, and how it has helped guide families through challenging and unfamiliar topics.

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