

A Method for Architectural Inclusive Design: the Case of Users Experiencing Down Syndrome

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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 principles, useful to design smart environments, be they ICT-enabled or not. This paper closes on prevalent models of disability in architecture and how they articulate with the model of “architectural handicap”.

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

I. INTRODUCTION

This paper, an extended version of a previous, shorter publication presented at the conference Smart Accessibility 2017 [1], 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 concerns 15% of the European population, i.e., more than 80 millions individuals [2]. 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 [3]. We are therefore all concerned with disability, whatever our current situation.

Designers are yet struggling with the inclusion of disabled people, given the challenge of end-users’ inclusion into the design process in general, the variety of disabilities and the variety of adaptations those disabilities require on both spatial and functional levels. In architectural design, and 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 who use a wheelchair or the needs of blind people. This regulation, yet, does not take into account cognitive impairments (nor hearing loss) that are thus generally neglected during the architectural design process. Likewise, in ICT related fields, cognitive impairments seem to be less often considered than visual or hearing loss impairments [4].

Consequently, this paper aims at offering some concrete design methodology to architects confronted to the needs of people with cognitive disabilities, and more specifically people with Down syndrome. The paper will first aim at studying the impact of architecture on the spatial perception of people with cognitive disabilities. 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 multi-sensory level.

This paper is structured in five more sections. In Sections II and III, literature review and the resulting research questions are presented. Section IV details the methodology developed in order to conduct the observations. Section V describes the obtained results, presented in four subsections: space perception of participants with Down syndrome (Subsection A), representativeness of those results (Subsection B), handicapping situations (Subsection C) and methodological recommendations for inclusion of Down syndrome in architectural design (Subsection D). Section VI closes 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. Some insights built in this paper might be relevant for universal/inclusive design in ICT related fields.

II. STATE OF THE ART

Since the modernist era, a distance has been created between the architect and the end-user, the latter being considered as some abstract, hypothetical subject required to adjust him-/herself to the designed building [5]. Phenomenologists such as Juhani Pallasmaa argue that this “modernist reductionism”, i.e., this way of conceiving some architectural artifact that “standard” users will encounter mainly in a visual way, has globally impoverished both the professional praxis and the architectural experience [6][7]. In order to re-instate a more inclusive, multi-sensorial approach of architecture (both in its design and experience), some researchers and practitioners have developed since the 70’s some hands-on, participative methodologies. One has to observe that these methodologies, although being well-

meaning initiatives, often remain too distant from architectural practice, or too superficial in their implementation, and therefore still offer considerable room for improvement [8]. Indeed, participation methodologies have generally been implemented either as a way to collect end-users' post-building assessment [9], or as a way to secure users' acceptance at the very late design phases [10], rather than a tool helpful to take into account users' needs and perceptions as soon as the early phases of the design process [11]. This lack of effective upstream frameworks makes it very difficult for architects to integrate laypeople into the design process, and makes it even harder when considering a wider range of end-users, including people with disabilities.

This literature review section is structured into four subsections, starting with some observations about the current state of architectural practice, followed with the challenge of including disabled users into the design process, continuing with the specificities of people with Down syndrome and ending with an overview of how disability could be considered as an expertise, instead as an obstacle to design and creativity.

A. About architecture, end-users and their well-being

We highlight here two main observations from architectural state of the art: the uni-sensoriality and the environmental impact of current architectural design.

1) Uni-sensoriality

As observed by several phenomenologists, most of current architectural design projects are almost exclusively visually designed [7]: architects strive to impress with attractive and pleasing graphical designs, and often invest less efforts into the integration of users' various ways of experiencing space [12][13]. Architecture, authors argue, consequently suffers some kind of uni-sensoriality hegemony [6]. Yet architecture intrinsically is a multi-sensorial experience, since "*qualities of space, matter and scale are measured equally by the eye, ear, nose, skin, skeleton and muscle* [6 (p.41)]." In fact, all our senses interact together and complement each other in order to shape our understanding of the world, and particularly the spatial environment. For instance, the human mind unconsciously associates visual shapes with odors and emotions because "*the most persistent memory of any space is often its smell* [6 (p.54)]." Some authors associate this uni-sensoriality hegemony with an impoverishment of architectural experience and praxis, and retrace its roots to the modernist era where architecture, according to their critical historical analysis, has been reduced to the sole consequence of visual expression and experience, therefore neglecting the other perceptual senses and consequently deviating from the users' multi-sensorial realities [6][14][15].

This focus on sight is even sometimes considered as an "handicap" for the architects themselves [12], as such uni-sensorial approach does not only reduce the human capabilities but also the design opportunities and qualities. The whole body should therefore be considered as a complex

"thinking organ" [16] that combines multiple intelligences such as visual, haptic and kinesthetic ones. Taking into account the complete scope of the human mind and body, phenomenologists argue, aims at avoiding superficial and dehumanized architectural design [6] and at proposing more sensitive and creative projects.

2) Environmental impact

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 [17][18].

According to those theories, architects themselves sometimes accidentally generate discomfort and dissatisfaction feelings for the end-users of their buildings, simply by being unaware of the consequences their "disabling design" might have on people [18]. Most of the time those "architectural disablements" are completely independent of any medical disability end-users might themselves experience, and are rather more fundamentally related to building impediments such as, most commonly, ill-designed stairs or uncomfortable, confined spaces [13]. This is particularly true for a parent, for instance, who might experience difficulties when pushing a stroller through some heavy doors or narrow hallways [13]. As a result, the henceforth "architecturally disabled people" either manage to overcome the obstacles but only with effort and frustration, or simply are prevented to use the building.

B. About the integration of disabled users

Most prevalent approaches characterize disability as a constraint for both designers and users. Considering disability, and the norms associated to it, as obstacles to their creativity [19], most architects rarely expand their effort of integration beyond the simplest form of a user, such as the "*average, six-foot-tall, 20-years-old male, with perfect vision and a good grip* [20 (p. 60.7)]." As a consequence, users experiencing disability (either as a permanent or temporary condition) rarely see their specific needs and perceptions taken into account. This denial of diversity finds its roots as much as the uni-sensoriality hegemony in the modernist quest for economical and aesthetic design, considering only invariant body proportions [21] and predictable users' needs [22].

When relating to existing norms and regulations regarding disabled people, architects are moreover only informed about a limited variety of disabilities, not even considering variations within the same disability. Reference documents and standard procedures, for length and clarity, indeed generally tackle a limited range of bodily (in)capabilities. As a result, over-simplification of their interpretation causes shortcuts from "people with disabilities" to "people using a wheelchair" [21]. One has to observe that the main studied disabilities are actually motor impairments and blindness, while cognitive impairments are more rarely addressed, except for autism that has been

explored [23][24]. The resulting recommendations and designs are thus never perfectly adapted to the users with cognitive disability, whose needs and necessities are misunderstood and excluded [23].

C. About people with Down syndrome

Among the variety of cognitive disabilities one could design for, this paper focuses on Down syndrome, a genetic anomaly linked to the presence of a third chromosome on the 21st pair. This is not an illness per se, but rather a physical and cognitive state of the person expressed by several characteristics like physical appearance, medical fragility, cognitive disability, peaceable temperament and short life expectancy [25][26][27][28].

Among all those specificities shared by people with Down syndrome, some have a direct impact on the way they experiment architectural environments and spaces. First, their small size influence their space perception as their field-of-view is lower than average [26]. Second, because of their premature ageing [27], people with Down syndrome often develop early motor impairments and try to limit their moves, this behavior being yet sometimes counteracted by their curious and playful nature. Third, due to their lack of concentration [28], the presence of a disruptive element can generate trouble and monopolize so much of their attention that they completely ignore other environmental or spatial factors. They are also known to give much importance to rituals and habits in their daily lives, in order to limit the occurrence of such disruptive events. Yet, people with Down syndrome can show high adaptive capacity: after a while, they tend to accept all kinds of situations, even uncomfortable ones. In fact, their affability [28] disposes them to go beyond the drawbacks of one situation and to eventually get used to it.

Eventually, the cognitive disability brings two specific features regarding spatial apprehension. People with Down syndrome are first of all particularly receptive to their multi-sensory experience of space [28]. Similarly to people with autism spectrum disorders [29], people with Down syndrome moreover present a remarkable hypersensitivity and a particular spatial perception that induces spontaneous emotions and instinctive reactions towards some space. This spontaneity and peculiar way to experience space, revealing some of its specificities (qualities and/or defects), could potentially enrich assessment of any building for instance. By doing so, “*turning disability experience into expertise in assessing building accessibility* [30 (p. 144)]” or in designing multi-sensory spaces [7], a concept that has essentially focused on motor and visual impairments until now, could open towards other types of disability such as Down syndrome.

D. About considering disability as an expertise

Encouraging architects to question and reinstate users’ multi-sensory and sensitivity into their work, a few researchers propose to interact with disabled people and to

integrate their perceptions as soon as early stages of the design process [12][31]. The disability is then considered as an opportunity, both for architects who develop new ideas and for disabled people who take part into a process from which they are usually excluded. In this case, disabled people are considered as experts and become a real source of creativity for designers [31]. The literature documents two ways to integrate the disabled people’s expertise in the design process.

1) Disability as specific expertise for disabled users

In this case, disabled users are experts of their own ways of experiencing space and the generated results directly benefit people with similar disabilities. For instance, Tufvesson’s and Tufvesson’s study compares pupils with autism, hyperactivity and Down syndrome and provides some design strategies and environmental factors with positive (e.g., individual desks) or negative (e.g., low acoustical insulation) effects on the work atmosphere [29]. Studying children with learning disabilities thus primarily provides solutions for disabled children.

2) Disability as general expertise for all users

Another approach takes advantage of the expertise of disabled users either to design innovative projects addressing the needs of a larger audience, or to tackle additional challenges of the architectural field in general. A good example of that approach is Penezic and Rogina design of the “Glass House 2001 for a blind man” [32]. Given that transparency and reflection are both unperceivable properties for people with visual impairment, these architects developed technologies so that any user would experiment the building in an equivalent way. As a consequence, the walls are constituted of two layers of glass between which a fluid circulates at different temperatures and speeds, this way mobilizing two alternative perceptual senses, the touch and the hearing. Besides being particularly innovative and inclusive, this ingenious system solves two recurrent problems of glass buildings, i.e., acoustics and thermal insulation.

III. RESEARCH QUESTIONS

Considering people with Down syndrome peculiar multi-sensory and hypersensitivity, we suggest that their spatial experience should be valued as specific expertise and considered as a way to reinstate multi-sensory qualities into architectural design, and to limit “handicapping situations” for end-users. To this end, a methodological framework has to be developed in response to their specific needs and necessities.

This methodological framework will be nurtured by the answers to the following three research questions:

- How do people with Down syndrome perceive space at a multi-sensory level?
- Which “handicapping situations” do people with Down syndrome face?
- How to leverage Down syndrome’s specificities and expertise for architectural design?

IV. METHODOLOGY

To answer those research questions, we build an original methodology of in-situ observation and in-situ interaction with disabled participants, inspired by theories of inclusive design and Nijs' and Heylighen's own research methodology [30].

A. Inclusive design methodologies

Inclusive design theory relies on two main principles, i.e., (i) considering the users' and designers' complementarity given their respective specific knowledge and expertise [33], and (ii) re-integrating the users' experiences, emotions and reactions in order to design sensitive architecture ensuring their wellbeing [16].

Several methodologies share the idea that every user has a "potential equal contribution to the design outcomes" [34 (p. 524)]. For instance, methodologies of co-design and participative design endeavor to overcome the historical denial of end-users by giving them a real voice in the decision-making process.

Nonetheless, this objective is still considered ambitious because it threatens two widespread conceptions: on the one hand, the professional architect seen as the sole legitimate author of architecture, and, on the other hand, the user seen as an obedient spectator, contemplating the building as a piece of art [22]. As a matter of fact, most architects reject unpredictable and creative usages as well as any behavior that deviates from the original design of the building, starting from the premise that "art is the product of individual creativity" [22 (p. 22)].

When such methodologies are nevertheless implemented, a gap might subsist between architect's and end-users' habituses, i.e., between specialized knowledge of architectural practice and unfamiliarity with the architectural design process, that might generate misunderstandings or even conflicts [35]. End-users, although given a voice, might indeed feel disempowered when confronted to the unknown field of architecture, especially when they are asked to participate without being provided with any kind of support or formation [36].

The methodology developed here, inspired by the inclusive design theory and principles, therefore grant special care to the architect/investigator posture and to the support provided to the participants all along its in-situ implementation.

B. Nijs' and Heylighen's research methodology

Given the reluctance towards users' inclusion in general and the limits of current frameworks, Nijs and Heylighen have developed a specific methodology that considers disabled people as experts of their own peculiar way of experiencing spatiality and architecture [30]. Through several cases studies, these researchers invited disabled people to visit a building and to discuss their own experience verbally, thanks to different keywords suggested by the researchers.

The novelty of this approach, compared to classic accessibility assessments, is the creation of four groups, one for each type of disability (motor, visual, auditory and cognitive impairments). The methodology is the same for each group: participants were asked to follow a predefined route across the building while one of them, designated "research assistant", had to fill out a specific evaluation sheet for the group. The collected data are mainly the formalized transcript of participants' oral comments when moving freely in the rooms, and the expression of their feelings about spatial quality and accessibility. Supplemented by some pictures, the resulting evaluation report attests to the group's specific point of view and is then collectively debated with the other groups in order to write the final common report. Eventually, the participants' experience, identified problems and proposed solutions could be communicated to building practitioners and designers.

We believe this methodology works perfectly for three groups out of four, but is only half adapted to people with cognitive impairments, and more specifically to persons with Down syndrome. Indeed, those users undoubtedly show potential expertise in visiting different architectural spaces and in assessing their multi-sensorial qualities, but capturing that information by written and oral comments and debates seems unsuitable. While Subsection IV.C will develop how we implemented our specific methodology, Section V will thus come back on how and why our methodology had to be adapted in regard of Nijs' and Heylighen's one, given the communication difficulties of people with Down syndrome.

C. Implemented methodology

The methodology has been developed iteratively, on basis of two campaigns of observation. This section will first present the test observation and then the main observation, both corresponding to different observation techniques and different roles of the observer.

1) Test observation

A good observation is characterized by a good preparation and requires a well-trained researcher [37]. A first step of our methodology, particularly suggested to architects who would be willing to implement it, is to conduct some test observations in order to practice and to highlight the major elements requiring particular attention, i.e., the main themes of a future observation grid [38].

Before starting our main observations, we thus chose to test and fine-tune a first version of our observation criteria. This first testing phase was conducted in the context of a guided tour organized by a museum for a group of people with cognitive disabilities, including people with Down syndrome. During the visit, the researcher took the role of a complete observer, meaning that the participants had no clue they were observed, and used the "fly on the wall" observation technique [39]. As the name suggests, the observer remains discreet and collects information without

interacting with the observed people. The main advantages are the participants' spontaneity and the possibility to quickly gather data from several persons at the same time.

This first observation expanded our observation grid with some attention points such as emotions, disruptive elements and events as well as particular attention to personal vocabulary. Moreover, this visit of the museum initiated the idea of a playful interaction with the participants, which would go beyond the "fly on the wall" discretion of the researcher but would also offer richer insights in terms of participants' perceptions and emotions. The test observation eventually made us particularly aware of the impact an unknown place, such as a museum, might have on the participants.

2) Main observation

Initiating the main observation, we firstly proceeded to the selection of the participants affected by Down syndrome. Six participants were eventually chosen among the residents of a Belgian non-profit association welcoming adults with cognitive disabilities, and specifically intended to develop residents' artistic skills. Those participants were 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 severity of their disability and the impact it could have on their capability to express their experiences and feelings (Tab. I).

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. Those two observation sequences were video-recorded to ease post comparative analysis. The goal here was to compare the spatial perceptions of people with Down syndrome when confronted to familiar vs. unknown spaces. This choice, inspired by the test observation, was additionally confirmed by two different aspects of the state of the art. On the one hand, the review of Down syndrome's characteristics had informed us about the importance of daily routines and spatial memory [28], and we assumed we would more easily observe the impact of such factors inside some usual environment, i.e., inside the participants' private dwelling. On the other hand, research about disabling architecture shows that handicapping situations generally occur in public buildings [13], which confirmed our choice of unusual environment.

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), invited to join the whole observation in order to ease communication and interaction. We then organized a playful activity, operationalized with the help of two psychologists, which 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

TABLE I. DEMOGRAPHIC PROFILE OF THE PARTICIPANTS HIGHLIGHTING SOME ADDITIONAL SPECIFICITIES

#	Selection criteria				
	Gender	Age	Housing type	Cognitive specificity	Mobility specificity
1	female	25	family house	/	artificial hip
2	female	48	residence	/	slower motion
3	male	27	family house	verbalizes through onomatopoeias	/
4	male	36	family house	/	/
5	male	27	residence	/	/
6	male	49	residence	/	/

follow a person in his or her daily activities while asking him or her some questions to complete the observed information [40]. Within this framework, the researcher takes over the role of observer-as-participant, i.e., he or she spends more time observing than participating, while always clarifying the scientific objectives. 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 [41]. 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 [41], which could mainly be achieved 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 recreational photo activity in order to capture their experience when they were visiting the town hall on their own, in the absence of the observer.

The last step of our methodology was an artistic activity later organized in the drafting room of the day center. Participants were asked to draw or paint the buildings we visited the previous days. They could choose to sketch their private dwelling and/or the town hall from the inside and/or the outside, delivering their personal interpretation of those spaces. The drawings produced, as well as the pictures taken by the residents are an additional means of expression completing or confirming the information collected during the individual visits.

V. RESULTS

The four next sections will present the results of the in-situ observations, starting with factors impacting space perception of participants with Down syndrome and representativeness of those results, following with observations of "handicapping situations" and ending with some methodological recommendations.

A. Space Perception

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

Firstly, the people with 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 for instance, 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 and boundaries 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 with 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. 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, private 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 repeatedly, 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



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

windowsill of his bedroom, which was particularly well lit. This importance of natural light is moreover clearly illustrated by the participants through their drawings of the visited buildings. Most of the time, their representations were rather simple but they always involved drawings of the windows, including specific details such as frames, shadows and/or glazing (Fig. 2).

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 building material (e.g., local brown stone), were reassuring to them especially because they reminded them of aspects of their daily life and environments. In one of the residences, we visited a living room that had just been rearranged and refurnished. Inside this living room, social workers had left a small wooden table (Fig. 3) 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.

Fifthly, spatial perception of the participants was strongly impacted by their personal preferences and areas of interest. During the visits, the participants spontaneously went towards objects or pieces of furniture referring to one of their passions or to an episode of their personal history. For instance, one of the participants' interest for photography influenced his moves in the town hall, his path being essentially oriented towards specific photo frames.

Besides those five keys of space perception, we have observed two additional mechanisms engaged in different settings: first the visuo-spatial memory participants developed in regard of everyday spaces, and second the multi-sensoriality participants deployed especially in unknown spaces. Those two additional phenomena confirm our initial hypothesis stating that comparing familiar and unfamiliar places would reveal different behaviors regarding space perception.



Figure 2. One participant's drawing of the town hall and its bay windows.



Figure 3. Wooden table in the living room of one residence: the reassuring landmark easing the space re-organisation and appropriation.

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 described the room as he usually perceives it in situation of most frequent use, i.e., when he watches TV in the evening, this way appealing to his visuo-spatial memory instead of his instant capacities of observation. Another resident displayed the same memory capacity when he showed us the living room, which was being renovated at the time of the visit. Although all the furniture was stacked in the corner of the room, the participant told us which armchair was his favorite and, even though the room was very quiet, he explained us it was an animated place where he usually spent time with his friend. Compared with other rooms visited with this participant, we observed that he took more time to answer our questions, probably because he was looking for responses in his memories and could/would not rely on his feelings on the fly.

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. Some participants also appealed to kinesthesia and explored almost every inch of the room in order to appreciate the spatial quality of the room before answering the questions of the observer. We observed that multi-sensoriality was generally only engaged during the discovery phases of a new space or a potentially disturbing environment.

B. Representativeness

As mentioned earlier, the results were gathered from a rather limited sample of only six people with Down Syndrome. However, such a qualitative study provides representative results on the condition that the saturation criterion is respected.

The saturation criterion, originating from the social sciences, is “*the point at which no new information or themes are observed in the data* [42 (p.59)],” which means that the size of the sample may be limited to ‘n’ people if the person ‘n+1’ reveals no new essential data compared to the person ‘n’. This theory thus argues that the size of the sample, i.e., the number of observed people, should not be defined by a theoretical number fixed in advance, but should emerge from the research field [43]. The goal here is not to reach any statistical representativeness, but rather to “*reflect at best the possible variety of the testimonies* [44 (p. 58)]” through results built with observed data and confirmed by the forthcoming ones. In this prospect, social scientists use comparative analysis and follow an iterative process, constantly adapting their theory until recurrences reveal some clues of saturation [45].

Practically speaking, we made sure that the saturation point was reached by building a table structuring comparative analysis (Table II), in which the six space perception phenomena and the data provided by each of the six participants (both for their dwelling [D] and for the town hall [T]) were crossed. The idea was to check whether the results were observed in any situation, i.e., whether the saturation point was potentially reached, or if some exceptions remained.

The Table II, presenting a simplified version of this comparative analysis table, uses five symbols:

- “V” represents a phenomenon effectively observed in the dwelling of the resident;
- “O” shows a phenomenon effectively observed in the town hall;
- “X” corresponds to the absence of use of visuo-spatial memory in unknown places;
- “/” refers to the absence of multi-sensorial experience in familiar places;
- “!” indicates an exception, i.e., an unobserved phenomenon where we would have logically expected it to occur.

The theory of saturation is not necessarily opposed to the existence of exceptions and “*the singular fact, the negative cases, the misunderstood or enigmatic phenomena, although they are essential, do not call into question this saturation* [44 (p. 305)].” In our case, all exceptions find a rather simple explanation and some of them even share the same one. In Table II, we thus numbered from 1 to 5 each type of exceptions, for which we will provide below specific explanation.

TABLE II. COMPARATIVE ANALYSIS AND REPRESENTATIVENESS OF THE RESULTS REGARDING THE PARTICIPANTS' SPACE PERCEPTION

Space perception	Participants											
	1		2		3		4		5		6	
	D	T	D	T	D	T	D	T	D	T	D	T
Limits	V	!1	V	O	V	!1	!2	!1	V	O	!3	O
Privacy	V	O	V	O	V	!1	V	!1	V	O	V	O
Light	V	O	V	O	V	O	!4	O	V	O	!5	!5
Material landmark	V	O	V	O	V	O	V	O	V	O	V	O
Individual preferences	V	O	V	O	V	O	V	O	V	O	V	O
Visuo-spatial memory	V	X	V	X	V	X	V	X	V	X	V	X
Multisensoriality	/	O	/	O	/	O	/	O	/	O	/	O
<ul style="list-style-type: none"> - D: in the dwelling - T: in the town hall - V & O: observed phenomena - X & /: logically not observed phenomena - !1, !2, !3, !4 & !5: exceptions 												

In the first case (exceptions !1), two phenomena regarding space perception were not observed in the town hall: troubles with perceiving limits and search for an intimate space or a hiding place, that occurred only for half of the participants. For the other half such phenomenon didn't occur, either because some of them refused to participate when asked to walk around the room or because they were so tired that they remained seated in each room we visited. Under these circumstances, we cannot conclude whether they had difficulties with limits or not, as well as whether they felt the need for privacy or not.

In the second case (exception !2), the third resident did not manifest any problem with the identification of limits in his dwelling. In fact, all the spaces of his private house were clearly delimited by walls and doors, leaving no place for spatial confusion.

In the third case (exception !3), the sixth participant didn't expressed problems with limits in the residence where he stayed. All spaces were not necessarily physically delimited, but the levels of privacy generated some invisible but perceptible boundaries between them. Therefore, the resident clearly differentiated one functional area (e.g., TV lounge) from another (e.g., game corner) even if they were in the same large room.

In the fourth case (exception !4), the visit of the fourth participant's dwelling took place at the end of the day, when it was already dark outside. Obviously, we did not observe anything regarding natural light, but that might have been the case at a different time of the day.

In the fifth case (exceptions !5), the sixth participant did not show any interest for light and even preferred dark spaces, which can seem really surprising. Nevertheless, his appeal for darkness is linked to his character and personal history (see Section VI).

Finally, each phenomenon has been observed at least once for each participant, except for the two dark grey boxes of Table II. Consequently, identical phenomena were observed for each participant, without any new trend when

increasing the sample in size. The results therefore remain representative and respect the saturation criterion, allowing the involvement of small samples of participants in such methodology. However, the compared results also highlight that there is a variety of realities even inside the same disability. Building on this observation, our study suggests reconsidering the prevalent models of disability (see Section VI).

C. Handicapping situations

During the visits, we observed the two most common handicapping situations as defined by Goldsmith, i.e., confined spaces and stairs [13], but also a third one, which is the height of the furniture. Every time, the disabling situation is caused by an incompatibility between the spatial configuration and the users' characteristics.

In the residences, participants shared their rooms with other people and their personal space is reduced to a small area. As a result, nearly all the rooms become common places and there is no specific area really respectful of privacy, which is yet very important for the participants as our observations revealed (see Section V.A). As a social worker told us, when one resident is arguing with others, he or she cannot take refuge in a quiet place to calm down. In order to limit these incidents and to respect the participants' need for privacy, individual bedrooms are recommended as well as several little shelters in different rooms of the residence.

During the visits, we also observed that some participants with minor mobility impairments (e.g., a slight limp) hardly came up and down the stairs. In fact, besides the effort it takes them to climb the stairs, the residents were afraid of losing their balance and falling down. Steps without risers are even scarier and, in her house, one resident had no choice but to slide down the spiral stairs on her back. In our view, the absence of risers is mainly justified by a search for aesthetics but it generates collateral damages like discomfort and fear, which could be easily limited with riders or even avoided with single stories buildings.

As previously mentioned, participants with Down syndrome are small-sized and, thus, the usual height of furniture is generally not suitable for them. For instance, one participant had difficulty in sitting on the kitchen bar stools and lost his balance because his feet did not touch the ground (nor the footrest). Similarly, social workers made some adjustments when providing lower shelves to store the objects that the residents use on a daily basis.

In those three handicapping situations, design choices can have architecture-independent consequences such as discomfort, promiscuity or risk of falling because they are not adapted to the residents' needs. In all cases, simple solutions can be found as soon as architects anticipate the users' specificities, an anticipation that requires a specific methodology.

D. Methodological Recommendations

Compared to traditional approaches, inclusive design requires a meeting with the end-users as soon as preliminary design phases. Critics may argue that considering end-users from the beginning is time-consuming, but on the contrary we believe it saves time in the long term and avoids calling into question projects that are about to be built. Moreover, our observations demonstrate that there are possibilities to get to know the users within a short time (about one hour), which should be considered as an investment rather than a waste of time. However, in order to make the most of the meetings with the users, the designer should be open-minded towards their requests and suggestions, keeping in mind that end-users are experts of their own needs and ways of living. Yet, one has to observe that it is not natural for end-users to take part in the design process by documenting their daily behaviors and expressing their feelings about space. Therefore, we suggest developing renewed forms of interaction (other than simple conversations), such as for instance narrative inquiries, scenario-based approaches, or, as for participants with Down syndrome, playful activities.

The following paragraphs summarize adaptations made to Nijs and Heylighen's methodology [30] in order to make it more suitable to the specificities of people with cognitive disability (for which oral expression and debate, for instance, can be difficult).

To begin with, the importance of the referee (family member, close relative or educator) was made clear during the first phases of "discussion tables" we added to the methodology: this actor, 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 and trust. In one particular case, the presence of the participant's parents turned out to be essential to "translate" his personal vocabulary mainly composed of onomatopoeias. Furthermore, the referee generally took pleasure recounting some anecdotes, which complemented the resident's comments and behaviors and contributed to faster reach the saturation point.

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 well as simply, as possible. 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 [46]. 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 [30] 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 additional means of expression, such as photography or drawing for instance, proved very useful to complete some participants' comments.

VI. 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 space) 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 [24]. This has proven also true for people with 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. Designers willing to replicate the suggested adapted methodology should therefore apply the saturation criterion [42] as a way to capture both specific and shared spatial perceptions.

Down syndrome, as any other cognitive disabilities, consequently ought to be considered as a complex condition, characterized by a variety of realities unfortunately confined to a rather limited global medical model [23]. Yet, current theoretical and practical disability frameworks hardly take into account this variability. In general, end-users' integration is hardly achieved, and reveals even more problematic for architects considering regulations about people with disability as an obstacle to their creativity rather than as a support to their design. Moreover, those 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 [47]. To put it another way, universal architecture goes beyond “design for special needs” and proposes a built environment usable by every user without exception and under all circumstances [18]. 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 designed object being consequently reduced to its lowest common possible use [48].

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. Even thought providing a real voice to end-users, inclusive design still goes with some limitations, such as becoming a danger for disabled users’ autonomy. In some cases, the search for “absolute well-being” leads to the design of spaces perfectly adapted to the users’ needs, at the risk of creating overprotected and aseptic places in contradiction with users’ personal development [23]. In the case of people with cognitive disabilities, there is a need to find a delicate balance between users’ autonomy and prosthetic architecture, i.e., between stimulating users’ empowerment [23] and providing adjustments that ease daily life and counteract impairments [49]. Regarding the height of furniture for instance, most used objects by participants with Down syndrome could be stored on the lowest shelf boards accessible without any help, while a stepladder could be used to reach the highest objects when necessary. In this way, a safe and comfortable environment would be provided on a day-to-day basis and the residents would be encouraged to make punctual efforts and to look for alternative solutions when required.

We argue that the methodology developed in this paper, favoring playfulness rather than simple consultation of the end-users, might potentially help architects conducting in-situ research and gaining knowledge about how specific groups of people with Down syndrome interact with architecture. In our case, a playful approach was favored following the advice of a child psychologist and given the pretty childlike nature of people with Down syndrome, but the methodology should be adapted according to the users’ profile and the type of disability concerned. Therefore, this methodology is characterized by its flexibility and proposes a non-rigid reflexive framework for designers. Furthermore, participants, considered as experts of their own disability and their own specific ways of experiencing space, might in this way contribute to architectural projects more prone to benefit the greatest number of users. As much as hypersensitivity [29], people with Down syndrome’s specific ways to apprehend an architectural space, for instance through higher multi-sensoriality, could equip designers in their perception of end-users’ needs. Whereas universal design aims at the lowest common denominator, inclusive design, we argue, provides more diversified avenues for design exploration.

Including participants with Down syndrome as soon as preliminary phases of the architectural design process, and specifically empowering them with a certain expertise, moreover suggests 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 disability in architecture. This model, focusing exclusively on disability as an illness together with its symptoms, nurtured a hygienist design of specialized institutions. At that time, architects had no responsibility at all regarding exclusion of people with physical and/or mental impairments, whose specificities were identified as the cause of handicap creation [8]. Furthermore, disabled users were supposed to adapt themselves to the built environment whatever their individual characteristics [18]. 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* [50 (p. 11)], quoted by [51 (p. 19)]” to the design of adapted spaces. 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* [51 (p. 24)].” Following this model, some architects became highly conscious about environmental impact on our perceptions; and even managed to use this architectural externality as a design key. For instance, the Maggie’s Centers are well known for their spatial capacity of becoming psychological and moral support for cancer-sick patients, which is enhanced by a welcoming and convivial architecture [52].

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* [51 (p. 25)],” while redefining the role of both architecture and the architects.

This concept, introduced by Goldsmith in the context of a research focusing on motor and visual impairments [13], states that architecture can constitute a proper physical barrier as much for disabled users than for people with temporary limited mobility (injured or pregnant person for instance). This “architectural handicap” therefore translates into an uncomfortable and constraining situation for the user, caused by the lack of consideration or anticipation from the designer that would not, or could not take into account the specificities of a larger group of potential users [18].

We argue this notion of architectural handicap extends to any type of disability, including cognitive ones, as well as any type of design field, including ICT-related 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 (e.g., loss of autonomy, fear of falling or lack of privacy). 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 handicapping situations: the design keys and methodology proposed in this paper offer support to architects who wish to deal with this new responsibility.

CONCLUSION AND FUTURE WORK

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 end-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 cognitive impairment, seniors or children who share some characteristics with people with Down syndrome. However, this methodology should not be applied as it stands for all user profiles, but should remain flexible and adaptable according to their specificities.

Our research also highlights the limits of the current normative frameworks. Nonetheless, the actual lack of consideration for people with cognitive impairment 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 people with cognitive disability 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. This sensitiveness could be leveraged as a source of creativity for the designer (“disability as opportunity”), while architecture could be considered as a potentially handicapping factor for the user (“architectural handicap”).

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