

Trends in Pediatric Palliative Care Research (TPPCR) 2025; Special Edition 1: Parent Perspectives: Commentary on Tiefenbacher, R.

Michelle Martin, Parent of children who are patients of BCCH, British Columbia, Canada

Email: michelle@michellemartin.co

Abstract:

This TPPCR commentary discusses the 2023 paper by Tiefenbacher, R. et al., Finding methods for the inclusion of all children: Advancing participatory research with children with disabilities, published in Children & Society.

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As a mom of newborn twins, each with their own set of health complexities and disabilities as a result of Twin-to-Twin Transfusion Syndrome and prematurity, I felt unprepared, unsure, and frankly unsuited for the job. Not exactly a baby whisperer before, I hadn't a clue what to do with two bronze-skinned aliens in NICU incubators. I eagerly absorbed everything the nurses taught me.

Through the early years, I followed every doctor's recommendation and made every follow-up appointment. I tried medications and procedures I was wary about and wrote off my misgivings as misguided parental anxiety. I trusted my children's medical providers and their advice — still do — but these decisions were never easy. I would watch friends laugh at their own tales of “going full Mama Bear,” usually relating to a developmental stage my older children hadn't reached and probably never would, sounding so sure of themselves even in retrospect. I couldn't relate to the situations or the autonomy of my friends.

The article by Tiefenbacher featured here details her experience gathering feedback from young children with disabilities about their favourite activities at a local leisure space. Even with an open mind and believing she had found “a good method for ensuring the participation of all children,” Tiefenbacher sums up her early results with a dry wit: “Difficulties with conducting the walk-and-talk conversations arose as soon as I began collecting data. I was, in fact, never able to conduct a walk-and-talk conversation with any of the participants.”

Like research, disability parenting often ventures into unexpected territory and requires time, patience, and a willingness to go rogue to really listen to what a child is communicating, in their own way.

Tiefenbacher states: “How we conduct research has implications for understandings of children with disabilities, given that method is not only a way to investigate realities but rather, that method produces realities.” A cycle I’m well familiar with. One of my sons has a mobility disability, is non-speaking, and has low vision — the combination of these factors often making it too easy for others to pass judgment on his level of understanding within a few seconds of meeting him.

I’m often asked by medical professionals for my interpretation of my children’s communication, behaviour, and actions. Sometimes I’m so sure that a certain action means one thing, but other times I wonder if I’m seeing only what I want to see, if I am willfully misinterpreting out of a ego to prove my son understands the world around him as I think and hope he does. But how do I know?

Tiefenbacher went rogue when she switched to watching video footage of her interactions instead, discovering that some of the children whose interactions she had found “ambiguous and difficult to interpret” were actually telling her their favourite activity, in their own way. For one girl, even though she never verbally told Tiefenbacher she liked taking her stuffed lion down the slide, it was evident from the video that she did. It was the same for the other children: whether they answered verbally or not, each child was playing an activity they liked. By focusing on doing research with the children — playing alongside them, analyzing their interactions for preferred games rather than relying on definitive verbal or body language answers — Tiefenbacher found she had the data to answer her question of what children liked doing at the leisure centre. The data wasn’t gathered in the way she expected it would be, but it was still data.

The article captures the complexities of real-world interactions with children with disabilities in a way that also highlights the beautiful array of possible responses. Responses that are impossible to standardize into one scale or answer key, but that are — with enough time, patience, and openness — individualized and informative.

As a mom of a child who has been excluded from both direct 1:1 communication and assessments supposedly designed to help him access resources and diagnoses on the basis of his inability to respond in a standardized way, nothing makes me happier than when someone either speaks directly to him instead of through me, or adjusts their materials or workflow to fit his expressive needs. I realize health systems are overburdened and underfunded, but Tiefenbacher's study demonstrates the profound effect of including children with disabilities in research: the outcomes directly affect the children's realities. By knowing the children's true preferences, the play centre can provide a fun, calming space for everyone.

I remember the first time I experienced a professional shifting their approach to match my son's needs. I watched with amazement as a nurse, running through an inpatient vitals check, asked my son a question I no longer remember. Quickly seeing he couldn't answer her verbally, she told him that a "yes" could be a smile or tapping her hand, and no could be doing nothing, and repeated the question kindly. I watched his face light up, smiling, then smiling wider as she acknowledged his answer and double-checked its accuracy, chatting with him as she completed her work.

While I have my own system of gestures and communication with him while we work on acquiring more formal AAC tools, the remarkable part was I didn't have to tell this nurse anything. I didn't have to preface the conversation with his abilities, I didn't have to redirect her

question to him, or worse, answer for him with my own assumption. She just effortlessly adapted the question to him, in a way he could participate.

Time, patience, and being a bit rogue are the key ingredients to producing better realities for all of us, in research and life.