

Inclusion of Down Syndrome in Architectural Design: Towards a Methodology

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Abstract—This paper develops an in-situ methodology to help architects insure better inclusion of people with Down syndrome all along preliminary phases of the architectural design process, and eventually to the designed space. This methodology first offers architects some design keys in regard of how people with Down syndrome interact with two types of spaces: their personal dwellings and some completely unknown spaces. The methodology then unfolds towards more pro-active inclusion of the participants thanks to playful expression of their feelings and perceptions. This paper discusses how this methodology relates to inclusive and universal design principles as well as prevalent models of disability in architecture.

Keywords-disability; Down syndrome; inclusive design; universal design; methodological framework.

I. INTRODUCTION

This paper tackles the challenge of disability inclusion to architecture, disability considered here as a temporary or permanent condition likely to show up at any time of everyone's life. Statistically speaking, disability affects 15% of the European population [1], i.e. more than 80 millions individuals. Among them, only 20% are disabled from birth, while 80% will experience impairment later in life, as a result of an accident, an illness, ageing or a more temporary condition such as pregnancy [2]. We are therefore all concerned with disability, whatever our current situation.

Architects are yet struggling with the inclusion of disabled people, given the variety of disabilities and the variety of adaptations those disabilities require on both spatial and functional levels. In Belgium, more specifically, norms about persons with reduced mobility (PRM) constitute one of the few frameworks available to help designers integrate the needs of people using a wheelchair or experiencing limited sight. This regulation, yet, does not take into account intellectual (nor auditory) impairments that are thus generally neglected during the architectural design process.

Consequently, this paper aims at offering concrete design tools to architects confronted to the needs of mentally disabled people, and more specifically people affected by Down syndrome. The paper will first aim at studying the impact of architecture on the spatial perception of mentally disabled people. In situ observations of participants evolving through various spaces will provide some useful design keys in that regard. The methodology will then be expanded in order to include those users into a more active encounter

with architecture, providing architects with fruitful information about how people with Down syndrome experience space on a more multisensory level. The paper will close on a theoretical discussion considering prevalent models of inclusion and disability in architecture and how these models should be revised in order to consider people with Down syndrome's sensitiveness as opportunity rather than threat to the architectural design process.

II. STATE OF THE ART

We highlight here two main observations from architectural state of the art. First, as observed by several phenomenologists, architecture suffers some kind of uni-sensoriality hegemony. Architecture, according to these authors, has been reduced through the Modernist era to the sole consequence of visual expression and experience, neglecting the other perceptual senses and consequently deviating from the users' multisensorial realities [3; 4; 5]. This hegemony, authors argue, has impoverished the architectural experience and, as a result, the whole design process [6]. Second, theories of environmental psychology and healing environments suggest that the architectural environment influences the wellbeing, considering architecture either as a factor having a positive (curative architecture) or a negative (disabling architecture) impact on the emotional and physical experience [7; 8].

Building on these two main observations, some authors propose to interact with disabled people and to integrate their perceptions as soon as early stages of the design process [9; 10]. This early integration helps architects consider other users than the "average, six-foot-tall, 20-years-old male, with perfect vision and a good grip" [11 (p. 60.7)], encouraging them to question and reinstate users' multi-sensoriality and sensitivity into their work. In this case, disabled people are considered as experts and become a real source of creativity for designers [10]. The disability is then considered as an opportunity, both for architects who develop new ideas and for disabled people who take part in a process from which they are usually excluded.

This design approach fits the inclusive design theory and its two main principles, i.e. (i) considering the users' and designers' complementarity given their respective specific knowledge and expertise [12] and (ii) re-integrating the users' emotions and reactions in order to design sensitive architecture ensuring their wellbeing [13].

As opposed to this inclusive vision, more traditional approaches characterize disability as a constraint for both

designers and users. Architects indeed sometimes apprehend the norms regarding disabled people rather as obstacles to their creativity [14]. Those traditional approaches, along with their regulations, moreover only consider limited variety of disabilities, not taking into account variations within the same disability. The main studied disabilities are indeed motor impairments and blindness, while intellectual impairments are more rarely addressed, except for autism that has been widely explored. Yet, just like people affected by autism spectrum disorders, people affected by Down syndrome present a remarkable hypersensitivity and a particular spatial perception [15]. Even studies aiming at «turning disability experience into expertise in assessing building accessibility » [16] or at designing multi-sensorial spaces [6] until now remained essentially focused on motor and visual impairments, neglecting the assessment of other peculiar ways to experience space.

The resulting recommendations and designs are thus never perfectly adapted to the intellectually impaired users who can then feel excluded and misunderstood [17]. We therefore formulate the following two research questions:

- How do people affected by Down syndrome perceive space at a multi-sensory level?
- How to set up a specific methodology to approach and leverage Down syndrome's specificities in architectural design?

III. METHODOLOGY

To answer those research questions, we build on a methodology of in-situ observation and interaction with disabled participants as suggested by Nijs and Heylighen [16]. Their methodology consists in considering disabled people as experts of their own peculiar way of experiencing spatiality and architecture. Through several cases studies, these researchers invited groups of disabled people (mainly PRM and blind people) to experience a building and to discuss their own experience verbally, thanks to different keywords suggested by the researchers. While this section will develop how we implemented this methodology, the Results section will come back on how and why this methodology had to be adapted given the communication difficulties of people affected by Down syndrome.

Firstly, we proceeded to the selection of the participants affected by Down syndrome among the residents of a Belgian non-profit association welcoming adults with intellectual disabilities and specifically intended to develop residents' artistic skills. Six participants were eventually chosen on the basis of several criteria such as the sex (to ensure gender parity), the housing type (in order to compare the participants' experience in terms of living with family or living permanently in the residence) or the gravity of their impairment and the impact it could have on their capability to express their experiences and feelings.

Secondly, we conducted two phases of in-situ observations: first the visit of the residents' own dwellings and later the discovery of a public building, a local town hall unknown by the participants. The goal here was to compare the spatial perceptions of people affected by Down syndrome when confronted to familiar vs. unknown spaces. Those two

observation sequences were video-recorded for practical reasons.

At the beginning of the visit of each dwelling, we set up a discussion table in order to collect some basic information such as, for instance, the resident's age or favorite room(s). This stage also helped us create a climate of confidence with the participant and his or her referee (family member or close relative). We then organized a playful activity that consisted in visiting the resident's three preferred rooms and interviewing him or her about his or her felt experience thanks to illustrated cards.

This combination of observation and interview methods, close to the « shadowing » technique, enables the researcher to follow a person in his or her daily activities while asking him or her some questions to complete the observed information [18]. Within this framework, the researcher takes over the role of observer-as-participant, i.e. he or she spends more time observing than participating. This role has several benefits: it is especially adapted for short interviews, it enables real-time filling of observation grids and it ensures transparency of the research goals towards the observed subjects [19]. However, given the brevity of each session (40 minutes in average), a mutual misunderstanding can occur between the observer and the observed person, hence the need to quickly build confidence [19], in particular thanks to the presence of the participant's relatives.

The methodology implemented during the visit of the town hall was rather similar: a few days later, we invited the same six participants to visit three rooms of the town hall, this time chosen by the researcher in order to compare each participant's reactions. The visit of those three selected rooms was made individually, in the meantime the five other participants were guided by a social worker for a photo recreational activity. The pictures taken by the residents as well as drawings produced later are a diverted means of expression completing or confirming the information collected during the individual visits.

IV. RESULTS

A. Design Keys in regard of Space Perception

During the two observation phases, four main phenomena have been observed.

Firstly, the people affected by Down syndrome who took part to this study all experienced some difficulties in identifying the limits between spaces that were not clearly delineated by a physical boundary. In the town hall, the reception and entrance halls were separated by a simple inner bay frame (Fig. 1), but the participants designated those two spaces as one single room. When asked to walk around the reception hall, they indeed systematically travelled both halls, obviously confused by the proximity of two sub-spaces whose functions were insufficiently distinct. Similarly in the case of private dwelling, one participant walked around the living room when asked to delineate the kitchen.

Secondly, and in contrast with the previous point, people affected by Down syndrome who took part to this study paid particular attention to the privacy of a space and how this sense of privacy could delineate one space from another.



Figure 1. Reception and entrance halls separated by an inner bay frame.

During the visits of their dwellings, the participants have always chosen their own bedroom as their favorite room, which underlines their need to have a personal space available. This characteristic could also be observed while experiencing the public building, especially when some residents felt the need to be alone and left in search of some smaller, more comfortable and/or less traveled space to retreat to for some time. In the case of their private spaces (their rooms), privacy did, in spite of its intangible nature, build some boundary between two subspaces. This phenomenon was specifically observed in a bedroom shared by two residents who never crossed the invisible line dividing the room into two individual and appropriated zones.

Thirdly, the participants demonstrated a particular attraction for light, bay windows, illuminated objects and surfaces. This characteristic was observed several times, particularly when participants were asked to point to their favorite object within a room. One of them, for instance, showed us his stereo, occupying a special spot on the windowsill of his bedroom, which was particularly well lit.

Fourthly, our observations revealed the great importance of material landmarks in the everyday-life of the participants, especially in regard of their day-to-day rituals and habits. Those well-known elements, which could be objects, pieces of furniture or even a specific material (local brown stone or piece of fabric), were reassuring to them especially because they reminded them aspects of their daily life and environments. In one of the residences, we visited a living room that had just been rearranged and refurbished. Inside this living room, social workers had left a small wooden table (Fig. 2) greatly appreciated by the participants because it had been crafted by one of the residents. This small table, placed there as a landmark of the previous space configuration, greatly facilitated the occupants' appropriation of this new way of organizing the room. The presence of this recognizable piece of furniture helped the acceptance of a new situation otherwise potentially disturbing.

Besides those four design keys of perceiving space, we have observed two additional mechanisms engaged observed



Figure 2. Wooden table in the living room of one residence: the reassuring landmark easing the space re-organisation and appropriation.

in different settings: the visuo-spatial memory participants developed in regard of everyday spaces, and the multi-sensoriality participants deployed especially in unknown spaces.

When interviewed inside their dwellings, the residents generally looked beyond the current situation and appealed to their memory to describe the space as they generally experience it, rather than describing it in regard of its specificities at the time of observation. For instance, one participant stated that the living room was a place where “*it was dark*” while it was a bright middle of the afternoon at the time. The participant indeed described the room as he usually perceives it in situation of most frequent use, i.e. when he watches TV in the evening, appealing to his visuo-spatial memory instead of his instant capacities of observation.

In the town hall, moreover, participants largely mobilized their five senses to experience space. For example, they relied on their hearing to determine the level of activity of the rooms: one participant said that the entrance hall was “*here, quiet, everything is quiet*” because we were alone in the room, while another one later found the space “*animated*” because several employees were present at the time. We observed that multi-sensoriality was generally only engaged during the discovery phases of a new space or a potentially disturbing environment.

B. Methodological Recommendations

In this section, we summarize adaptations made to Nijs and Heylighen’s methodology [16] in order to make it more suitable to the specificities of mentally disabled people (for which oral expression, for instance, can be a real challenge).

The importance of the referee (family member, close relative or educator) was made really clear during the first phases of “discussion tables” we added to the methodology: this person, acting as mediator between the observer and the observed person, played a crucial role in decoding both stakeholders’ words, intentions and behaviors and in ensuring their mutual understanding. In one particular case, the presence of the participants’ parents turned out to be

essential to « translate » his particular vocabulary mainly composed of onomatopoeias.

Expression of feelings and perceptual spatial experiences were moreover greatly facilitated by the use of four cards illustrated with cartoony human faces, each featuring one of the most widespread human primary emotions (happiness, sadness, nervousness and fear). These cards, chosen with the help of a psychologist specialized in assisting people with Down syndrome, were voluntary simple (free of superfluous details) and limited in their number in order to help participants express their feelings as accurately as possible given their abilities. Participants were nevertheless free to combine several pictures to enrich their answers if necessary. Those cards as suggested by Chase, adequately complement the content usually collected through narrative inquiry [20]. One important preliminary step, when presenting these cards for the first time, was to proceed to the emotions' recognition, i.e. to align our understanding to what the cards meant in the eyes of the participants. For instance, one resident had identified the card of the scared figure as a person "*who winced*", and this definition was therefore used for the rest of those observations. Those cards proved really useful to interact with the participants once on the field, and could efficiently replace the keywords used by Nijs and Heylighen [16] when interacting with people experiencing difficulties with verbal expression.

From an organizational perspective, we visited each room in two phases: first we started interviewing the participant, and then we let him or her walk around the room. During the visit of one dwelling, one of the residents at first refused to sit and to answer our questions. We had to wait until he stopped moving before obtaining a single answer. Organizing the intervention in several, distinct and repeatable phases thus allowed us to progressively channel the resident's attention on our questions. We moreover observed that interviewing each participant separately proved particularly important to avoid participants influencing each other: at one point of the town hall visit all six participants started to interact about the space and the influence of one of them was clearly at the disadvantage of self-expression.

Eventually, considering diverted means of expression, such as photography or drawing for instance, proved very useful to complete some participants' comments.

V. DISCUSSION

Our in-situ observations contribute to an adapted methodology and to design keys useful for architects willing to include people with Down syndrome (their specific needs, their specific ways of experiencing spaces) into preliminary phases of their design processes. Since the results presented here are issued from six participants only, the findings should not be generalized to a larger group. As Kinnaer, Baumers and Heylighen underline in their research about autism, individual preferences play an important role for the perception and appreciation of certain spaces and should not be dismissed [21]. This has proven also true for people affected by Down syndrome, as one of the participants distinguished from the five others by his particular appeal for dark spaces. In this case the participant considered his own

bedroom, indeed rather dark, as his personal shelter of privacy, a space where he could freely unleash his emotions. He therefore associated dark spaces to this personal space, a protective cocoon where he could express himself untroubled.

Down syndrome, as any other mental disability, consequently ought to be considered as a complex condition, characterized by a variety of realities confined to a global medical model [17]. Yet, current theoretical and practical disability frameworks hardly take into account this variability. On the one hand, norms and regulations have the tendency to reduce the user to a single, « representative » profile: even the architectural norms applied to the inclusion of PRM tend to dismiss personal specificities one wheelchair user can develop in regard of another. Theories such as Universal design, on the other hand, intend to transform architecture into some universal product including the diversity of needs of all potential users [22]. Such Universal architecture, by doing so, might even reduce the model of the user and his/her uses, as each Universal user potentially accumulates the incapacities of a larger diversity of users, the design object being consequently reduced to its lowest common possible use [23].

This research is therefore rather in favor of the inclusive model, taking into account the specificities of users and considering them, as much as possible, as creative input. We argue the methodology developed in this paper, favoring playfulness rather than simple consultation of the end-users, might potentially help architects in conducting in-situ research and in gaining knowledge about how specific groups of people with Down syndrome interact with architecture. Participants, considered as experts of their own disability and their own specific ways of experiencing space, might this way contribute to architectural projects more prone to benefit the greatest number of users.

Including participants with Down syndrome as soon as preliminary phases of the architectural design process and empowering them with a certain expertise moreover suggest a possible evolution of current models of handicap in architecture. Disability has originally been considered the result of a medical condition, therefore building the "medical model" of impairment in architecture. This model, focusing exclusively on disability as an illness together with its symptoms, nurtured a hygienist design of specialized institutions. Later, a social model of disability in architecture rather focused on the human being rather than on the mere "patient" and integrated notions such as "*origin, milieu, education, profession, economical position and social status*" to the design of adapted spaces [24 (p. 11), quoted by 25 (p. 19)]. This social model, as a consequence, informed the design of healing environments outside the institutionalized boundaries of the hospitals and proposed living environments "*accommodating people with a social framework and, thus, supporting residents in developing their identity*" [25 (p. 24)].

Following our observations, we would advocate a third model of disability, i.e. architecture considered as a potentially disabling factor. This model, as an extension of the social model, would "*focus on individuality, difference*

(instead of commonality), experience and giving voice to people” [25 (p. 25)], while redefining the role of architecture and the architects.

This concept, introduced by Goldsmith in the context of a research focusing on motor and visual impairments [26], states that architecture can constitute a proper physical barrier as much for handicapped users than for people with temporary limited mobility (injured or pregnant person for instance). This “architectural disability” therefore translates into an uncomfortable and constraining situation for the user, caused by the lack of consideration or anticipation from the designer that wouldn’t, or couldn’t take into account the specificities of a larger group of potential users [8].

We argue this notion of architectural disability extends to any type of disability, including mental ones. In the case of people with Down syndrome, our results suggest that architecture sometimes not only constitutes some physical barrier to one’s mobility, but also a psychological barrier. Unclearly delineated spaces, for instance, can generate loss of reference points, misunderstanding of sub-functions and consequently loss of autonomy and social exclusion.

Architecture and architects therefore have a crucial role to play in terms of avoiding such disabling situations: the design keys and methodology proposed in this paper offer support to architects who wish to deal with this new responsibility.

CONCLUSION

This paper develops a methodology to approach Down syndrome in architectural design, in line with inclusive design theories. The originality of this methodology lies in its early integration of participants and its playfulness, enabling to go beyond simple consultation with users and to value the disability experience as an expertise.

The methodology and design keys suggested in this paper may be suitable to other user profiles, such as people bearers of another intellectual impairment, seniors or children who share some characteristics with people affected by Down syndrome.

Our research also highlights the limits of the current normative frameworks. Nonetheless, the actual lack of consideration for mentally disabled persons compared with other disabilities, like motor impairment, demonstrates the benefits of such a norm. Since a strict regulatory framework would not be an adequate solution, this paper rather paves the way for a toolbox for designers, encouraging them to take into account intellectual disabled people and suggesting them some interaction techniques to reach this goal.

No longer considering disability as a threat or obstacle for architectural design, this work rather suggests that people with Down syndrome experience space with some specific sensitiveness that could be leveraged as a source of creativity for the designer (“disability as opportunity”), while architecture could be considered as a potentially disabling factor for the user (“architectural disability”).

ACKNOWLEDGMENTS

The authors would like to thank all who contributed to this research, in particular the team and residents of “Les Hautes Ardennes” center (Vielsalm, Belgium). The authors also thank Ms. Henry, psychologist at “Cité de l’Espoir” (Andrimont, Belgium), for her advices in carefully choosing the content of the illustrated cards.

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