

Voice and Representation: Engaging with the Voices of Children Who Have Disabilities

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DIALOGUES: Standpoint

Consider the following scenario: *Grace is a 9-year-old child who communicates using body movements, vocal sounds, and a paper-based book with graphic icons. Two years ago, her teachers and therapist assessed her abilities to use an electronic communication aid, and consequently issued her a high-spec, eye-gaze-enabled, speech-generating device. To date, she mostly uses this with her teachers to respond to rehearsed topics during class. Despite everyone having high hopes and fighting hard to fund the device, Grace isn't keen on it and chooses to use other modes instead.*

This scenario is all too common in designing for disability and children. Many studies have looked at the reasons for underuse and abandonment of assistive technologies for communication, which include ease of use, technical support, and environmental barriers [1]. However, bringing these concerns into the realm of interaction design, the underuse and abandonment also make us ask: Does the design of these technologies reflect the contemporary concerns and preferences of children with disabilities?

In recent work, we discussed how assistive technologies, like speech-generating devices, have predominantly been designed for a limited range of purposes [2]. Often, they foreground corrective or developmental goals, for example, providing language options to account for a lack of verbal speech or supporting children to “catch up” with traditional stages of child development. These technologies are undoubtedly important for overcoming some of the real challenges that children can face, yet design for disability still has some way to go to expand the potential roles that assistive technologies can take in disabled children's lives. In order to promote more varied perspectives in designing for disability, one option is to revisit how we listen to and respond to children's contributions.

The HCI community continues to advocate for carefully considering how children are involved in the design process [3], including ethical and pragmatic concerns for involving children who have disabilities [4]. Yet while political and academic discourses are

increasingly viewing children as competent social actors, there are inescapable challenges in understanding how to legitimately engage with children's voices for the purposes of informing change.

We propose that child-centered perspectives can inform new and generative ways of designing for disability by examining children's lived experiences. In line with a constructivist view that recognizes voice, disability, and childhood as socially enacted, we consider how our own actions as researchers have an impact on constructions of new knowledge. One way of doing this is to use reflexivity as a tool [5] for problematizing and critically engaging with the issue of voice. Drawing on our empirical research that investigated some of the salient features of communication from the perspectives of children with severe speech and physical impairments, the remainder of this article considers how methodological decisions can have a significant impact on constructions of voice in the design process.

The Histories that Shape Our Orientations

Theory. Whether directly or indirectly expressed, as design researchers, we hold assumptions about *ways of being* that ultimately inform *ways of acting*. For instance, considering the subject matter of *communication*, two opposing perspectives might separately treat communication as a) human centered or b) not human centered. Researchers who align with the former might choose to study communication by focusing on the child's agency in creating meaning and expressing themselves. In the latter perspective, another researcher might instead study how meaning is created through a distributed network of people, objects, and actions. In our own work, we recognize that power is a fundamental aspect of relationships and interactions. We therefore focused on how children used resources that were available to them for advancing their goals. In doing so, we aimed to advance a strength-oriented perspective by attending to how children with severe speech and physical impairments communicated on their own terms.

Practice. The field of HCI is vastly interdisciplinary. It is this richness in perspectives that makes the work presented at the CHI conference and related venues so interesting. Design for disability can sometimes be motivated by personal experiences with disability, but also professional experiences as practitioners working across disciplines. We acknowledge that our professional *ways of seeing* can greatly influence how we treat the contributions of children with disabilities. Many HCI researchers working in disability have also worked as teachers or allied health professionals. Given that their research is often carried out in schools or therapy contexts, this can present challenges in the relational roles that they and the children have learned to take. For the purposes of design research, being aware of these underlying roles can be helpful in regulating how our own behaviors support or hinder the production of new narratives. Alongside the challenges of mitigating their past roles, a strength for researchers who have been practitioners is that they are able to recognize these role dynamics. This can be generative for design by allowing researchers to

problematize ways of supporting children’s agency in conversations that involve people and technology—for example, by regulating the volume of questions that the teacher asks or allowing for interactions that have more open-ended topics or are child-initiated.

Producing Credible Accounts Through Prominent Ideas

In qualitative research, it is critical to apply analytic techniques that ensure the researcher’s interpretation of the data is credible [6]. One way to do this is to use a variety of methods. This allows the researcher to identify strong and prominent ideas that are consistently conveyed across methods used. In our own work, as our goal was to represent what children might value or prioritize for communication, we attempted to build a picture of what children were expressing over time. We did this both by attending to how varied data sources conveyed ideas that would repeatedly occur across methods, as well as by examining how varied methods helped us to reach detailed understandings about different dimensions of complex situations. Our findings included that children valued protecting their privacy as well as the ability to advance social interactions. For example, during an interaction with a child participant, the researcher asked the child a series of questions about what he would like to do during playtime. The child responded by holding up his hand to indicate “stop” or “no” to the researcher’s repeated requests for information (Figure 1). In this instance, by regulating his disclosure, the child expressed a need for protecting privacy.



Figure 1. Protecting privacy was one prominent idea expressed across methods.

Children’s Ways of Participating Evidencing Their Voices

There are explicit and implicit ways in which children can contribute to the design process. One major challenge for researchers is interpreting what a child appears to be expressing on their own terms. In some cases, there can be huge disparities in what children express through different modes of action, as well as how they express themselves in alternative contexts with different researchers. As researchers interpreting these actions, there is often a risk of filtering out disabled children’s contributions that are not understood or not seen as legitimate. For instance, when a child doesn’t respond to an adult’s question or looks away for an extended amount of time, one might assume that the child is disinterested or is not understanding, leading the researcher to question their ability to participate. These

challenges can be further exacerbated in cases where children communicate in ways that are unfamiliar to the researcher.

To understand how children would take part in research, we focused on what children's forms of involvement might be conveying and how child voice was influenced by adult-designed agendas. Sometimes this involved carrying out a detailed analysis of social interactions through recording and transcribing to understand the conversational dynamics. At other times, we focused on how children responded to our methods. We anticipated that children's contributions could expose multiple understandings beyond face value and observed that children's behavioral engagements with the methods expressed insights about what was important in their lives. For example, on one occasion a child participant expressed her desire for regulating her privacy by tearing up and discarding a sheet of sugar paper that had her photograph attached to it, otherwise intended to be used for creating a collage of her interests (Figure 2).



Figure 2. Children's behavioral engagements with methods signified what was important to them.

On a different occasion, during a baking session in class, another child challenged the adult's assessment of her capability to hold a spoon and whisk an egg mixture, by attempting to pull away from the adult, extending backward in her standing frame (Figure 3). In this moment, she expressed her desire for less physical adult support. These instances highlighted the need for being prepared to adapt methods in the moment, to potentially interrupt existing power dynamics that are common in teaching contexts.



Figure 3. Child expresses her desire for doing a physical activity without adult support.

Conclusion

In this article we have identified how methodological decisions can support design researchers to engage with the voices of children who have disabilities. Through our examples, we identify considerations that relate to issues of recognition on the part of the design researcher. We recognize that theories shape the capabilities we see in children, for those who have been teachers or related practitioners, and that our past professional histories allow us to see contextual dynamics as well as sometimes influence how we interact with children. We also recognize that there are multiple interpretations of what children are expressing through the ways in which they engage with methods, and that as researchers, we decide to foreground the parts of these interpretations that we treat as representative of children's voices. By scrutinizing our methodological decisions, we force ourselves to consider whether we are credibly producing child-centered accounts, and to justify why we treat certain insights as more important than others. Ultimately, our goal is to be more generative so that design can serve multiple purposes and move toward acting on what children express as important in their own lives.

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Endnotes

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