

Parents' lived experience of their role in mediating community environments to facilitate the participation of their child with Complex Communication Needs

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Short Abstract

Background: Community participation is a right of every child and is linked to improvements in health, development, social interactions, and a sense of inclusion and belonging. For children with Complex Communication Needs (CCN) ongoing support from others is often necessary to participate in community environments. Parents typically provide this active support. Further research is required to understand how parents experience their role in facilitating this community participation.

Aim: This study explores parents' lived experiences of community participation for their child with CCN. This presentation focuses on an initial theme emerging from the data: how parents describe their role in mediating community environments to facilitate their child's participation.

Method: Semi-structured 60-90 minute interviews were completed with parents in person and online. Data were analysed using reflexive thematic analysis.

Results: Participants were 11 parents of 10 children aged 3-6 years with CCN, who lived across metropolitan and rural areas of Australia. Parents shared community participation stories, illustrating how they facilitate community participation of their child with CCN. They described actively mediating their child's participation regarding their relationship with their child (monitoring regulation, playing together), community members (providing education, advocating), and physical environments (layout, busyness). Parents reflected on their internal struggles with this responsibility and how it changes over time and context.

Conclusions: Parents have a vital multifaceted role in mediating community environments to facilitate the participation of their child with CCN. Understanding parents' insights provides opportunities to collaboratively reduce the load on parents and uphold children's right to experience positive community participation.

Long Abstract

Background: Participating in community environments is a core right for every child (United Nations, 20 November 1989) and supports their development across multiple domains. Through early childhood community participation, children improve their mental and physical health (Anaby et al., 2014; Shikako-Thomas et al., 2012), create a sense of identity, belonging, and inclusion (Department of Education and Training, 2009; Law et al., 2012), expand their

social interactions and friendships (Kaljaca et al., 2019; LaVesser & Berg, 2011), and gain skills in communication and cognition (Chien et al., 2014). However, research indicates that for children with disabilities, including those with Complex Communication Needs, to participate in community environments, they often rely on ongoing support from others (Batorowicz et al., 2014; Shields & Synnot, 2016). This active support typically comes from their parents (LaVesser & Berg, 2011). Further research is required to understand how parents of children with Complex Communication Needs perceive and describe their role in supporting this community participation.

Aim: This study explores parents' lived experiences of community participation for their preschool-aged child with Complex Communication Needs. In particular, this presentation focuses on understanding the essence of how parents describe their role in facilitating their child's community participation.

Method: A phenomenological approach was used to explore the lived experiences of community participation for children (3-6 years) with Complex Communication Needs from the perspectives of their primary carers. Semi-structured 60-90 minute interviews were completed in person and online with participants. Interviews were transcribed, and narrative summaries were created to outline the essence of community participation experiences for each family. Participants were given the opportunity to review these before further analysis was conducted (McAllister & Lyons, 2022). Data were analysed in NVivo (QSR International, 2018) using reflexive thematic analysis (Braun & Clarke, 2019).

Results: Participants were 11 parents (10 mothers and 1 father) of 10 children aged 3-6 years with Complex Communication Needs. All families were two-parent households based across metropolitan and rural areas of Australia, categorised into the Modified Monash Model areas 1-5 (Department of Health and Aged Care, 2021). Their children (3 female, 7 male) used a range of communication modes, including hand leading, gestures, keyword signs, Augmentative and Alternative Communication devices, vocalisations, and some verbal speech.

Parents shared community participation stories, providing insight into the multifaceted nature of their experiences and views. Parents described their roles in mediating community environments to facilitate the participation of their child with Complex Communication Needs by highlighting the parent-child, parent-community members, and parent-physical environment relationships. The parent-child link involves being in tune with their child, monitoring their child's regulation, playing with them, and providing hands-on support during participation. Parents' stories highlight their role in educating and building awareness regarding their child's communication and how they can best be supported. This involves responding to people's questions regarding their child's age and why they 'don't talk'. Parents shared how this role can become a 'constant battle' when they must advocate for their child's participation and support needs. Behind the scenes, parents describe 'all [the] mental calculations' that happen when they consider physical environments before going anywhere. They describe the cognitive burden of factoring in physical layout, busyness, familiarity, and whether the community environment or activity is generalised or disability specific. Finally, parents shared the internal struggles they face with their multiple roles and how these can shift over time and across contexts.

Conclusions: Parents have a vital, multifaceted role in mediating community environments to facilitate the participation of their preschool-aged child with Complex Communication Needs. Parents' lived experience of their role is three-fold regarding their relationship with their child, community members, and physical environments. Understanding these parents' stories of community participation and how they describe their roles provides insights into opportunities

to collaboratively reduce the load on parents and uphold the right of every child and their family to experience positive community participation (United Nations, 20 November 1989).

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