Effects of Design on Health and Wellbeing I. Verma and L. Arpiainen (Eds.) © 2024 The Authors. This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/SHTI240962

# Children with Stroke: An Investigation of Their Home Environment

Anne-Sophie SCHOSS<sup>a,1</sup> and Gesine MARQUARDT<sup>a</sup> <sup>a</sup> Chair of Social and Health Care Buildings and Design, Faculty of Architecture, Technische Universität Dresden, Germany ORCiD ID: Anne-Sophie Schoss <u>https://orcid.org/0000-0003-3451-7190</u>

Abstract. Existing research on stroke in adults highlights the role of the built environment during recovery. However, this role has been greatly overlooked in the everyday lives of children with stroke. A stroke in childhood brings substantial changes for affected individuals and their families. Special care and treatments are necessary even many years after the stroke. Although many children recover after a stroke and can lead largely normal lives, cognitive and physical impairments are not uncommon. Typical consequences of childhood stroke include one-sided weakness (hemiparesis), ataxia, seizures, and visuoperceptual deficits. These conditions influence the children's everyday life. For example, home modifications are sometimes necessary to alleviate difficulties, but their implementation and effects on family life remain understudied. This study investigates the role of the built environment in the daily lives of children and families affected by this rare disease, aiming to understand how the built environment hinders and supports the daily lives of children with stroke and their families in their home environment. Using a participatory approach, children serve as experts, offering insights into their home environments. Fifteen German families participated, with guided tours documenting barriers and support measures through floor plans and photos. From an architectural perspective, it was noticeable that 1) large renovation measures were rarely implemented, instead, small aids in daily life were more common, 2) even small everyday aids can significantly improve the lives of these children and their families, 3) children are constantly developing, thus requiring adaptable solutions that can keep up with their growth and changing needs. In summary, this study illuminates the built environment's impact on paediatric stroke survivors, providing insights to inform interventions and enhance the quality of life for the children and their families.

Keywords. Childhood Stroke, Built Environment, Healthcare Architecture, Participatory Research, Home Modifications

# 1. Introduction

The diagnosis of "stroke" is often known as a condition occurring in the later stages of life. However, when a stroke occurs in childhood, parents experience it as "shocking and unexpected." [1] Childhood stroke is considered a rare condition, with an incidence of one to eight new cases per 100,000 children annually. [2] Despite its infrequency, statistics indicate that it is the tenth most common cause of death in children. Childhood

<sup>&</sup>lt;sup>1</sup> Corresponding Author: Anne-Sophie Schoss, TU Dresden, Faculty of Architecture, Chair of Social and Health Care Buildings and Design, 01062 Dresden, Germany. E-Mail: anne-sophie.schoss@tu-dresden.de

stroke can occur at any age. [2] Only about one-third of affected children fully recover, with a majority experiencing long-term neurological impairments. [2]

The challenges of childhood stroke range from delayed diagnosis [3, 4, 5] to various lasting impairments. [6] This is often a result of inadequate awareness and knowledge among parents and clinicians, as well as the existence of several conditions that mimic childhood stroke and the diverse range of symptoms that can manifest. Therefore, because of its complexity and impact, this condition requires special attention.

Although it is assumed that children recover better from a stroke than adults, this is often not the case. [7] Most of them experience persistent cognitive, physical, and behavioral symptoms. [8, 9] Stroke in childhood is one of the main causes of lifelong disability. [10] Therefore, most children still require comprehensive care and a variety of therapies many years after the stroke. In this context of ongoing care, the home as a place for health care becomes particularly important. Sometimes, home modifications may also be necessary to alleviate disabling circumstances resulting from a stroke.

# 1.1. Returning Home after Childhood Stroke

During the stay in clinical facilities, parents report feeling lost [11] and abandoned upon their return home after their child's acute care in a hospital, not knowing how to care for their child. [1] Even with specialized residential rehabilitation, children may still need assistance with basic self-care tasks like washing and dressing. [12] Moreover, the full extent of their child's impairments may not become apparent until they are back in the home environment. [13] Many children require ongoing support with daily activities, affecting their participation at home. [12] Additionally, the impact of stroke during childhood can significantly influence children's overall quality of life and well-being, with both children and their parents often reporting diminished quality of life across physical, emotional, social and cognitive domains. [14]



Figure 1. The pathway of a childhood stroke until returning home.

The necessity of care and support for children post-stroke can persist for years, with the rehabilitation process extending into the home environment, often resulting in lasting changes to the entire family's life (see Figure 1). Research on adults with stroke has indicated that the home environment may also become unsuitable after returning from

care facilities and may need modification for home rehabilitation and everyday life after stroke. [15, 16] However, the manner in which these adaptation measures, as well as their effects on families, has not yet been investigated but holds great potential.

Understanding how the home environment can improve children's health and facilitate rehabilitation after a stroke is crucial. Thus far, there has been no research investigating the role of the home environment in the everyday lives of families affected by childhood stroke.

## 1.2. Understanding Children's Perception of Their (Home) Environment

Just as the physical environment influences adults, it also impacts children. Adults, like children, perceive their environment with all their senses. Even in early childhood, children primarily explore their environment through their bodies, highlighting the connection between body and spatial perception. [17] When toddlers move in space, they simultaneously sense and observe their individual steps and sensations, relating them to the surrounding space. In this way, they come to know themselves as part of the space and experience themselves as the centre of the room. [18] Consequently, it can be inferred that children interact with the built environment through their bodies and senses.

This study proposes that this environmental interaction changes after a stroke due to stroke-related motor, visual, and cognitive changes. Various symptoms associated with neurological conditions in childhood alter spatial perception and significantly influence the relationship between the affected individual and the spatial environment. Depending on the type and severity of the stroke, symptoms may vary in intensity. Key symptoms of childhood stroke include hemiparesis (partial paralysis affecting one side of the body), ataxia (movement disorder), aphasia (speech disorder), seizures and visual-spatial deficits. [6]

The opportunity for architecture to create a built environment, or rather a home that perceives children's needs while breaking down barriers is crucial. Children do not move in an empty space. Whether at home, in their children's room, or in the immediate neighbourhood – they are always surrounded by scents, tastes, textures, noises, loud or quiet spaces. These are spaces experienced and lived in, which, during illness, during a stroke, take on a different meaning, a different perception.

Therefore, this study hypothesizes that the environment, particularly the home environment, significantly influences children's recovery after a stroke.

## 1.3. Research Question and Objectives

To better understand and address the needs of children with stroke, it is essential for designers and architects to comprehend not only their abilities and strengths but also their impairments. Equally important is integrating the perspective of children into the design process, understanding how they perceive their home environment. Hence, it is crucial to explore what insights architects can glean from children with stroke and their homes.

Therefore, the research question of this study is: What are the factors in the home environment that support children with stroke (and their families) after returning home?

The aim of this paper is twofold: 1) to examine facilitators and obstacles in the home environment of children with stroke, and 2) to develop a first draft of a guideline for families to modify their homes.

# 2. Methods

In order to design the home environment to meet the needs of children with stroke, it is crucial to consider the different perspectives of these children. This cognitive process of taking on various perspectives aims to enable architects and planners to understand and empathize with the needs, intentions, and experiences of children with stroke. Studies have shown that perspective-taking is essential in design thinking, helping architects, designers, and other stakeholders empathize and address the unique requirements of different user groups. [19, 20]

Involving children in design research and processes is widely recognized as crucial for achieving a better alignment between design outcomes and the diverse experiences of children, which often differ significantly from assumptions made by professional designers. [21] Therefore, each child can be regarded as a unique and valued "user/expert" of our world. [22] According to E. Ostroff [22], a "user/expert" can be anyone who has developed natural experience in dealing with the challenges of our built environment.

To gain a deep understanding of the lived experiences of children with stroke, a qualitative research approach was employed.

## 2.1. Study Design

Families of children who have had a stroke were visited in their homes in Germany. During these visits, semi-structured interviews were conducted with the families, utilizing participatory methods to engage the children. These interviews provided insights into the everyday experiences of parents and children with the built environment.

As a participatory method, a guided tour was employed to identify elements of the family's home environment that proved to be supportive or hindering. During this tour, children led two researchers through their own homes, allowing for a participatory and creative exploration and representation of the children's experiences with their built environment. The main task for the child was: "Lead me through your home." Children were given the role of a guide to the researchers, allowing them to freely navigate their surroundings and react spontaneously to the space. If the task was not feasible for the child, parents were asked to assist.

This immersive approach enabled researchers to gain a comprehensive understanding of the families and their home environment, not only in terms of physical details but also in relation to their daily routines, habits, values, and other qualitative aspects that influence the experiences of children affected by stroke. Through one-onone interaction in a familiar space, the guided tour facilitated clear and detailed insights into the families' lives.

The guided tour was documented through photos, notes and floor plan sketches. The following steps were used as a guideline for the photos und notes, based on a study by P. Vermeersch & A. Heylighen [23]:

- a) Situations that are impossible to overcome;
- b) Situations that require assistance;
- c) Situations that require personal tactics;
- d) Situations that can be dealt with independently;
- e) Situations that are comfortable.

These situations demonstrate the varied ways building users encounter and address obstacles, showing that barriers extend beyond mere physical objects. This approach also

acknowledges factors such as personal creativity or assistance in overcoming obstacles. [23]

During the tour, one researcher drew a non-scale floor plan of the family's home and photographed spatial details. Meanwhile, the other researcher asked questions and made notes regarding situations a) to e).

This approach aimed to identify spatial elements that either support or hinder children with stroke within their home environment and in their daily lives. The visits lasted an average of two hours.

## 2.2. Ethical Approval

This study received approval from the Ethical Committee at Technische Universität Dresden (approval number: SR-EK-355082022). Prior to including a child with stroke in the research, children's assent was obtained and written consent was provided by their legal representatives. Participation was voluntary and participating families had the right to refuse or withdraw at any time without facing any consequences.

# 2.3. Participants

This study included participants who 1) had a perinatal or childhood stroke; and 2) were between 4 and 14 years old. Families with children in other age groups or unable to communicate in the languages German or English were excluded. No children were excluded based on their abilities. Recruitment of families was facilitated through the support of the patient organization SCHAKI e.V. In total, fifteen families from Germany were visited in their homes between July 2023 and May 2024 (see Table 1). Among the participants, thirteen children had experienced perinatal strokes, while two had a stroke in later childhood. The children ranged in age from 4 to 13 years old, with an average age of 8.8 years. Of these, nine were girls and six were boys. Seven children had strokes affecting the right hemisphere, six affecting the left hemisphere, and one child was affected on both hemispheres. In the case of one child, it is still unclear whether it was a stroke. The abilities and impairments of the children, as well as assistive aids, were documented using the Housing Enablers Tool developed by I. Iwarsson. [24]

ID	Gender	Age at stroke (y; m)	Age at study (y; m)	Lesion side	Impairments	Assistive Aids
1	female	0; 0	8;4	both	Visual impairment, Incoordination, Hemiparesis	Wheelchair
2	female	0; 0	4; 5	right	Poor Balance, Incoordination, Hemiparesis left	Foot and hand orthosis
3	male	0; 0	9; 9	left	Visual impairment, Incoordination, Hemiparesis right	Glasses, Foot orthosis
4	male	0; 0	6; 7	left	Difficulty interpreting information, Visual impairment, Poor Balance, Incoordination,	Glasses, Foot orthosis

Table 1. Participants' demographics and characteristics.

					Limitations of stamina, Hemiparesis right	
5	male	7; 5	11; 11	right	Visual impairment, Poor Balance, Limitations of stamina, Reduced fine motor skills left: Tremor	Glasses
6	male	0; 0	13; 2	right	Difficulty interpreting information, Poor Balance, Incoordination, Hemiparesis left	Foot orthosis
7	female	0; 6	9;6	left	Difficulty interpreting information, Incoordination, Limitations of stamina Hemiparesis right	Foot orthosis
8	female	0; 0	8; 7	-	Visual impairment, Incoordination, Limitations of stamina, Hemiparesis	Glasses, Wheelchair, Foot and hand orthosis
9	female	0; 0	12; 2	left	Difficulty interpreting information, Visual impairment, Poor Balance, Incoordination, Hemiparesis right	Glasses, Foot and hand orthosis
10	female	0; 0	6; 0	right	Difficulty interpreting information, Visual impairment, Poor Balance, Incoordination, Limitations of stamina, Hemiparesis left	Glasses, Foot orthosis
11	female	0; 0	12; 9	right	Visual impairment, Poor Balance, Incoordination, Limitations of stamina, Hemiparesis left	Glasses, Foot orthosis
12	female	0; 0	9; 9	left	Poor Balance, Incoordination, Limitations of stamina, Hemiparesis right	Foot and hand orthosis
13	male	0; 0	8; 5	left	Visual impairment, Poor Balance, Incoordination, Hemiparesis right	Glasses, Foot and hand orthosis
14	female	0; 0	5; 7	right	Difficulty interpreting information, Visual impairment, Poor Balance, Incoordination, Hemiparesis left	Glasses, Foot and hand orthosis
15	male	0; 0	5; 11	right	Visual impairment, Poor Balance, Limitations of stamina, Hemiparesis left	Glasses, Foot and hand orthosis

### 2.4. Data Analysis

In the floor plan, all important places and elements in the home environment that were discussed with the families were marked. The field notes and maps on floor plans gathered during the guided tour are (re-)read to gain a holistic understanding of what was shown. Data analysis was done manually. Thematic analysis was conducted to categorize the results. The presented results combine a narrative description of observations during the guided tour and characteristics of the home environment.

# 3. Results

The floor plan analysis in Figure 1 were numbered from 1 to 15 according to the table listing the characteristics of the participants.

Firstly, it was observed that families reside in diverse housing arrangements, including rented apartments, townhouses, and single-family homes. It is crucial to recognize that the rental status of certain families may impact the approach to home modifications. Additionally, it was noticeable that modifications in the home ranged from rearranging furniture to remodelling bathrooms to redesigning the flow of the home. Next, the housing modifications will be presented according to the different situations from a) to e).



Figure 2. Floor plan analysis of fifteen homes belonging to children with stroke and their families.

## a) Situations That Were Impossible to Overcome

This chapter addresses situations encountered during the guided tour that proved insurmountable for the children. For example, thresholds and uneven surfaces are mentioned as problems that are hardly manageable for some children with balance issues due to a stroke. Especially unpaved walkways or curbs in the neighbourhood in particular pose a stumbling risk and prove to be impossible to overcome. One parent summed it up: "[...] it's relevant because even a small curb or a stupidly placed stone can cause her to fall. She's not entirely aware of it, but sometimes she also stumble from a standing position."

Another situation that some parents described as nearly impossible to overcome is the staircase in their own home or immediate neighbourhood. During the guided tour, it was noticeable that some children were either carried up and down the stairs by their parents or were only allowed to use the stairs accompanied by their parents for safety reasons. Often, the lack of a second handrail was mentioned as an obstacle, or if the handrail was not at the appropriate height for children. It was noted also that carrying up and down the stairs will no longer be possible as the children grow taller, and it is uncertain how this situation will be managed in the future. Some parents stated that despite knowing about their child's stroke and uncertainty about whether they could walk or climb stairs, they moved into a house with stairs.

One parent expressed concern about how difficult it is to find a playground where their child can play without barriers: "What we've really noticed in recent years is that outdoor playgrounds are a real issue. It's a real horror to even find a playground where a child can go up the stairs without a climbing ladder or without these colourful climbing stones. It's really extreme. [...] It starts right here in the village. He doesn't want to go there anymore. I can no longer lift him up [...] and climbing up just doesn't work. [...] But I think it's actually such a simple issue. It doesn't always have to be a ladder, stairs are for all children. It's nothing special as an aid, it's really there for everyone."

The subsequent chapter discusses situations where help is needed with daily activities due to the challenges mentioned.

## b) Situations That Require Assistance

Many parents described dressing as difficult or something their children couldn't handle without assistance: Until last year, she only wore leggings because it wasn't possible to undo a button [...] she practised that in rehab. For other children, undoing and fastening a button is a banal thing and for her it took a few physiotherapy lessons to do it." or "He still needs a bit of help putting on clothes, like a T-shirt, because he can't get out of it with his right arm on his own. He needs help with that. Or getting dressed on his right side. "During the guided tour, benches for dressing were often found in the entrance area. Especially when dressing, it was often mentioned that sufficient space is needed, as well as for storing aids such as orthoses, etc.

Activities requiring both hands often required assistance, such as dressing, tying shoelaces, washing hands, or opening a yogurt pot, and so on: "She couldn't make herself a sandwich, she couldn't open a yoghurt pot [on her own]. These are such trivial little things, she couldn't do them. [...] Actually, she really needs someone around her all the time in every situation."

During the guided tour, it was observed that kitchen aids such as one-handed cutting boards and one-handed plates were frequently used for cutting or spreading bread, as well as aids for opening jars and bottles. Especially in children whose fine motor skills were affected by the stroke, these aids were often used. However, one parent emphasized clearly: "As many aids as necessary, as few as possible."

Everyday tasks like blow-drying hair, tying a braid, or brushing teeth posed a challenge, as these are all bimanual activities and are often not possible without assistance or aids. Some children with stroke describe difficulties when using the toilet, as they have trouble overcoming both the height of the seat and maintaining balance. Flushing and the toilet paper holder are often positioned on the inappropriate side for children with hemiparesis, making them difficult to reach.

To encourage the children's two-handed use, a climbing wall was integrated into some families' homes to provide the opportunity to promote and rehabilitate the impaired hand.

# c) Situations That Require Personal Tactics

For example, situations like opening door handles sometimes required personal strategies. One family reported that they wrapped door handles with a rope for a period of time to make it easier for the child to open and close the doors. Due to limited fine motor skills, the child was unable to turn the hand to open the door. A parent mentioned: *"That she uses her left hand at all and brings her hand into play is something we also practiced intensively in rehab."* 

It was also remarkable that when asked about their difficulties, children had developed their own strategies and tactics to cope, or they did not perceive obvious difficulties as such (see Situation d).

Another individual approach was to adjust the handling of the impaired body side, or more precisely, one's own mindset regarding it. For example, some children referred to their impaired hand as *"the magic hand"* or *"the favourite hand"*. A hand orthosis, for instance, was also referred to as a "power glove".

# d) Situations That Can Be Dealt with Independently

Situations that can be dealt with independently are aptly described by a quote from a parent: "We paid a lot of attention to ensuring that she can act as autonomously as possible and that we don't put anything in her way [...]" It was remarkable that motor impairments like hemiparesis were not perceived as limitations or barriers by some children themselves. This can be attributed to the fact that 13 out of 15 children suffered a stroke before birth and have had this limitation for their entire lives, so the children do not know any different. For these children, this is their "normality", their "veeryday life". One parent emphasized: "Honey, it's not at all that I want to talk badly about it, it's all good the way it is, [...] I just want to explain it to someone who doesn't experience that every day."

Another example of this perception is when the researcher asked if the child sometimes had difficulty seeing, to which the child replied in the negative. The parent added: "She is half-blind [on the left], that's what I mean by her perception, she doesn't know any other way." and "Since she doesn't know any other way, she is not impaired [according to her perception]".

Consequently, the children perceive themselves as much more independent and show remarkable adaptability to new challenges that daily life presents.

# e) Situations That Were Comfortable

Observations of comfortable situations included the adaption of a handrail at child height on both sides of the stairs, allowing the child to independently navigate the stairs. One family had a custom solution made by a carpenter, where the height of the handrail could be flexibly adjusted to the child's size.

Additionally, the children enthusiastically showed their own rooms during the guided tour. At first glance, these rooms appeared like any other children's rooms, where the children's interests and hobbies were the focus of the design. However, upon closer observation, small adjustments were noticeable, such as tools on the desk, like a scissors for one-handed use, an anti-slip mat, as paper often slipped when drawing and colouring if it could not be held in place with a second hand, ergonomically and tactically adapted pens for a better grip, bookends for reading, or rulers with handles. It was also seen that furniture was adapted for more comfortable use. For example, a desk had a border attached so that papers and pens could not simply fall off. Beds were often floor-level to allow the children to get in and out independently, although it was often mentioned that the children still often slept in the parents' bedroom.

Additionally, a garden or outdoor area in close proximity was highlighted positively during the guided tour.

It was also noteworthy that families mentioned consciously seeking out places where the stroke does not play a role or where the limitation is not noticeable, such as *"directly in the water"* or *"At the rehab clinic in any case. The children's rehab centres are always very nice. Every child is somehow simply accepted as they are, no matter what they have. And because these play areas, the playground itself, are relatively barrier-free and there is something for every type of disability, [the stroke] doesn't really play a role there."* **Comments like these also reflect this observation:***"For us in no place, … but we try to make it as easy as possible for ourselves and intentionally look for places that bring her joy [...]."* 

In summary, this highlights the crucial role of tailored environments in bolstering the comfort and autonomy of children with stroke.

# 4. Discussion

The different situations from a) to e) can be applied to individual areas of the home such as entrance, arrival, kitchen and living area, bathroom, and children's room. Before discussing initial recommendations for these areas, one thing must be considered first: The human scale.

# 4.1. Scale

The human scale is a crucial factor in planning spaces and home adaptations for children. Often overlooked in planning is the fact that children's body dimensions require specific spatial scales and equipment dimensions that differ from those of adults. Not only are children's sight and eye levels neglected, but also their spatial needs, particularly in the case of disability. For example, the grip space of children with hemiparesis is almost reduced by half. Safety aspects for children such as body dimensions in grip heights, window openings, furnishings, etc., also play a role in avoiding injuries and further health complaints.

Furthermore, a clear differentiation between the age groups "child" and "adolescent" is explicitly necessary due to different stages of development and abilities. To make the most extreme comparison: Adolescents have different needs and design requirements than toddlers. Therefore, it is important to consider these differences in planning to meet individual requirements.

# 4.2. Access

The following points must be considered for exterior access areas: Both unpaved walkways or curb edges in the neighbourhood and any thresholds at entry doors, as well as interior doors, pose a tripping hazard for children with balance issues following a stroke. Additionally, these barriers are impassable for children using wheelchairs. Therefore, a step-free transition into the home should be aimed for.

For interior and exterior stairs and steps: To ensure safe use of stairs for children with motor impairments like hemiparesis, handrails should be installed on both sides of the stairs and intermediate platforms (see Figure 3). This provides secure support during use. Handrails for children should be positioned at a height of 65 cm to 75 cm. Solutions that can be adjusted to accommodate children's varying sizes, such as adjustable handrails, are advisable.

Since fine motor skills vary significantly, especially in children with stroke, the design of access elements is crucial. It is recommended to adapt door handles, handrails, and handholds to the ergonomic shape of children's hands and avoid sharp, angular, or excessively hard edges. It is also crucial to consider whether elements are operated with the right or left hand. For example, door handles may pose a challenge for children with left-sided paralysis if the door opens to the right. In case of limited hand or arm motor skills, door handles should be designed for one-handed use and positioned at a height of 85 cm for children. Doors should also open with minimal effort.

# 4.3. Entrance

Especially in the entrance area with cloakroom, there is a need for increased space. This area should accommodate items such as strollers, wheelchairs, or mobility aids like orthoses. It is important to ensure that the manoeuvring space in the entrance area is not restricted by furniture for children in wheelchairs or with mobility aids (see Figure 3).

Seating in the entrance facilitates the bimanual activity of dressing and undressing for children with hemiparesis. Benches with a seat height and depth of 30 cm are suitable for children. Adequate storage space and coat hooks at an appropriate height and shape are advisable.

Additionally, a mirror at child height should be installed in the cloakroom to observe everyday bimanual movements. This allows for incorporating approaches from mirror therapy into everyday home life: By observing movements of the "healthy" arm or leg in the mirror, it creates the impression that the affected arm or leg is moving without difficulty. This visual feedback specifically activates certain brain regions and learning processes. [25]



Figure 3. Identification of barriers and facilitators for access and entrance area.

# 4.4. Kitchen and Living

In children post-stroke, fine motor skills vary, making kitchen equipment design crucial: Kitchen aids like one-handed cutting boards and jar openers are useful. A "learning tower" or stool for kitchen assistance is also helpful, though stability is crucial for children with balance issues. Solutions at child height may be more practical. For balance issues, antislip surfaces on dining chairs are recommended, as well as and chairs with footplates for balance support (see Figure 4).

In the living area, soft flooring materials like carpets or mats are suggested for children with poor balance in order to cushion possible falls.



Figure 4. Identification of barriers and facilitators in the kitchen and living area.

## 4.5. Bathroom

Everyday task such as blow-drying hair, tying a braid, or brushing teeth can be challenging for children post-stroke, as they require the use of both hands (bimanual tasks). This suggests that modifications or assistance may be necessary to help these children perform such tasks more easily or independently, especially in the bathroom (see Figure 5).

When designing the toilet area, it is advisable to include features for stability such as additional handholds, as some children post-stroke may have difficulty maintaining balance on the toilet. It is also important to ensure that the flush and toilet paper holder are reachable from the seated position. For children with left- or right-sided paralysis, these elements should be placed accordingly on their respective side.

Regarding the sink, it is recommended to position the mirror at a height accessible to children. Faucets should be designed as single-lever or touchless. A one-hand soap dispenser should be located within reach near the sink. An electric one-hand toothpaste dispenser also enables single-handed use.

For the shower, prioritize a walk-in design with a non-slip floor covering suitable for bare feet. Handholds in the shower provide additional support and safety. Shower controls such as the faucet and handheld shower ideally should be installed at a height of 85 cm and designed for one-handed use. Additionally, a one-hand soap dispenser is recommended in the shower.

For the bathtub, handholds for entering are helpful. There should be no sloping ceiling above the bathtub as it may hinder lifting children into the tub.



Figure 5. Identifications of barriers and facilitators in the bathroom.

# 4.6. Children's Room

The spatial area of children is by no means limited to the children's room; it encompasses the entire home and the associated outdoor areas. However, as they grow older, the "own room" gains greater significance as an individual spatial area. Children's rooms serve not only as spaces for sleep and retreat but rather as multifunctional areas used for playing, crafting, household chores, reading, socializing with friends, listening to music, and much more. The requirements for these spaces and their furnishings change with the different ages and developmental stages of children who have experienced a stroke (see Figure 6).

As a child progresses through developmental stages, the initially very close bond with parents also loosens. Consequently, the requirements for spatial separation or connection between the areas of children and parents also change. For infants and toddlers, spatial proximity to the parents' sleeping area is advantageous. Depending on possible developmental delays due to a childhood stroke, a direct connection between the areas may also be desirable.

It is advisable not to fully plan children's rooms but to consciously provide furnishings that are changeable or selectable by the child. This allows children to "appropriate" their spatial areas and gain creative experiences simultaneously. Additionally, the design should encourage children to incorporate both hands in playful activities.

Children have a stronger perception of the third dimension than adults. Their view moves not mainly horizontally but rather vertically. Therefore, spatial offerings for children should also allow for a change in perspective and movement in the vertical dimension. Loft beds and platforms offer one possibility here. In combination with a climbing wall, they also promote the two-handed use of children who have experienced a stroke and enable climbing to be integrated into everyday life, as well as for therapeutic purposes.



Figure 6. Identifications of barriers and facilitators in the children's room.

#### 4.7. Strengths and Limitations

The main strengths of this study are that 1) it offered insights into the daily live from families and children with stroke in their home environment and 2) illuminating the significance of the home as a crucial setting for well-being and rehabilitation after stroke.

This research study also has some limitations that need to be mentioned. For example, only a small sample of fifteen families was used. Due to the rarity of the condition, fewer families and children were available for participation and inquiry in the study.

Additionally, the study primarily focused on children who had experienced stroke some time ago. Consequently, home modifications may not have been as pressing or relevant for these families, potentially leading to the oversight of important renovation measures or aids. This also applies to children who experienced stroke and also their impairment before birth, who may not have perceived obstacles in their environment as such, possibly resulting in the oversight of potential barriers.

Also to note is that the children who participated in the study tended to have motor impairments such as hemiparesis and balance issues. This study cannot make statements regarding home modifications for children with cognitive impairments following a stroke.

## 5. Conclusion

The findings of this study offer preliminary insights into the daily challenges faced by children with stroke and their families, illuminating the potential influence of architecture on their health and well-being. This study suggests that the home environment can pose challenges for children following a stroke.

Key insights derived from the family visits include the observation that large-scale renovation measures are infrequently implemented, highlighting the need for costeffective and straightforward solutions. Furthermore, even minor design interventions within the home environment and small everyday aids could significantly enhance the well-being and confidence of children with stroke.

Moreover, recognizing the home environment as a form of therapy and utilizing architectural design to encourage children's movement and development are crucial. Children with stroke are in a constant state of development, requiring adaptable solutions to meet their growth and evolving needs.

Both families and planners stand to benefit from further research into creating home environments that foster the essence of "becoming a child". In conclusion, this study underscores the importance of understanding the nuanced relationship between the built environment and the well-being of children with stroke. Further research in this area is desired to enhance the quality of life for children with stroke and their families.

#### Acknowledgments

The authors express gratitude to the families and their children who participated in the BUILD CARE Study, as well as to SCHAKI e.V., the support group for families of children with stroke, for their assistance in recruiting the families.

Special thanks are extended to our partners within the BUILD CARE Collective for their collaborative efforts in developing the protocol for conducting family visits:

Maja Kevdžija, Birgit Moser, Pleuntje Jellema, Piet Tutenel, Andrea Jelić, Ann Heylighen, Anna Franziska Kalhorn, Magdalena Muszynska-Spielauer, Anna-Theresa Renner, Sophie Mandl and Lisa Bartha-Doering.

Additionally, appreciation is extended to Student Assistant Anna Hella Borsch for her invaluable assistance in organizing family visits, maintaining communication with families, her support during family visits, and for crafting graphical representations.

## Funding

This research was funded by the European Union's Horizon 2020 research and innovation program [EJP RD COFUND-EJP N° 825575], and the Federal Ministry of Education and Research (BMBF) in Germany [01GM2109].

Views and opinions expressed are however those of the authors only and do not necessarily reflect those of the European Union or BMBF. Neither the European Union nor the granting authority can be held responsible for them.

## References

- McKevitt C, Topor M, Panton A, Mallick AA, Ganesan V, Wraige E, Gordon A. Seeking normality: Parents' experiences of childhood stroke. Child Care Health Dev. 2019 Jan;45(1):89-95, doi: 10.1111/cch.12622.
- [2] Gerstl L, Borggräfe I, Felderhof-Müser U, Steinlin M, Heinen F, editors. Pediatric Stroke Manual. Schlaganfall bei Neugeborenen, Kindern und Jugendlichen Stuttgart: Kohlhammer Verlag; 2019.
- [3] Martin C, von Elm E, El-Koussy M, Boltshauser E, Steinlin M; Swiss Neuropediatric Stroke Registry study group. Delayed diagnosis of acute ischemic stroke in children - a registry-based study in Switzerland. Swiss Med Wkly. 2011 Oct 19;141:w13281, doi: 10.4414/smw.2011.13281.
- [4] McGlennan C, Ganesan V. Delays in investigation and management of acute arterial ischaemic stroke in children. Dev Med Child Neurol. 2008 Jul;50(7):537-40, doi: 10.1111/j.1469-8749.2008.03012.x.
- [5] Rafay MF, Pontigon AM, Chiang J, Adams M, Jarvis DA, Silver F, Macgregor D, Deveber GA. Delay to diagnosis in acute pediatric arterial ischemic stroke. Stroke. 2009 Jan;40(1):58-64, doi: 10.1161/STROKEAHA.108.519066.
- [6] Steinlin M. A clinical approach to arterial ischemic childhood stroke: increasing knowledge over the last decade. Neuropediatrics. 2012 Feb;43(1):1-9, doi: 10.1055/s-0032-1307449.
- [7] Goeggel Simonetti B, Cavelti A, Arnold M, Bigi S, Regényi M, Mattle HP, Gralla J, Fluss J, Weber P, Hackenberg A, Steinlin M, Fischer U. Long-term outcome after arterial ischemic stroke in children and young adults. Neurology. 2015 May 12;84(19):1941-7, doi: 10.1212/WNL.000000000001555.
- [8] Gomes A, Rinehart N, Greenham M, Anderson V. A critical review of psychosocial outcomes following childhood stroke (1995-2012). Dev Neuropsychol. 2014;39(1):9-24 doi: 10.1080/87565641.2013.827197.
- [9] Bartha-Doering L, Novak A, Kollndorfer K, Schuler AL, Kasprian G, Langs G, Schwartz E, Fischmeister FPS, Prayer D, Seidl R. Atypical language representation is unfavorable for language abilities following childhood stroke. Eur J Paediatr Neurol. 2019 Jan;23(1):102-116, doi: 10.1016/j.ejpn.2018.09.007.
- [10] Fox CK, Fullerton HJ. Recent advances in childhood arterial ischemic stroke. Curr Atheroscler Rep. 2010 Jul;12(4):217-24, doi: 10.1007/s11883-010-0113-8.
- [11] Grover KS. The self-directed learning experience of mothers whose child has had a paediatric stroke, International Journal of Lifelong Education, 2014, 33:4, 488-503, doi: 10.1080/02601370.2013.876558.
- [12] Wales L, Dunford C, Davis K. Following severe childhood stroke, specialised residential rehabilitation improves self-care independence but there are ongoing needs at discharge. *British Journal of Occupational Therapy*. 2020;83(8):530-537, doi:10.1177/0308022619894870.
- [13] Soufi S, Chabrier S, Bertoletti L, Laporte S, Darteyre S. Lived experience of having a child with stroke: A qualitative study. Eur J Paediatr Neurol. 2017 May;21(3):542-548, doi: 10.1016/j.ejpn.2017.01.007.
- [14] O'Keeffe F, Ganesan V, King J, Murphy T. Quality-of-life and psychosocial outcome following childhood arterial ischaemic stroke. Brain Inj. 2012;26(9):1072-83, doi: 10.3109/02699052.2012.661117.

- [15] Kylén M, von Koch L, Wottrich AW, Elf M. Living with the aftermaths of a stroke in the era of the COVID-19 pandemic; the significance of home and close surroundings. Health Place. 2022 Jul;76:102852, doi: 10.1016/j.healthplace.2022.102852.
- [16] Marcheschi E, Von Koch L, Pessah-Rasmussen H, Elf M. Home setting after stroke, facilitators and barriers: A systematic literature review. Health Soc Care Community. 2018 Jul;26(4):e451-e459. doi: 10.1111/hsc.12518.
- [17] Butterworth G, Hopkins B. Hand-mouth coordination in the new-born baby. British Journal of Development Psychology 6, 1988: 303-314, doi: 10.1111/J.2044-835X.1988.TB01103.X.
- [18] Rochat P. Self-perception and action in infancy. Exp Brain Res. 1998 Nov;123(1-2):102-9, doi: 10.1007/s002210050550.
- [19] Mavros P, Dalton R, Kuliga S, Morad M, Robson S, Hölscher, C. Architectural cognition cards: a cardbased method for introducing spatial cognition research and user-centred thinking into the design process. Architectural Science Review. 2021 65. 1-18, doi: 10.1080/00038628.2021.2008299.
- [20] Chou YJ, Tversky B. Changing Perspective: Building Creative Mindsets. Cogn Sci. 2020 Apr;44(4):e12820, doi: 10.1111/cogs.12820.
- [21] Ramioul C, Tutenel P, Heylighen A. Reflections on Methods for Exploring Children's Encounter with the Urban Environment. In: Langdon P, Lazar J, Heylighen A, Dong H, editors. Designing for Inclusion: Springer; 2020. p. 107-114, doi: 10.1007/978-3-030-43865-4\_11.
- [22] Ostroff E. Mining Our Natural Resources: The User as Expert. Innovation, the Quarterly Journal of the Industrial Designers Society of America. 1997.
- [23] Vermeersch PW, Heylighen A. Mobilizing disability experience to inform architectural education. Lessons learned from a field experiment. Engineering 4 Society. 2015 June, doi: 10.1109/Engineering4Society.2015.7177899.
- [24] Iwarsson S. The Housing Enabler. An Objective Tool for Assessing Accessibility. British Journal of Occupational Therapy. 1999;62(11):491-497, doi:10.1177/030802269906201104.
- [25] Altschuler EL, Wisdom SB, Stone L, Foster C, Galasko D, Llewellyn DM, Ramachandran VS. Rehabilitation of hemiparesis after stroke with a mirror. Lancet. 1999 Jun 12;353(9169):2035-6, doi: 10.1016/s0140-6736(99)00920-4.