

# A Seat at the Table: A Reflection on Engaging Disabled People and Their Families in Research and Service Design

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The metaphor “a seat at the table” has been used to describe the inclusion and engagement of Disabled People and their family members in system-level service design and research. While it is easy to agree with the sentiment that Disabled People and their families deserve a seat at the table when designing and evaluating the services and research that affects them, we are less sure about ‘the table’ as an accessible and inclusive rhetorical device. In examining ‘the table,’ we question: who ‘owns’ the table, who ‘gets to’ sit at the table, what is discussed at the table, and what happens when the table is ‘put away’?

## An Exercise in Reimagining

In this reflection, we invite you to reimagine the table and to think about who ‘benefits’ from being there and what counts as beneficial. The authorship team includes a disabled young adult (MPa); parents of a disabled child (RM, SS); a trainee and leader in family-engaged research (SM); and a clinician-scientist (MPh) who prepared this reflection following a panel

presentation (November, 2021) on the topic of family-engagement in research.

RM facilitated the panel presentation, asking thought-provoking questions about the successes, challenges, and pitfalls in doing family-engaged research, and prompting all panelists and audience members (families, trainees, child health researchers, decision makers) to deeply consider how to improve meaningful and authentic engagement. This stimulated enriching discussion and reflection about ‘the table’—with considerations of a critique of power, the place of kindness and warmth in relationships, diversity and accessibility, meaningful outcomes, and sustainability. Following are the reflexive questions we posed and the insights they inspired .

### WHO OWNS THE TABLE?

In this metaphor, the table is seemingly inanimate, powerless, and non-relational. In real engagement work, no one cares about the empty table, and ‘the table’ does not exist outside of the structure and people

who animate it. Picture a table in a hospital boardroom or a family's kitchen around which a discussion begins. In these respective contexts, you are likely to picture either organizational leaders or caregivers who have ownership and control over these tables. They have the power to determine who is invited in and what is discussed. Consider the activities and conversations that happen at a hospital versus a kitchen table.

We have experienced deeper, slower listening and relationship building over kitchen tables, but recognize that the decisions that affect services, systems, and policies are more likely to be made in hospital boardrooms. The context in which the table is situated imbues the table with norms and expectations about who is invited, how to conduct oneself, and what activities and discussions should occur. As such, the cold, sterile metal table of an operating room conjures notions of precision and intensity that are wholly different than the pictures conjured by a chaotic family table with coffee stains and scattered chairs. When we speak of 'inviting people to the table' it is incumbent on us to fully consider what table we are inviting people to and the implications, including power dynamics, therein.

If the power and value of Disabled People and their family members were truly recognized, could we meet at their tables? By their invitation, in their homes, over warm cups of tea, to listen and talk about the issues that are important to them. In homes, we might be more likely to book meetings according to nap or medication schedules, or school and work hours. Could the tables be turned so that these were the spaces in which services were designed, funded, and evaluated?

"As a parent to a disabled son and executive director of the Waterloo Region Family Network, I (SS) prefer

to be at a table where people refer to me by my name, not Mom. Although I love being a Mom, using my name makes me feel welcome and gives a personal and less medical and scripted feel to the conversation. I appreciate when people sit beside me at the table, instead of across from me. This facilitates collaborative conversation rather than a 'them' and 'me' approach. In times of difficult discussions, sharing a box of tissues and shedding tears together are actions that show the professional truly cares. I feel authentically included and respected when people ask me what I would like to do and check with me to see if I feel my voice has been heard."

### **WHO GETS TO SIT AT THE TABLE?**

We have explored who invites people to the table, but we must also consider who is invited. Often they are people who look like, or are equally positioned to, the person who did the inviting. They often speak the same language, have comparable communication modalities, literacy, and language abilities. Some people have titles, roles, and positions that entitle them to a seat. At some tables, the title of Mom, Friend, Elder, and/or Ally might grant you an invitation, and at others, the titles CEO, Clinician, Principal Investigator, and/or Associate Dean might be an all-access pass. While roles and titles help us to understand people's identities, we must recognize the multiplicity of these for each person; parents are not solely parents, researchers are not solely researchers. We are all whole people and bring a wealth of diverse experiences and expertise to the tables at which we sit.

"As a researcher who lives with a chronic illness, I (SM) bring multiple identities and experiences to my work, and call us to acknowledge the unique perspectives each person can bring outside of the one title they are

often invited in for (if they are comfortable to do so).”

We wonder what happens if we bring kitchen chairs to a boardroom table. Invitations to the table are not enough. When asked to sit at the boardroom table, if there is little to no effort to truly make space for those invited, kitchen chairs would sit in stark contrast against the boardroom table. People are expected to fit into spaces and structures that were not designed for them. Consider the tokenistic effort of squishing a fold-up chair between the existing seats around a table, in a spot that easily disappears just as fast as it was created. Meaningful inclusion may mean planning for accessibility and investing in a bigger table, where community members can comfortably join the discussion.

For example, we could create spaces that fit wheelchairs, highchairs for children, and cushioned or high seating for people who experience frailty or pain. Virtual tables should be provided whenever possible to allow access from home, especially for those for whom mobility is a challenge or for those at risk of illness when environments do not require masks or have appropriate ventilation. We question whether ‘sitting at the table’ is even an apt metaphor for people who are not comfortable sitting due to pain or sensory needs. At the very least, we must recognize that where the table is situated, who is invited, and who does the inviting shape the conversations and ideas shared with an influence on actions, services, and policies.

“As a young adult who has a disability, I (MPa) often feel torn when healthcare leaders—whether clinicians or executives in the ivory tower—ask if I can sit in on a discussion. On the one hand, if I am the only patient present, then no lived experience will be heard if I say no. But on the other hand, if I’m the only [Disabled Person] at the table, I feel the participation is

tokenistic. This feels like a checklist for the healthcare team where it doesn’t feel my voice is wanted, included, or valued at the table.”

## WHAT IS DISCUSSED AT THE TABLE?

Perhaps we are dreamers for imagining that, if we swapped the traditional tables in hospitals and universities for tables in homes and communities, the conversations would change, the agenda would be different, and perhaps there would be no formal agenda at all. We dream of a table that fosters more humanism, care, and nurturing relationships. Conversations might shift from feasibility and efficiency to experiences and hopes.

In the academic languages of patient-oriented research, family-centered care, and experience-based co-design there is credence given to the idea that people with lived experience have important insights that can guide service improvement and evaluation. Still, these processes are often done under the guise of a named partner on a grant, on academic timelines, and/or formalized in strategic plans and advisory committees. They can lack the time and flexibility to begin by asking about someone’s day, taking breaks or sharing food before rushing to the deliverable or the next meeting.

“As a researcher who contributed to this reflection, I (MPH) fear being written off as someone who is unserious about service design and research. I worry about being seen as non-academic, with presumptions that I don’t understand the importance of grants, and ethics, and rigor, and publication. I understand these academic demands and am writing to problematize and resist them in favor of alternatives that are judged by a yet unimagined set of metrics.

We dream of new ‘metrics’ and a truly patient-oriented

academia where we know how our partners take their coffee, where we exchange birthday cards, where we ask about kids and dogs and share videos, when we make a personal call in the season when bereavement grief is hardest, and where we don't need to fill silence with agenda items. With these metrics we can imagine that vulnerability is embraced, new ideas flourish, care is prioritized, and impact is felt through friendships and a smile instead of an impact factor.

“Two co-authors on this paper (RM and SM) recently had an opportunity to meet in-person for the first time after working together virtually (due to COVID and geographic location) for over 2 years. The meeting's purpose stemmed from a shared on-site project presentation. However, it also provided an opportunity to connect over a physical table at some of SM's favorite local places, to socially share food and drinks, and for us to literally and metaphorically fill our cups. This has led to other social activities and conversations based on shared interests, deeper discussions about family engagement, and renewed excitement for our future work together. The social nature of coming together at a table to eat inspires a feeling of community. The same can be said when we effectively come together to work on a common cause.”

### **WHAT HAPPENS WHEN THE TABLE IS PUT AWAY OR BROKEN?**

Projects end, deliverables are submitted, funding closes, and people move on. We leave the table and often there are no obligations to extend further invitations. We wonder about whether anyone cares about these fractured relationships, because we do, and we continue to miss people and to wonder about their wellbeing after the project's end. We question whether these relationships were purely transactional or if there is an element of friendship involved and a desire to stay

in one another's lives. Perhaps sustained involvement risks breaching ethical guidelines, but discontinuing relationships may also raise moral concerns.

We are not suggesting that there is an expectation that people must stay connected, but as researchers, consider whether it is fair to pack up the table when only your needs have been met. Perhaps community partners go back to their tables and leave the researcher's seat empty. It would not make sense to close those tables, as people are still there in the community, living their lives and perhaps using the health and social services that were the focus of the project. We wonder if there is a sense of abandonment or relief that the commitment has ended?

We have witnessed the closing of virtual tables as people return to 'the office' regardless of the increased accessibility that these spaces afforded Disabled People and their families. In academic terms, we speak of sustainability, impact, and ethical responsibility, yet we have seen those concepts pertaining to the services themselves, not the relationships of the people who contributed to their development or evaluation.

But sometimes tables break before the project was planned to end. Perhaps the table was set upon wobbly ground on a foundation of mistrust and injustice. Perhaps the table's legs were weakened, its bolts came loose, and the tabletop was scarred from broken promises, unresolved conflict, and antagonistic relationships. Perhaps the table was battered and bruised when moving from one environment to another. It takes attention and reflection to notice these harms, and kindness and empathy to care about them.

Beyond care, we propose there is a responsibility to hold ourselves, our colleagues, and our systems accountable for harm and to work toward the

restoration of trust and relationships. When the broken table is left or discarded, the people who once sat around it may scatter. It could be replaced with a new table—but that may suffer the same fate if care isn't taken to repair the conditions that led to a broken table to begin with. A new table might also bring new people and promises—and opportunities for growth and learning from past experiences.

### **CAN WE REIMAGINE THE TABLE?**

We aim to move past the uncritical adoption of the table metaphor to determine if it can be reimagined and whether this metaphor is needed at all. If Disabled People and their families were the ones to invite researchers, policy makers, and service providers to their tables, we would be excited to see whether the priorities and discussions also shifted, and if relationships felt more authentic and long-lasting. We propose there are times when tables are not needed at all. Those tables could instead be picnic blankets that encourage children and families to attend, with no formality or head of the table, and allow open entry and exit.

“When MPh and SM attended a 3-day symposium to advance Equity-Based Co-Creation, the small group discussion and prototyping tables were interspersed with tableless periods of learning and connection through kayaking, dance, beading, eating, and storytelling by the campfire—as seen in this video. This event was held at the Gathering Place by the Grand at Six Nations, along the banks of the Grand River in Ohsweken, Ontario and was planned, led, and experienced by local and international people with lived experience, community members, and researchers. This allowed for dynamic, creative, experience-driven conversations that enriched the empathy and understanding that informs service design, delivery, and evaluation.”

### **Conclusion**

We have hope that those who are comfortable in boardrooms and ivory towers will take the time and effort to climb down and look for other tables, to forge relationships that garner invitations and mutual care and respect, and lead to transformative knowledge-sharing that cannot be undone at a project's end.

## *About the Author/s*



**Michelle Phoenix, PT, DPT** is an Assistant Professor in the School of Rehabilitation Science and CanChild Scientist at McMaster University. She is a speech-language pathologist with clinical experience working with young children and families. She has studied family-centred care, models of service delivery, parent mental health, cultural adaptation, and engagement in rehabilitation services. She believes that disabled youth and caregivers should have meaningful opportunities to inform service delivery and evaluation. Her research has included developing theories, teaching tools, and guidelines to improve meaningful and equitable engagement in research. She has found that embedding the arts in research methodologies and knowledge sharing has sparked creativity, passion, connection, and joy through the vulnerable sharing of emergent and messy ideas.



**Rae Martens** is a Knowledge Broker with the Family Engagement in Research (FER) Program through Kids Brain Health Network and CanChild Centre for Childhood Disability Research. She is a bereaved parent of a disabled child and a disabled advocate herself. She has given talks all over the world regarding child health and disability. She is also a writer and science communicator. She believes that the humanities are important because they help us to better understand human culture and why we do what we do. In the world of engagement, that's a vital practice.



As a founding parent, **Sue Simpson** has been part of the Waterloo Region Family Network (WRFN) story since the beginning. She has watched the network grow from a small group of volunteer families into a thriving organization that's equipped to support thousands of people touched by exceptional needs. In her role as executive director, Sue oversees all operations and represents WRFN on many community collaboratives. Sue has been an active advocate for disability-related issues since the premature birth of her youngest son 34 years ago. Her personal and family journey with critical and emergency medical issues has shaped her inclusive approach to supporting other families facing similar experiences. She believes in building strong reciprocal relationships and a community of respect and belonging for all. A Wilfrid Laurier University graduate, Sue enjoys spending time with her family, including her husband, two adult sons, and her

daughter-in-law. She is the proud recipient of the 2018 Empowered Kids Ontario (EKO) Tribute Award for Leadership.



**Maya Pajevic** has been a patient partner for a decade, contributing to different aspects of the healthcare system. She believes that person-centred care starts in the heart, that engaging with different stakeholders, especially those with lived experience, does not only result in a more robust and resilient system, but also a safer one. Maya graduated from Mount Royal University in 2023 with a degree in Information Design and a minor in Social Innovation. Currently she is the communications lead for two CBI-Health-led programs, which look at meaningful employment opportunities for those that identify as having a disability in Alberta. When not working or advocating, Maya can be found on the hiking trail or ski hill, and she enjoys endless snuggles with her dog Dyna.



**Samantha Micsinszki, RN, PhD** is a registered nurse and currently a postdoctoral researcher at CanChild Centre for Childhood Disability Research at McMaster University, and Training Director of the Family Engagement in Research (FER) Training Program. Sam has a particular interest in patient and family engagement in research as well as knowledge translation and research impact. Her work focuses on participatory approaches to inclusive and meaningful patient and family engagement across the lifespan. In 2021, Sam was diagnosed with Crohn's disease, an experience that has had a significant impact on her personally and professionally. She is keen to use her experiences and her new perspective to create awareness of and advocate for equitable patient and family centered research and care through creative methodologies. When not working, you'll find Sam lacing up her skates, learning how to play hockey.