HARMS AND BENEFITS

Navigating disability identity and language in research involving children and young people

Background context:

Despite contemporary tourism research being more inclusive of previously neglected groups, the views of children with disability are still largely absent, reflecting a disregard for both their agency and voice. My research sought to address this gap by focusing on understanding the holiday experiences of disabled children, using their self-reported narratives.

Locating the study in New Zealand, I invited children and young people aged 5-18 years who have a disability and who had holiday experiences in the past 12 months (domestic or international) to take part. This included children and young people with a range of intellectual, cognitive and physical disabilities. I utilised child/age/disability-friendly consent procedures (e.g., easy-read pictorial versions) and obtained dual consent from children and parents. To meet the unique characteristics and requests of the participants, I tailored the interviews (face-to-face or online), adopting a variety of approaches such as photo-elicitation. Overall, I worked hard to facilitate a respectful and participatory research process. However, a central challenge was addressing questions about disability identity (*Who are disabled children? Is that the 'right' language?*). In struggling to understand and address such foundational issues, I consulted a wide range of literature. However, navigating questions related to disability identity and language was tough in practice, given diverse expectations, interests and beliefs among the different groups of people with whom I was working (e.g., disability service providers, disabled people's organisations (DPOs) and parent groups).

The ethical challenge:

Who are disabled children? This question re-emerged during the recruitment phase with more specific queries (e.g., *Do you consider children diagnosed with Type I Diabetes as disabled children?*). I experienced the weight of responsibility in considering my answers, knowing these may influence gatekeepers' thinking (positively or negatively) and result in inclusion or exclusion of some children from the study. In such scenarios, I shared my thoughts based on definitions and understandings available from relevant literature, but I was conscious this was insufficient to capture all fluidities around disability identity. As a researcher, I was in no position to categorise or label someone as ‘disabled’, especially for a socially constructed category with no clear boundaries and/or defining feature(s). Besides, it would be disrespectful to fit these children’s fluid identities (Davis, 2012) in a box.

Similarly, conflicting issues about the *‘right’ language* also resurfaced at the recruiting stage. All my recruiting content (i.e., research advertisement, information and consent sheets) was designed using identity-first language (i.e., disabled children and young people) instead of person-first language (i.e., children and young people with disabilities). I opted for the former because the language used by New Zealand self-advocacy groups (e.g., Disabled Persons Assembly NZ) and the Office for Disability Issues (see New Zealand Disability Strategy 2016-2026) reflects identity-first phrasing (Office for Disability Issues, 2021). Despite my reasoning, making this decision was challenging and uncomfortable given the ongoing, unresolved debate on this issue (Boggis, 2018).

With no universally acceptable language, I expected some reaction from diverse stakeholders (e.g., parents, disability service providers). However, the response was stronger than I expected. For example, expressing disapproval for identity-first language, one service organisation explained that children and families might not affiliate with this term. I could relate to this argument, with some scholars noting parents’ (Lalvani, 2015) and children’s (Asbjørnslett, Helseth, & Engelsrud, 2014) resistance to labels that are seen as devaluing and/or positioning them as different. As gatekeepers, some parents firmly said ‘NO’ to identity-first language and requested I consider alternatives (e.g., children with diverse needs and abilities). Some of the options reflected their own child/children’s disability experience (e.g., autism, nonverbal). Yet, not all shared these views. Some took the middle ground (i.e., language does not matter as long as you show respect) while others applauded the use of identity-first language.

In navigating such strongly held but divergent views, two things became apparent. First, there was no consensus or consistency regarding preferred language. Second, the nomenclature strongly endorsed at the advocacy level was not acceptable to all. Finding myself tangled in a complex web of language and ideology, I wondered who has the right to decide on appropriate language? The researcher, child, parents, advocates, scholars, service organisations…? Whose voice should take prominence? With no decisive answers, I directed my attention to what *can* and *should* be done to navigate these challenges.

Choices made:

I had the choice to ignore some of this debate and move on with the research. However, with an ongoing commitment to pursuing what was ethically right, I took all gatekeepers' responses (critical and constructive) very seriously. I actively sought their perspectives to inform my actions. For example, I found it important to start with an opening statement about the complexity of the disability context and how there are varying constructions of disability, with none being right or wrong. Taking a neutral stance was helpful as it invited an open dialogue. Similarly, I actively inquired about their preferred language, and requested feedback and suggestions that gatekeepers could share (e.g., ideal ways to reach potential participants).

This open dialogue was useful as it fostered mutual understanding. Through this process some service organisations that had previously resisted circulating my research information to their members became more willing to do so when they understood my intentions, keenness to listen and adapt. I adapted the research information for these organisations as per their suggestions (for example, to person-first language). In all my correspondence, I added a note that read, *"the term 'disabled children' is used as the preferred terminology among self-advocacy groups. If this term is considered inappropriate, I am happy to adapt to an acceptable alternative"*. To address some parents' concerns, I modified the language of the information and the consent forms accordingly. Such adaptability was possible as my institution's ethical clearance allowed for tailoring the research to serve the best interests of the participants and their families.

The practice of inviting different perspectives and critically reflecting on the views made the recruitment process more respectful, less stressful and more manageable. However, I struggled for almost three months to develop understanding and respect with some groups and potential participants. Despite the time involved in building trust and gaining the support of gatekeepers, the outcomes for including children with disability in research make this necessary, ethical and worthwhile.

Reflexive considerations:

- What else could have been done by the researcher to anticipate and navigate disability identity and language issues? Is it possible to develop more explicit guidelines that could inform and guide researchers?

- How might I have been able to minimise the conflicting issues around identity and language? Would it be fair to exclude/include based on disability types?
- What are children and young people's own constructions of their disability? How are these formed? Are children's constructions of disability aligned with or at odds with advocacy stances?
- Are researchers adequately informed about different understandings of disability and are they attuned to the ways in which language shapes perceptions of disability (and the children involved)? What are the risks of altering language to meet the desires of parents or service providers?

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Please note: You can find the issues reflected in this case study along with some others experienced during my fieldwork in:
Shiraani, F., Shaheer, I., & Carr, N. (forthcoming) Procedural ethics vs. Being ethical: A critical appraisal. In F. Okumus, M. Rasoolimanesh, & S. Jahani (Eds.), *Contemporary Research Methodology for Hospitality and Tourism*. Emerald Publishing Group.

References

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Boggis, A. (2018). Dis/abled Childhoods? A Transdisciplinary Approach. Cham, Switzerland: Palgrave Macmillan.

Davis, J. (2012). Conceptual issues in childhood and disability: Integrating theories from childhood and disability studies. In N. Watson, A. Roulstone & C. Thomas (Eds.). *Routledge Handbook of Disability Studies*. New York: Routledge.

Lalvani, P. (2015). Disability, stigma and otherness: Perspectives of parents and teachers. *International Journal of Disability, Development and Education, 62*(4), 379-393. doi:10.1080/1034912X.2015.1029877.