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# How to Study Interactions between Challenging Behaviour and Space? Exploring the Relevance of Routinely Collected Data

**Berit Ann Roos [1]\*, Mark Mobach [2], and Ann Heylighen [3]**

[1]  Institute of Future Environments, Hanze University of Applied Sciences, Groningen, The Netherlands; KU Leuven, Department of Architecture, Research[x]Design, Leuven, Belgium; b.a.roos@pl.hanze.nl; ORCID ID 0000-0002-7340-970X

[2]  Institute of Future Environments, Hanze University of Applied Sciences, Groningen, The Netherlands; m.p.mobach@pl.hanze.nl; ORCID ID 0000-0002-1490-4540

[3]  KU Leuven, Department of Architecture, Research[x]Design, Leuven, Belgium; ann.heylighen@kuleuven.be; ORCID ID 0000-0001-6811-3464

**Abstract: Aim**. This study aims to identify ways that allow studying how intellectually impaired persons showing challenging behaviour interact with space, without impacting their daily lives. **Background**. Research about space that better suits these persons' needs is challenging to conduct, since they may have difficulties expressing themselves verbally and are extremely sensitive towards sensory stimuli. Therefore, researchers collecting data may be disturbing and intrusive, and requires great caution. Tapping into existing data may be a promising alternative. Residential care organisations routinely collect data about residents during their regular work processes, such as personal information and incident registration. Also useful may be routinely collected spatial data, such as drawings and repair reports. This study explores how routinely collected data (RCD) can provide insight into how residents interact with space, without impacting their daily lives. **Methods**. We reflect on the possibilities of using RCD (related to resident or space) based on explorations in the context of a case study at a Dutch very-intensive-care facility. The data were analysed to identify general patterns, such as locations with a high density of incidents/repairs and verified initial findings by member checking with staff. **Results**. The RCD analysed provide a basic and relevant insight into incidents and repairs connected to challenging behaviour. However, most data were neither complete or relevant for analysis. Therefore, we discussed the RCD were with staff and only then it was possible to draw conclusions regarding relevance of RCD and the residents-space interactions. **Conclusions**. Only in conjunction with an extended approach on member checking the use of RCD seems relevant. RCD have little meaning of their own. But the combination of RCD with member checking seems to provide insight into the interaction between residents and space, without interfering with the residents' daily lives.

**Keywords:** Challenging behaviour, intellectual impairment, member checking, routinely collected data, space.

## 1. Introduction

The quality of life (QoL) of intellectually impaired persons engaging in behaviours that challenge is influenced by their physical surroundings (Bradley & Korossy, 2016; Carpenter, 2011). This influence might be even more relevant, since a high percentage of persons with intellectual impairments engaging in behaviours that challenge have a diagnosis

on the autism spectrum, (Carpenter, 2011; Green et al., 2018) and may be more sensitive to sensory stimuli. Since research relating architecture to behaviours that challenge remains underexplored (Casson et al. 2021; Roos et al., 2022), more knowledge is needed on their interrelatedness with architecture. Unfortunately, research with intellectually impaired persons engaging in such behaviours might not be easy to conduct. There are several reasons.

First, intellectually impaired persons engaging in behaviours that challenge may have difficulties expressing themselves in conventional ways. But, although they often find it hard to express themselves and communicate verbally, they do so clearly and eloquently, through the way they interact with their living environment (Bradley & Korossy, 2016; McAllister & Li, 2012).

Second, these persons are extremely sensitive to sensory stimuli. The presence of a researcher may influence these persons and even trigger behaviours that challenge. It could not only create challenging situations for them, which might affect their lives negatively, it may also influence the data.

Third, the researcher may also be affected by the behaviours that challenge. The behaviour may be frightening and even be directed at the researcher, which might influence the researcher and lead to a researcher bias.

Fourth, research involving vulnerable groups, situations, or sensitive contexts, requires significant investments in terms of effort and time (Jellema et al., 2021).

This raises the question how research on the interaction between intellectually impaired persons and space can be conducted efficiently, relevantly, and with minimal impact on their lives. Part of the answer may lie in the use of existing and routinely collected data (RCD). RCD are data collected in various care settings during regular work processes, without a specific research question developed prior to their use (Spasoff, 1999). They are used as tools to improve patient care and transform health research (Benchimol et al., 2015). Examples of RCD are incident reports on aggression of persons engaging in behaviours that challenge towards care providers, repair reports, personal files, and drawings of the building. The advantage of using such data could be that these provide insight into how intellectually impaired persons engaging in challenging behaviour interact with space, with minimal impact on their daily lives. Also, the data can be retrieved relatively efficiently after ethical clearance.

We reflect on the relevance of RCD based on their exploratory use in a case study. Also, we aim to gain insight into the research question on how RCD can help to improve the understanding of how persons engaging in behaviours that challenge interact with space and how this interaction can be studied efficiently, relevantly, and with minimal impact on their lives?

## 2. Theories and Methods
### 2.1 Theories
This paper is based on data sources related to persons and space, and explores their interaction in the context of discovery. To gain an understanding on how we define 'person', 'space' and their interaction in this research they are described here briefly. We use these definitions to categorize and interpret the findings.

Persons: The data sources are related to intellectually impaired persons engaging in behaviours that challenge. Challenging behaviours are common among persons with an intellectual impairment (Embregts et al., 2009). Emerson (1995) defines them as culturally abnormal behaviours of such intensity, frequency, or duration that the person's or others' physical safety is likely to be placed in serious jeopardy. These behaviours can be considered as '*adaptive responses to 'challenging' situations*' (Emerson, 2001) and a way of communicating distress and unmet needs by persons who are unable to communicate in more conventional ways (Bradley & Korossy, 2016; Green et al., 2018). We understand challenging behaviour as a way of communication and as a form of interaction of persons with their (social and physical) environment.

Space: *"Buildings tell stories, if they are allowed"* (Brand, 1995, p.4) and show traces of use and change, which Brand (1995) calls the six shearing layers of change: Site (location); Structure (foundation and load-bearing elements); Skin (exterior surfaces); Services

( working 'guts' of a building); Space plan (interior layout); Stuff (furniture etc.). We mainly focus on the structure, space plan, and stuff (curtains, garbage bins or shower hoses etc.). Every building consists of a border, a space outside, and a space inside, which are connected through an entrance (Hillier & Hanson, 2009). We explore data about the inside space and the entrance.

*Interaction:* Many intellectually impaired persons engaging in behaviours that challenge live in environments that do not meet their needs and affect their QoL negatively (Bubb, 2014). Their interactions with a living environment that does not meet their needs may result in behaviours that challenge (Bradley & Korossy, 2016; NCCMH, 2015), which reflects the stress that the living environment produces in them.

## 2.2 Methods

*Case study setting:* The setting of this case study is a very intensive care work home (VIC) located in a residential care park in the Netherlands and in use since 2013 (Figure 1). The VIC, designed by the first author (henceforth 'the researcher'), consists of five apartments, housing 24 intellectually impaired persons engaging in behaviours that challenge, hereafter referred to as residents. The VIC offers intensive care to small groups of residents, whose former living condition, treatment, and behaviour turned into an undesirable dead-lock. The study focused on the data collected about one apartment from 2015 until 2020. The appartement was selected in dialogue with the care organisation based on the most consistent occupation of residents.



Figure 1: VIC viewed from the street

*Ethical clearance:* The Social and Societal Ethics Committee of KU Leuven granted approval for this study (No. G- 2018 02 1116). Moreover, the management of the studied care organization has approved the study; the collaboration has been formalized and the use of the RCD has also been formally approved. Finally, the research is also supported by ZonMw (No. 8450006107) and respects prevailing ethical conditions.

*Data collection:* The choice of a specific type of RCD used in this case study was based on the expectation that they would provide insights into the interaction between residents and space. A total of six RCD sources were used, divided into two main datatypes: sources related to residents include personal files of residents; incident reports of aggression from a resident towards care providers; and incident reports of aggression of residents towards themselves, residents, or objects; sources related to spaces include repair reports; architectural drawings; and traces of behaviours that challenge; the latter being photographed during a site visit in May 2018 by the researcher. Retrieving the various RCD required involvement of different stakeholders within and outside of the residential care organisation, such as care department, facility management, and the architectural office that designed the VIC.

*Data analysis:* We explored and tested the selected data sources with respect to their relevance. After further selection, we analysed the architectural drawings to gain an understanding of the design and use of the space. Then, the location of the repairs or traces of behaviours that challenge (photographs) were investigated. Also, we analysed the RCD related to residents to gain an understanding of these persons by reading the personal files and by analysing the incidents: where did the incidents take place, by whom were they caused, whom or what was the behaviour directed at, which reasons were mentioned, and when did the incidents occur?

Then, the RCD were translated into tables and heatmaps, based on the architectural drawings. We explored patterns, such as locations with a high density of incidents/repairs, or hours with a higher frequency of incidents. These initial patterns were examined to see whether they were connected to personal traits or more general patterns. General patterns were considered as preliminary findings.

Finally, during member checking, we interviewed staff members, as witnesses or victims of the behaviours that challenge during member checking to validate and verify the preliminary findings (Figure 2). The staff members were specifically chosen because of their relevant knowledge, such as two location managers (budget responsibility and overall responsibility for residents and staff of the VIC), a representative of care providers (knowledge of and experience with the residents and their behaviours), and one real estate advisor (expertise in real estate for persons showing behaviours that challenge, also being a mother to a resident engaging in behaviours that challenge).

Member checking can be used to validate, verify, and enhance the trustworthiness of a study (Doyle, 2007). It is a technique of returning an interview or analysed data to a participant and to reduce possible researcher bias (Birt et al., 2016). In this study, member checking was applied to check and improve the validity of RCD findings. This step included several rounds of meetings. The interviews were based on the preliminary findings and transcribed afterwards. The themes resulting from analysis of the transcripts were the basis of another round of member checking to verify them.
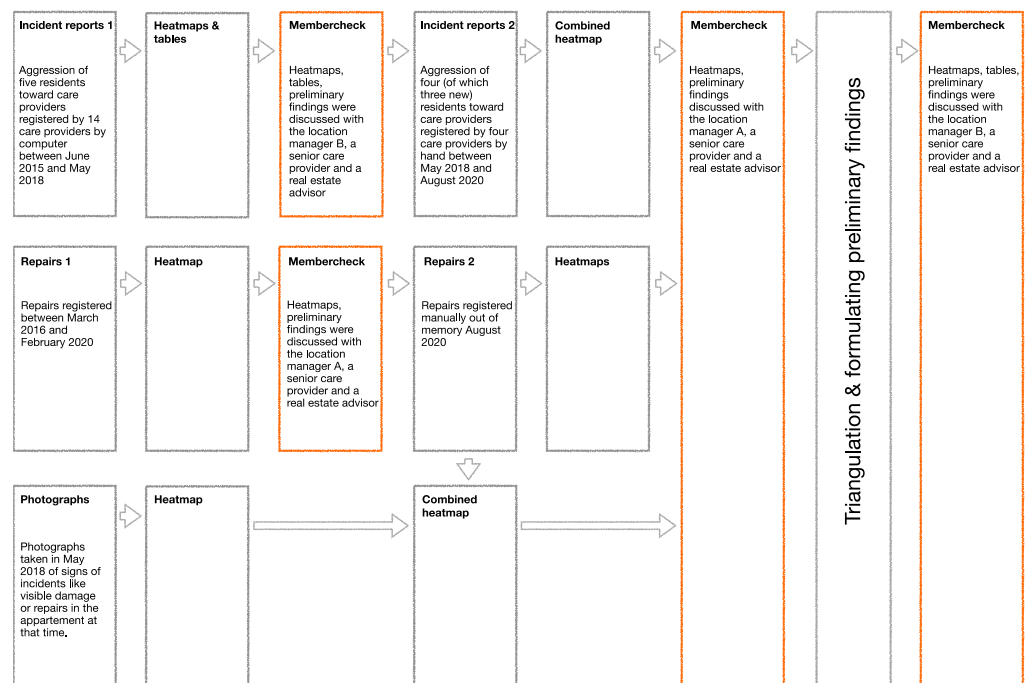


Figure 2: Visualization of the methodology

## 3. Results

This research reflects on two types of data sources: related to residents and related to spaces.

### 3.1. Data related to the residents

*Personal files:* Out of the eight residents living in the four-person apartment during the chosen study period, ethical clearance for personal files of three residents has been obtained. After reading them, it became clear that the included information was mainly related to the resident's history, impairment, treatment plan, and progress. Besides providing an understanding of who the residents are and how they developed, the files included little relevant information that offers insight into the interaction between the resident and space.

*Incident reports of aggression from a resident towards care providers:* Care providers who experience aggression from residents directed towards them, are asked to register these incidents in a software system. This registration consists of answering several questions: name, gender, position, location, and space in which the incident happened, date, time, description of the incident, measures to prevent another incident, and needs to be filled in by the care provider. We analysed and translated eighty-seven incidents into heatmaps (Figure 3) and tables, which showed us at which moments incidents happened, between whom, what happened, and often also gave a general indication of a reason and of the location. But this analysis also raised many questions, such as: why does it happen at this time? What is exactly the cause? Where exactly has it happened? Why are incidents happening here and are they truly happening here? These reports alone provided little insight into the interaction between residents and space, for several reasons: imprecise descriptions of the location, reason, and background of the incidents, and the fact that incidents appear to relocate as they unfold, which complicates an accurate registration. E.g. an incident may start in the living room and then transfer to the resident's bedroom, because the resident runs to barricade himself in there. The location of the incident might then be reported as either living room or bedroom. These imprecise descriptions create difficulties to draw conclusions on why the incidents happened on this specific location and time.
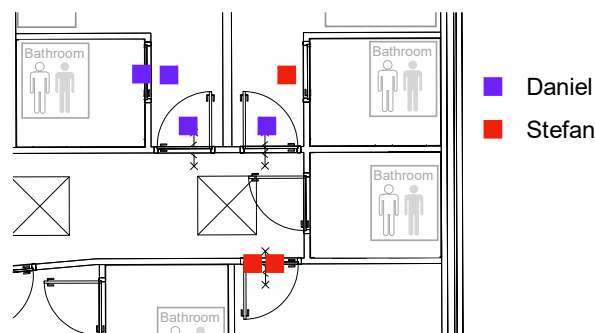


Figure 3: Excerpt of a heatmap showing the location of aggression from a resident towards a care provider (names of the residents are pseudonymized).

*Incident reports of aggression from residents towards themselves, other residents or objects:* These incidents are registered in the daily reports (separate software system) that describe the day of the resident in relation to the treatment plan (part of the personal file). Topics like medication, food, and exceptional behaviour are reported. Exceptional behaviour includes behaviours that challenge. This is only reported if it is exceptional that the resident engages in this specific behaviours. E.g., if a resident regularly tears up a mattrass or clothes, it will not be reported anymore. The fact that only exceptional behaviour is reported creates difficulties to gain insight into the resident-space interaction, since the reports exclude repetitive behaviours that challenge. Also, finding the relevant reports means inspecting all daily reports, which makes their use time consuming.

### 3.2. Data related to space

*Architectural drawings:* We studied the architectural drawings, from the concept to the final floorplans to gain insight in the intention and use of the building. The floorplans were the basis of the heatmaps and considered as starting point to investigate whether changes occurred in the layers 'structure' and 'space plan'. In the context of this study, the traces of behaviours that challenge were considered as changes.

*Repairs:* The repairs consist of two groups: repairs registered in a central registration system and repairs manually recorded by the location manager. In the central registration system, no distinction is made between repairs resulting from regular maintenance and repairs resulting from behaviours that challenge. In the manual registration, all repairs are connected to such behaviours and are paid from a separate budget administered by the location manager. We translated the repair reports into heatmaps, which provided insight into changes in the layers 'structure', 'space plan', and 'stuff' . But they also raised many questions: why were these repairs necessary here? What happened here and why? By what or whom was it caused?

*Photographs:* More than 100 photographs were made by the researcher during a visit, in absence of others. The layers 'structure', 'space plan', and 'stuff' of the spaces were explored (floor, walls, ceiling, and furniture and stuff) to photograph traces of behaviours that challenge (smeared walls, torn curtains, broken glass) (Figure 5). These traces were also translated into a heatmap. They were not self-explanatory either and raised similar questions as the repairs.



Figure 5: Traces of behaviours that challenge: a smeared wall painted over.

### 3.3. Member checking

*Member checking as a validation:* In this case study, member checking was initially intended to validate and verify the preliminary findings. But, during analysis of the RCD it became clear that the preliminary findings from the RCD were insufficient to allow the staff to validate and verify them. The RCD provided basic facts but also raised many questions. Also, the use of the various RCD needed further clarification, for which the staff members' viewpoint was helpful.

*Member checking as a social construction:* Instead of using member checking merely as a technique to enhance the trustworthiness of the findings by presenting staff the analysed data, we were forced to expand its application due to the reported limitations from above. Consequently, we adapted this technique and used it as a way to collaboratively construct and negotiate a possible reality (Doyle, 2007) and present the staff the visualized data (heatmaps, tables, and photographs). In this continuous process, we discussed the use of various RCD and the visualized data related to residents and space with the staff to gain insight into the resident-space interactions and to answer the questions that were raised by analysing the RCD.

*The relevance of various RCD:* The analysis of the files and reports together with member checking revealed that the personal files and incident reports of aggression from residents towards themselves, other residents, or objects were not useful to answer the research question. We scrutinized the remaining RCD and enhanced them with the discussions with the staff in order to gain refined insights into the interactions between residents and space. The incident reports of aggression from a resident towards care providers

needed member checking to clarify and fill in the missing information. The repair reports were not usable without informants clarifying causes of behaviours that challenge. With this clarification, incident reports and repair reports proved to be valuable. Also, the photographs in their reflection of behaviours that challenge were a relevant source.

*The construction of a reality:* The questions raised by the preliminary findings of the incident reports of aggression from a resident towards care providers, the repair reports, and the photographs were discussed and clarified: e.g., why do so many incidents occur here, or none at all? Does this correspond to what really occurred? What causes these repairs? Why is one door lock broken more frequently than others? Why do more incidents occur at certain times/days/months/years? What has not been captured in the preliminary findings?

The RCD proved to provide basic facts but also to have little value of their own. Only in conjunction with member checking, used to collaboratively negotiate and construct a reality, they did provide insight into the interactions between residents and space.

## 4. Discussion

This paper aims to gain insight into how RCD can help to improve the understanding of how persons engaging in behaviours that challenge interact with space and how this interaction can be studied efficiently, relevantly, and with minimal impact on their lives?

A important finding of this study seems to be that although RCD provide basic facts, they have little meaning on their own. This is partially due to the fact that the data were not collected with the research question in mind, which also leads to issues like missing variables (Benchimol et al, 2015) or missing data (Marston et al., 2010), which is common for RCD. In this case, some data and variables regarding (the interaction with) space were missing or were not sufficiently recognized as possible influence by the staff and may therefore lead to an unmeasured confounder (Benchimol et al, 2015). Possibly implying that the staff may not recognize the influence of space on the behaviour of the residents. The inclusion of more space related information in the RCD might therefore be useful to gain a better insight into the resident-space interaction.

The goal of member checking was to check, comment on, and approve the preliminary findings by involving staff (Creswell & Miller, 2000; Doyle, 2007), which is one of the goals of this technique (Iivari, 2018). Since the RCD have little value of their own, the staff could not be presented with analysed data. We were therefore challenged to adapt and use member checking with the goal to verify plausibility (Curtin & Fossey, 2007) and collaboratively create and negotiate a reality (Doyle, 2007) and by that create new information (Birt et al., 2016; Iivari, 2018). In line with the findings of Iivari (2018) this study also suggests that member checking may serve different purposes: increasing the validity of research, and/or to invite staff to take part in the research process, co-constructing the research outcomes together with us. During the study the purpose of the member checking shifted from increasing validity only to also co-construct the research outcomes with the staff. In this study, the staff were presented visualised data and, together with us, co-constructed a reality in a cyclical way, until saturation occurred. Therefore indeed, this new information constructed a new and richer image of the resident-space interaction and could also be used to inform the daily practice.

In this triangulation, data were gathered and analysed in multiple ways to explore the topic (Carlson, 2010; Curtin & Fossey, 2007), using data collected from various sources and different times (Torrence, 2012). This engages staff and ensures that the conclusions are not only a reflection of systematic biases of a specific collection method (Maxwell, 2005). RCD, data possibly allowing a more objective view (Aelvoet et al., 2005), in conjunction with member checking, providing insight into the lived experience (Candela, 2019) seem indeed a valuable source to conduct research efficiently, relevantly, and with minimal impact on the lives of the residents.

*Limitations:* This research emphasises the value of using RCD, but also shows the inconsistencies and inaccuracies of their registration, which makes it difficult to draw conclusions regarding the interactions between residents and space. Member checking revealed possible influences on the inconsistencies and inaccuracies: the care providers' work status; individual perceptions of aggression; and exclusion of repetitive behaviours that challenge. Also, this research has been conducted in the Netherlands, at one specific

healthcare institution, in a four-person apartment with a group of eight residents, and a specific set of RCD. Concerning the selection of the apartment, a selection bias cannot be completely excluded. A possible researcher bias is limited, on one hand by the use of member checking, which is "*ensuring that the participants' own meanings and perspectives are represented and not curtailed by the researchers' own agenda and knowledge*" (Tong et al., 2007, p. 356)'; on the other hand, by the use of RCD, which, according to the findings of Aelvoet et al. (2005, p. 271), "*allow an objective classification of cases prior to any knowledge of an endpoint.*" Therefore, the findings may only have value in this context. Given these limitations this paper hopes to present a valuable approach, combining RCD with member checking, which needs to be confirmed by further research, possibly in a different context and with different residents.

## 5. Conclusion

One of the major findings is that only in conjunction with an extended approach to member checking the use of RCD appears to be relevant and valuable. Although some RCD are more usable or relevant than others, in this case the studied data appeared to have little meaning of their own, mainly due to missing data. Member checking allowed adding the staffs' extensive, yet tacit knowledge of the residents spatially-related behaviour to the RCD. The use of RCD in conjunction with an extended approach to member checking appears to be a good technique to include the objective view and the lived experience and may support the collaborative construction of reality. It seems to provide insight in the interaction between residents and space, without interfering with the residents' daily lives.

### Contributor statement

Berit Ann Roos: conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, visualisation, writing - original draft

Prof. Mark Mobach: conceptualization, funding acquisition, methodology, supervision, writing – review & editing

Prof. Ann Heylighen: conceptualization, methodology, supervision, writing – review & editing

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