

# Improving the Quality of Life with Challenging Behaviour through Architecture: A Case Study at a Dutch Very-Intensive-Care Facility

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## ABSTRACT

**Background and aim** – Challenging behaviour, such as aggression towards oneself, others, or objects, arises in interaction with the environment and may prevent individuals from participating in society and enjoying a high quality of life (QoL). Literature suggests that architects can contribute to prevention, by influencing challenging behaviour before rather than after its occurrence. The objective is to explore how architecture can contribute to the quality of life of intellectually impaired (and autistic) individuals showing challenging behaviour (CB).

**Methods** – The case study is based on interviews with residents and care providers, and direct observations of their daily life.

**Results** – Residents turn out to be dependent on the (visual) connection with the care provider and may experience stress from the behaviour of fellow residents. They also may experience stress when faced with unexpected situations and by sensory overload.

**Originality** – The relevance of architecture for CB reduction is new to this particular field of healthcare.

**Practical or social implications** – If these preliminary findings can be confirmed, they provide a basis for developing guidelines to design better environments for intellectually impaired individuals showing CB. Architecture might promote choice in interpersonal distance, by generous floorplans, a variety of spaces, and escape possibilities. Predictability might be enhanced by providing visual overview and previews into rooms. Finally, architecture that promotes sensory adjustment might improve the QoL of individuals showing CB by preventing sensory overload, and by doing so, mitigate related behaviours

**Type of paper** – Research paper.

## KEYWORDS

Architecture, autism, challenging behaviour, intellectual impairment, quality of life.

## INTRODUCTION

In recent years we have seen a lively debate on the best living environments for intellectually impaired individuals showing challenging behaviour, such as self-injury and various forms of aggression towards persons or objects. From an architect's point of view this raises the question how architecture can contribute to creating environments that help reduce such behaviour. Although architecture cannot cure challenging behaviour, it does have impact on the occurrence of particular activities or psychological states (e.g., stress), which in turn affects behaviour.

Challenging behaviour is defined by Emerson (1995) as culturally abnormal behaviour(s) of such intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community services. It includes self-injury and various forms of aggression. The main reasons for showing challenging behaviour include a desire to increase social attention, to escape undesirable situations, to adjust levels of sensory stimulation, or to increase access to preferred objects or activities (Emerson, 1995).

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A high percentage of intellectually impaired people showing challenging behaviour have a diagnosis on the autism spectrum (Carpenter, 2011).

According to Simó-Pinatella et al. (2013):

*“...challenging behavior is one of the largest barriers to ensuring that people with intellectual disabilities [...] are able to participate in the community. These difficulties have become one of the main causes of social exclusion”* (p. 4582).

In the Netherlands, two cases illustrate living conditions bare of dignity, a sense of home, and choice. In 1988, images reached the media of a young woman chained naked to a wall, showing the helplessness of caregivers in handling challenging behaviour. That this helplessness did not vanish became apparent in 2011: videos were published of a Dutch boy chained to the wall in a barren environment. Both persons' quality of life (QoL) improved greatly with a change, not only of their treatment, but also of their living environment (Van Zijl, 1999; Vriesema, 2012). In an effort to prevent individuals from escaping or becoming aggressive, towards themselves, others, or the physical environment, spaces are sometimes made to feel sterile, stripped of a sense of home and in some cases even inhuman. Healthcare organizations tend to respond by trying to contain challenging behaviour through policies and procedures (Farrell, Shafiei, and Salmon, 2010), which may create a chain of risk reduction that compromises the QoL of individuals showing this behaviour:

*“Lack of control over one's [physical, interpersonal and programmatic] environment may lead to a vicious cycle of behavior. Environmental factors lead to an onset of behavior which challenges others, which in turn leads to the person's environment becoming more restrictive (less access to activities, less control etc.). This restrictive environment may in turn lead to an increase in behavior, which may lead to further environmental restrictions”* (Parris and Watson, 2011, p. 30).

This current research is motivated by the hypothesis that besides by appropriate treatment, people's QoL can be enhanced also by architecture. Architecture can be seen as an enabler of prevention, since it affects the occurrence of particular activities or psychological states, and by doing so, mitigates challenging behaviour before rather than after its occurrence. With their research on evidence based design, Roger Ulrich et al. (2008) demonstrated the effect of the physical environment, such as nature views and daylight, on patient outcomes. Moreover, spatial features like crowdedness, lack of privacy, or too much noise directly lead to stress (Mobach, 2009). Stress can also be triggered by an environment that causes uncertainty, lacks control, and presents too much novelty (Sternberg, 2009). At the same time, the physical environment has the potential to affect social relationships and the connection between people by stimulating chance encounters that might lead to a deeper connection (Mobach, 2009). In this context, the built environment is considered one of the most crucial factors influencing a person's QoL (Health Council of the Netherlands, 2009). The World Report on Disability (WHO, 2011) recommends creating enabling environments, environments – physical, social, and attitudinal – that do not disable, but foster participation and inclusion.

As mentioned, an important relation exists between challenging behaviour and the environment (Carpenter, 2011; Farrell et al., 2010). Farrell et al. even state that:

*‘manipulating the environment (physical and cultural) clearly offers one way to reduce CB (challenging behaviour ...’* (Farrell et al., 2010, p. 1649).

However, knowledge seems to be lacking of *how* architecture can contribute to the QoL of intellectually impaired individuals showing challenging behaviour, *how* enabling environments can be created for them.

## METHOD

To gain insight into how architecture can contribute to the QoL of people with an intellectual impairment, and possibly autism, showing challenging behaviour, we conducted qualitative research with a case study at a Dutch very-intensive-care facility. Our research group consists of researchers with backgrounds in architecture, facility management, healthcare, and real estate.

The very-intensive-care facility, in use since 2013, is located in a residential care park. The first author (henceforth, the researcher) designed this facility. Residents whose former living condition, treatment, and behaviour turned into an undesirable dead-lock, can be transferred to the facility, where they receive intensive treatment in small groups. The most stable group of four individuals, living in the facility since its opening five years ago with the highest level of communication skills was selected.

The interviews and observations took place in April/May 2018. During one week, the researcher was part of residents' daily life for observation and to conduct unstructured interviews with two members of the group, seven care providers, and the team manager, all of which was recorded. Five of the interviewed care providers are the group's primary care providers; the others provide care to other groups but function as a stand-in, if necessary. The latter provided insight into differences and similarities with other groups.

Since the members of the group have difficulties expressing themselves or their spatial experiences, only two of the residents were interviewed. A translating care provider was present at the interviews who adjusted questions to the individual's capacities.

All participants were informed on the study, and the fact that the researchers is also the architect of the facility, in written form and orally by the manager and all of them, or their legal guardians, signed consent forms to be observed and interviewed. The transcribed interviews and observations were analysed roughly following the QUAGOL (Dierckx de Casterlé et al. 2011). The findings of the case study were also compared with related work. To enhance the findings' trustworthiness, intermediary findings were discussed with a professional, who works in healthcare and real estate and is also a mother of a child with an intellectual impairment showing challenging behaviour.

The case study is still in progress. Therefore, our preliminary findings need to be confirmed by multiple triangulation.

## RESULTS

The case study is still in process. Therefore, our preliminary findings need to be confirmed by multiple triangulation. However, a first initial analysis shows a few topics that may be relevant.

Residents seemed to be dependent on the (visual or auditory) connection with the care provider. The nearness, visual or auditory, to their care providers provides them a sense of safety. At the same time, they may experience stress from the behaviour of fellow residents. The self-regulation of interpersonal distance, nearness to the care provider and distance from potentially frightful encounters with fellow residents, seems to be crucial for their QoL. The participating care providers also report a need for connection to the resident in visual and auditory sense, since it makes it possible to recognize the state the individual is in. They can immediately make a connection when the resident shows the first signs of stress and influence a possible onset of challenging behaviour.

Also, individuals showing CB experience stress when faced with unexpected situations, e.g. somebody entering a room unexpectedly, not knowing who is behind a door or around a corner. It appears crucial that the residents have overview and see visitors and other residents approaching and see what is happening at the place they are heading toward. Again, overview promotes the visual connection with the care providers and enhances their sense of safety. Not only unexpected situations, but also unexplainable noise, e.g. the gurgling sound of a nearby bath being emptied, may cause fear and lead to an onset of challenging behaviour. Other noises, like screaming and smashing doors may cause stress. Several care providers stated that the transfer of sound between the apartments was often a reason for the onset of challenging behaviour at night.

## NEXT STEPS

To gain deep insight into the group's daily life, more available data will be analysed and interpreted by multiple triangulation. Available data include personal files, incident reports, lists of reparations, and pictures of three different walks through the building. The mix of resident-centred data sources, various methods, and investigators with different backgrounds will provide a rich and credible representation of residents' life in the built environment.

Future research, specifically focused on intellectually impaired individuals showing challenging behaviour, is needed to better understand and confirm the relevance of our current findings. Moreover, empirical research on the similarities and differences between the needs of individuals showing challenging behaviour and the needs of autistic people is recommended.

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### Deltapremie

The 'Deltapremie' or Delta Prize is a new leading research prize in the Netherlands focusing on practice-oriented research by professors. The prize is developed for professors who have managed to repeatedly make a special difference with the social impact of their research over the years. It shows where practice and research can come together in an innovative way. Practice-oriented research has acquired a solid place in Dutch society. Almost 700 professors and more than 3,000 teacher-researchers are currently involved. The starting point of the research is always to find solutions for practice-based problems, also by partnering with practice. In this way, practice-oriented research provides applicable solutions to societal challenges.



An independent selection committee selected the winners. The committee consisted of six experts from Erasmus University Rotterdam, Innofest, Delft University of Technology, Netherlands Study Centre for Technology Trends, and the Association of Netherlands Municipalities. In the report the selection committee tributes Mark Mobach and his research group for the impact that they have on the crossroads of various domains from public transport to mental health. Mobach: "We see the prize as enormous encouragement to continue our research into space and organisation in healthcare, education, offices, and cities together with our partners. We extend our research to areas where there are perhaps fewer financial possibilities, such as research with the arts and frailty."

### Research focus area

With his research group, Prof. Mobach wants to contribute to the best buildings for people and organisations. He does so by devising better space and services in a multidisciplinary setting together with students, lecturer-researchers, Ph.D.-students, and postdocs. Better spaces and services for education, offices, and even cities that stimulate healthy behaviour, better healthcare buildings that reduce stress, but also prisons and stations that better meet the needs of society.