Over the past three years, I have worked for the Landon Pearson Resource Centre for the Study of Childhood and Children’s Rights (LPC) as the National Coordinator for a youth-led consultative and collaborative model known as STM. As the National STM Coordinator, my role has entailed designing and administering rights-based training for youth facilitators, supporting youth facilitators, networking with provincial STM organizers, attending nation-wide STM workshops to engage with youth facilitators and participants, organizing logistics of the workshops and simply listening attentively to what children and youth would like movers to know about their lived experiences that pertain to rights-based topics. Since my time as the National Coordinator, the workshops have focused on the themes of children’s rights and climate change, the rights of children on the move and this year’s focus was on children’s rights and discrimination. Apart from the LPC’s regular annual workshop series, I was invited to help lead a special project with a research team at Ryerson University, the Inclusive Early Childhood Service System project (IECSS). The IECSS wanted to adopt the STM model to facilitate a workshop that focused on children’s rights and disability. Given my previous background working as a youth inclusion specialist and my interests in children’s rights and disability, I was hired as a research coordinator to help lead and organize the event.

On October 13-14th, the Inclusive Early Childhood Service System project (IECSS), in partnership with the LPC, hosted a two-day youth advisory workshop on children’s rights and disability. The goal of IECSS is to examine how the organisation of early childhood institutions are understood from the standpoint of families and children when they have a disability and to re-consider what it means to have healthy institutions that are informed by the standpoint of those who may be most harmed by those institutions. In partnering with IECSS, the workshop adopted STM to offer an inclusive and accountable method for working with children and young people in planning and designing research on children’s experiences of disability with early childhood institutions. The event took place at Carleton University with the objective to hear from young people about their ideas and perspectives on their lived experiences of disability using a rights-based approach. Youth facilitators were recruited from across the country to lead in the design and facilitation of the workshop which hosted 30 children aged 10-18. Participants were also recruited from across Canada. All of the facilitators and participants identified as having a disability, disability experience, as deaf or as having gifts (consistent with Indigenous worldview).

The key guiding question of the workshop was “Can disability be positive?” This provocative question challenged me to think and re-think about power relationships between children and adults, especially in relation to the concept of child participation. I was reminded by
children and youth with disabilities that marginality and relationality shape their everyday lives. These experiences ultimately shape the environments, interactions and relationships for researchers and professionals working with young people. I was challenged to think critically about the concepts of marginality and relationality and how they work to disrupt adult-centric views about young people, disability and participation. I share the following key messages that young people taught me about both the negative and positive realities of disability which worked to disrupt and challenge the concept of disability more broadly.

The children and youth provided reflections on the importance of their participation and shared their lived experiences to highlight how they often felt silenced as individuals. Consider the following quotes:

“The thing that is the most frustrating is being left out of the conversation. I am right there and everyone is fighting about accommodations and no one bothers to ask me. Even when I speak up, they don't seem to want to listen.”

“Decisions about our lives are being made based on generalized understandings of disability.”

"They always make decisions on my behalf and I don't always understand what they want me to agree to.”

“People should talk to youth themselves rather than just talk to their parents.”

“Bring young people with disabilities into discussions more often. Right now, youth sometimes have a hard time finding a voice because adults have a thumb on this.”

Quotes derived from STM Facilitators and Participants, Oct 13-14th 2018 (see STM Report by Bernincasa, St. Dennis & Caputo, 2018).

The excerpts reveal that children and youth with disabilities often feel frustrated with the lack of power, agency, voice, and participation that they have in decisions that affect their lives. What came from my observations was the realization that as researchers, practitioners and professionals working with children and youth with disabilities, it is important to critically reflect on the ways that we sometimes assume what children with disabilities want or need – even if these ideas are accompanied by good intentions. If the model asks adults to relinquish their power and control to children and youth, what happens to those who require assistance from adults? How can we ensure children with disabilities are able to participate or want to participate in ways that we as researchers, consider meaningful? What is meaningful participation and how can it be fostered for children and youth with disabilities?

Despite the challenges, I also observed how the interdependent relationships between these children and their interpreters, chaperones and caregivers could also be viewed as positive. For instance, for deaf children, not only did they rely on the interpreters, but the interpreters also relied profoundly on the children in unique ways. As one example, the children indicated when they had something to say while the interpreters followed their lead and generated conversations that the children controlled and led. Throughout the workshop, I watched how these children and youth challenged adult-centric views and created their own unique pathways of participation.
Many of the children and youth expressed that they often felt enabled as opposed to disabled because they could do things that people without a disability could not. For instance, one participant spoke about her ability to turn her hearing aids off in order to tune out the world. Other participants talked about their ability to read with their hands in ways that others might not be able to. They spoke about their ability to speak a different language (American Sign Language) which made them feel empowered because others might not have been able to engage in the same way. The participants also reflected on the fact that they could exercise compassion with others facing social exclusion in unique ways. Some of the facilitators and participants spoke about the clubs, communities, networks and friendships they had developed because of their disability and felt that they would not have established these unique relationships if they did not have a disability. Drawing on these examples, the children and youth explained that disability was not always something to think negatively about and these instances reinforced how disability had also had a positive role in their lives.

The following excerpts highlight some of the facilitator and participants thoughts regarding the positivity surrounding disability and how their disabilities enabled them in unique ways:

“No matter the skills, I have a unique way to accomplish tasks — I constantly have to adapt to broken equipment.”

"I want the movers to know that kids with disabilities can do stuff just as much or better than kids without."

"I have a superpower... I have ADHD. I am able to multitask in ways other people can't."

“Sometimes it may take time for me to share my thoughts, but I still have them so give me time to think and share.”

Quotes derived from STM Facilitators and Participants, Oct 13-14th 2018 (see STM Report by Bernincasa, St. Dennis & Caputo, 2018).

In reflecting on the strengths of the STM model and the instances where adult-centric assumptions were challenged and modified, I hope that others will carry these important messages forward in their planning to create meaningful, consultative and collaborative participatory spaces for children and youth with disabilities. As a STM participant reminds us:

“The shouldn’t be only the person with the disability to always adapt.”