

Concept Paper

# Spotlight on Siblings: Considering Social Context in Home Modification Practice

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**Abstract:** The United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes the role of Assistive Technologies (AT) in enabling independent living and inclusion of people with disabilities. Research into the provision of AT and disability services in general has highlighted the importance of social context and its influence on individual outcomes. However, there is little recognition of sibling roles, relationships and rights in the guidance available for practitioners. This paper explores the socio-technical context of home modification practice and the importance of involving siblings. The international context and concepts behind AT provision, including home modifications, and issues emerging from practice in Australia's new National Disability Insurance Scheme (NDIS) are discussed. Based on extensive practical experience and peer review, the "5 S's for Siblings" is presented as a practice approach for involving siblings in the home modification process. Policy and practice implications are presented, including communication strategies for working in partnership with individuals and their families, and alignment with national standards and human rights principles. Involving siblings in the home modification process recognizes the important role they play in the lives of people with disabilities, both now and in the future.

**Keywords:** siblings; disability; human rights; assistive technology; home modifications; social context; National Disability Insurance Scheme (NDIS)

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## 1. Introduction

Disability is a unique, shared experience for a family that can affect all aspects of family functioning, including relationships [1]. One of the longest relationships a person with disability may have will be with their sibling(s) and because of this, siblings can contribute much to their well-being over a lifetime [2]. Fostering and supporting the relationship between a person with disability and their sibling(s) can have significant long-term benefits, with the relationship providing invaluable support, love and enrichment in each of the family members' lives. Additionally, as the parents of a person with disability age, siblings often become carers and key supports for the person with disability in adulthood [3]. The willingness of siblings to take on a caring role can be influenced by many different factors, including familial expectations and experiences, and the siblings' sense of importance, connection and voice within their family unit [4]. Siblings' involvement in modifications to the family home during childhood may therefore contribute to the development of this important relationship.

People with disability often require assistive technology, including home modifications, to improve safety, promote independence and access support services. Modifications are often made to shared spaces such as bathrooms, which have the potential to change the way "home" is

experienced by all members of the family [5]. When undertaking home modifications, many practitioners adopt person-centered approaches so that an individual's goals and aspirations are met. However, focusing on the person with disability without adequate consideration of their social context may neglect the relationships with, and needs of other family members.

Siblings can be a forgotten stakeholder in home modifications, as government policies espouse and fund the needs of the person with disability (and sometimes a carer). Home modification assessment processes and forms rarely include prompts to consider siblings' needs. Recent research by Siblings Australia [3] found that siblings feel there is little understanding from their families and service providers about the specific issues they face. Additionally, due to the lack of research into sibling involvement in home modifications, there is minimal evidence to guide practitioners. This concept paper presents an approach for practice to encourage a more holistic person-centered approach that considers the individual's social context by involving siblings in home modifications.

## 2. Assistive Technology

Accessible environments and assistive technologies are key factors in enabling full and effective participation of people with disability in society on an equal basis with others. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) identifies access to assistive technology as a human rights obligation that every Member State must fulfil [6]. The term assistive technology (AT) generally refers to products or devices used by people with disability, but also refers to a range of services or practices that support the use of assistive products [7]. Adaptation or redesign of an environment or activity is often required to support the use of assistive products [8], so home modifications are generally considered part of an assistive solution in Australia [9].

Research has shown that the success of AT in enhancing inclusion and participation is dependent on the way in which it is conceptualized and delivered [10]. Person-centered approaches that combine functional knowledge with consumer engagement are considered necessary for competent AT service provision [7,11]. Researchers have suggested that non-use of assistive products is more likely when consumers are not involved in or given some sense of control in the process [12,13]. Several studies have described the actions taken by practitioners to facilitate person-centered practice, such as anticipating problems and discussing expectations with consumers during assessment processes [14]; collaborating with consumers when planning and implementing interventions [15], and; individualizing interventions by understanding consumers' perspectives [16]. While AT researchers have acknowledged the importance of caregivers' perspectives in AT acquisition and use [17], the rights, roles and relationships of siblings have not been specifically addressed.

## 3. Home Modifications

People with a disability often require home modifications to enable improved safety and independence and to access support services. Home modification processes are complex and involve multiple stages from design through to construction and evaluation [18]. Collaborative consultation is essential and involves the person with a disability, their family, the home modification practitioner and external stakeholders, including AT suppliers, building professionals, architects, and local council planning departments. The outcomes of home modifications tend to be largely positive. However, negative outcomes can arise when all aspects of the modification have not been well considered [19].

Researchers call for practitioners to be cognizant of the needs and wants of the family during home modifications and to ensure that participatory methods are utilized in determining solutions [19]. Research reviewing home modification outcomes tend to focus on partners, spouses or parents of the person with disability, with scarce literature that includes siblings' perspectives. Article 12 of the United Nations Convention on the Rights of the Child affirms the right of children to express views in matters affecting them, and that these views be given due weight [20]. Rights-based approaches encourage practitioners to hear the voices of all affected parties regardless of limitations

in current policies or research evidence. Siblings voices need recognition by practitioners, as their experience of home is affected and they play an important role in the family's social context.

#### 4. Australian Context and Emerging Challenges

After Australia ratified the CRPD in 2008, the Australian Government created a National Disability Insurance Scheme (NDIS) that funds lifetime supports for individuals with permanent and significant disability. The NDIS is designed to provide the individual supports, or reasonable accommodations, necessary to enable people with disability (called 'participants') to enter and actively participate in society. AT, including home modifications, is an important support for many NDIS participants. AT was included in 39% of all participants' plans in NDIS trial sites, and in the plans of more than 50% of participants aged over 45 years or under 18 years [21].

Practitioners play a pivotal role in assisting NDIS participants by assessing individual needs and making recommendations for supports considered 'reasonable and necessary'. The National Disability Insurance Agency (NDIA) are legislated to use the "reasonable and necessary" criteria to guide decision making about what individualized supports will be funded. The NDIA published Complex Home Modification templates, asking practitioners to provide evidence for their recommendations, discuss the cost-effectiveness of solutions, and clearly differentiate between the participant's needs and preferences. The templates make little reference to other residents in the home, unless they are carers or a sibling who also has a disability. In the next section, we introduce a fictional practice example that demonstrates some of the emerging issues. A new approach, the "5 S's for siblings" is then presented to encourage practitioners to address the social context in home modification practice. This practice approach is particularly important given the current context of NDIS, where siblings appear not to be well considered.

#### 5. Practice Example

A fictional case study of home modifications in a family context, based on a combination of recent experiences with NDIS participants, was created to exemplify issues and highlight important themes:

**Example 1.** *The Jones family live in a 4-bedroom, 1-bathroom home and have five children aged between 2–16 years. A referral was received for bathroom modification advice for their 8-year-old daughter Molly who has Cerebral Palsy (GMFCS Level V) and uses a tilt-in-space commode for showering. The planning and scope of works was based on Molly's functional needs and involved an occupational therapist, architect, builder and parents. Molly's siblings had not been present during the home visits. A bath was removed, and a level-access shower was installed with an overhead and handheld shower, and inbuilt niche (storage). On completion, the bathroom modifications were safe and effective in meeting Molly's functional needs, but had unintentional consequences for Molly's siblings and parents. The siblings did not have access to power outlets for their personal items such as shavers, hair dryers, and toothbrush chargers. This was due to Molly's hearing aid charger and electric toothbrush using the existing power outlet and taking priority. There was insufficient storage space for shampoo and body wash products because of the space required to store specific shower products used to manage Molly's skin care. The siblings reported being woken in the morning by the noise of support workers assisting Molly in the bathroom. This issue is a common occurrence for families and could have been minimized by retro-fitting sound proofing as a preventative measure. The modification allowed new and needed AT to be introduced into the home, without additional storage space provided. The youngest child climbed onto Molly's commode for showering, creating a safety risk. Due to the removal of the bath, the parents had to use a bucket under the shower to bathe the youngest child.*

The bathroom environment was selected as a practice example because it is traditionally an area of high AT use for people with disability, along with being a significant shared space within the home setting. This results in the need for careful consideration of the person, environment and task being performed. The way personal care tasks are completed and the routines used during the task are highly individual for both person with a disability and their siblings. Common examples of this

could include preference or need for a bath instead of shower, water temperature for bathing tasks, or whether grooming is completed at a vanity unit or in the shower.

This case study highlights how family dynamics and the needs of siblings can be overshadowed by a procedural focus on an individual's needs. Despite the involvement of multiple stakeholders and careful planning in all phases of the home modification, the bathroom modifications created some frustrations, delays, safety hazards and postural difficulties for parents, siblings and support workers. The approach introduced in the next section asks practitioners to explicitly include the social context of the person with disability in their clinical reasoning, by considering carers and siblings when contemplating home modifications in shared spaces.

## 6. The 5 S's for Siblings

The 5 S's for Siblings attempts to bridge the knowledge-practice gap by highlighting considerations for practitioners modifying bathrooms in the family home. It was developed as part of a quality assurance activity in a regional health service in Australia, following a review of research literature into home modifications and two of the authors' (JM and AS) clinical experiences. The literature search included both national and international sources, of published and unpublished research in English language. Due to limited results yielded, an extended date range from the past 25 years was included along with a grey literature search. JM and AS have combined 24 years of clinical experience as occupational therapy home modifications practitioners, working with people with disabilities, across the lifespan in a regional community setting in Australia. An earlier version of the 5 S's for Siblings was peer reviewed by 18 community and disability sector practitioners, validating the content and incorporating additional practice knowledge related to siblings' needs. Table 1 presents practice considerations for home modifications across five interconnected themes: Safety, Space, Structure, Support and Style. These prompt consideration and discussion to elicit and value the views and contributions from siblings in home modifications.

**Table 1.** Practice considerations for home modifications using the 5 S's for Siblings.

Practice Considerations	
Safety	Have the safety needs of all users of the space been considered?
	Have risks of burns, scalds, strangulation, and other injuries from fixtures/fittings been minimized?
	How are chemicals/products and AT stored in the space?
	What are the manual handling issues for all users?
Space	Is there enough space for all users to complete necessary tasks including all needed AT?
	Is the planned modification in the best location?
	What space is required to store everyday items and how can privacy of possessions be respected?
Structure	What are the gender and privacy considerations, and how will these change for users as they age?
	What design features are needed currently and in the future? This includes electrical, plumbing, structural, sensory and physical requirements.
	Is soundproofing required to protect the privacy needs of people using the space and nearby areas?
Supports	Will the removal of existing bathroom structures or features (e.g., bath) adversely affect siblings or others in the home?
	How can support workers' intrusion on siblings' space and privacy be minimized?
Style	Do siblings require assistance to learn new ways of completing a task or using a space once it is modified?
	How does the family value the need for function versus aesthetics?
	What are the siblings' thoughts and feelings about their home and understanding of having it modified?
	What communication style and resources are needed to work well with all members of the family?

### 6.1. Safety

Safety is an important consideration in any AT intervention, including home modifications. Practitioners need to consider all people that may use or access the space being modified. In a bathroom setting, there are specific safety considerations for children that influence the selection of fittings, fixtures and assistive products. Safety is not a standalone theme and should be considered at every stage of the home modification process.

### 6.2. Space

The importance of space in the home is recognized in the World Health Organization's Housing and Health guidelines [22]. These guidelines highlight the direct correlation between inadequate living space and adverse outcomes such as mental health issues, infectious diseases and poor educational attainment. A lack of space is a common issue reported by families of children with disability [23,24], and can also be a source of stress [24], particularly when siblings share their bedrooms or other spaces. It is important to find out how the space is used and how much space is needed, because home modifications often reduce the usable living space, affecting family life [24]. Inadequate space in bathrooms has ramifications for safe storage and the use of assistive products as well as completion of personal hygiene tasks. Space cannot be addressed without consideration of structure.

### 6.3. Structure

Structural considerations are critical when planning home modifications, and influence outcomes for each of the other themes. Building construction professionals work with practitioners to ensure structural changes meet relevant construction codes and standards. Planning for the future and allowing for further modifications can extend the life of the modification and allow the person with disability and their family to remain living in their home. Soundproofing has not traditionally been considered in bathroom modifications, but has emerged as an issue in practice due to the social impact of noise and availability of solutions. Mitigating the effect of noise for siblings or other family members who sleep next door whilst early morning care is provided could alleviate both physical and emotional harm and improve sleep and other personal routines. Soundproofing can also address children's right to privacy (Article 16) [20], as carers or support workers in the home may not be cognizant of who may hear them whilst providing care.

### 6.4. Supports

The NDIS aims to "support the independence and social and economic participation of people with disability" (Section 3(1)(c)), stating that "The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected" (Section 4(12)) [25]. It is therefore appropriate to consider supports required by both the person with disability and their siblings, whether related to age or impairment. How siblings interact with support workers is also important to consider. Strangers coming into the family home can be confronting. Home modifications can be designed to facilitate positive interactions between support workers and siblings. This could be as simple as considering the path of travel of support workers within the home, choosing the most optimal spaces to modify, and providing education to all parties regarding best use of the space.

### 6.5. Style

Style and aesthetics are highly personal to home owners and residents. Home designs and decorations can influence how someone feels when they enter or use a room. Lack of consideration of style can affect levels of stress and anxiety, making a person reluctant to use the space. Style is also an area that may allow siblings to contribute to the home modification process.

Style also refers to the way in which a practitioner works with a person with disabilities and their family. Patterns and style of practice often evolve over time and are influenced by experience and practice setting. Practitioners may need to reflect on their practice, adjust their working style and use additional resources in novel ways to include ensure that sibling's needs and rights are realized.

## 7. Implications for Practice

Considering the needs of siblings in home modifications recognizes the importance of social context and is consistent with rights-based approaches to practice. The introduction of the NDIS in

Australia is part of a broader cultural shift away from charitable practices of the past, where a lack of funding and support for people with disabilities gave them little hope for anything but survival. The NDIS is built on a rights-based approach that promotes inclusion, aiming to enable people with disabilities to thrive rather than just survive. A narrow focus on individual needs in current templates provided by the NDIA may inadvertently constrain practice. However, new and evolving systems present both challenges and opportunities. The 5 S's for Siblings was developed to assist practitioners to explore siblings' needs in home modification practice.

To ensure effective partnerships between service providers, individuals and families, practitioners are encouraged to consider all members of a family. To align with person-centered approaches and human rights principles, it is important to recognize, consider and involve siblings in all stages of the home modification process. This is not straightforward in practice, and the extent of sibling involvement may depend on their age, ability, interest, and involvement in the care of the person with disability. Anecdotal evidence suggests that one of the prime reasons for not involving siblings in the home modification process is that they are often at school or other care arrangements during home visits. Practitioners may need to be proactive in advising parents that siblings can and should be included in home modification discussions. This may require flexible approaches from service providers to enable visits outside of school hours or during school holidays.

Options to increase sibling involvement can include discussing the choice of fixtures and fittings, colors, styling and providing feedback on the modification. Evidence-based tools for communication with children, both with and without disability, can include dolls, props, drawings, pictures, photographs and Lego. These are participatory methods for accessing children's views and experiences which utilize non-confrontational strategies [26,27]. Another existing tool that can be highly effective to explore siblings' and children's views about their environment is Talking Mats (TM) which is aligned with the International Classification of Functioning, Disability and Health (ICF). Talking Mats is a research-based tool to help people think about a topic and communicate their opinions, ideas and preferences more effectively [27]. Once the modification is completed, siblings should be involved in the review process, so they can see the importance of their input.

## 8. Implications for Policy

The 5 S's for Siblings promotes a rights-based and collaborative approach to home modifications that is more closely aligned to the Australian National Standards for Disability Services (NSDS) than current practices. The NSDS promote a nationally consistent approach to quality improvement in the disability services sector [28]. First published in 1993, the most recent version was produced following consultations with more than 1291 stakeholders including people with disability, families and caregivers, and service providers [29]. The Standards are not legally binding, but organizations or practitioners registered as NDIS providers must meet the NSDS as evidenced by audits.

The revision of the Standards reflects the move towards individualized supports and person-centered approaches promoting choice and control by people with disabilities to align with the aims of the NDIS. The NSDS are clear about being informed by principles from human rights and quality management, and emphasize relationships and collaboration [29]. They comprise a set of six standards to be applied across a broad range of circumstances: Rights; Participation and Inclusion; Individual Outcomes; Feedback and Complaints; Service Access; Service Management. The Standards provide an explicit definition and recognition of family and friends [29–31], and promote their involvement with individuals and practitioners in decision making and evaluation, "...to strengthen the focus on partnerships" [28] (p. 9). The 5 S's for Siblings is an approach that helps link the rights and needs of siblings in an area where they are rarely heard. The approach encourages conversation about how family needs can be met within an individualized funding model.

## 9. Conclusions

There is limited research literature and practice guidance recognizing the rights and roles of siblings when undertaking home modifications for children with disabilities. This concept paper is based on extensive practice experience and peer review and applied in the context of bathroom modifications. Practitioners are encouraged to consider social context in home modifications to ensure the needs of all family members, and the roles they play in the lives of people with disabilities are recognized and valued. The 5 S's for Siblings provides practical guidance with an explicit focus on the needs of siblings that is consistent with Australian Standards and legislation. Empirical studies using this approach may assist in developing an evidence base for future policy and practice. When practitioners incorporate siblings' needs in home modifications, they promote the right of the person with disability to thrive within their family social context.

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