

Student life on the autism spectrum

How the built and social environment affect the experience of living in a student accommodation

Elise Tackx

Thesis submitted to obtain the degree of Master of Science in Engineering: Architecture

Promotor:

prof. Ann Heylighen, PhD

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PROFM

After working a whole year around this topic of how autistic students experience living in their student accommodation, I learned much about how I experienced living in a student accommodation myself. For me these 5 years of going to college and living on my own, were years I really enjoyed. I learned to deal with stressful situations, made friends I want to keep for the rest of my life and developed my own key values. One of these is that I believe all people should have equal opportunities in life, which was one of the factors for choosing this topic. Because of this interest in equality I added the aspect of gender to this thesis. I enjoyed learning many new things about autism, gender, college life and how this is all related to the built environment.

A second factor for choosing this topic was that I was already interested in knowing more about what autism exactly is. This was due one to family members often saying I'm autistic and I wanted to know whether they were making sense, and two the series *Atypical* which showed in a very interesting way the road to independence and social relations of an 18 year-old boy on the high functioning end of the autism spectrum. The series turned out to be very accurate with what I had found in literature. *Atypical* shows a more nuanced image of what autism is, which I liked.

I also would like to thank a couple of people, which helped me in making my master's thesis the way it turned out to be. First of all I would like to thank my supervisor, Ann Heylighen and assistant, Nguyen Lan for guiding me through the whole process and always being positive and critical towards the work I did. Your positive attitude always gave me a boost to work harder. I also want to thank all the participants for making time for me and my research. I really enjoyed listening to your stories. I also thank Stijn Baumers for his willingness to assess my master's thesis.

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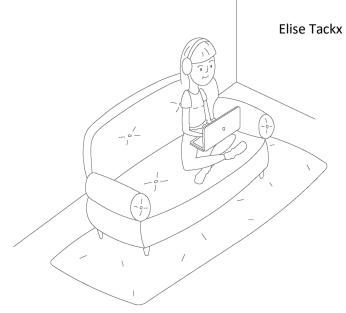


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ABSTRACT

Going to college is a critical transitional phase in becoming independent. Through shared living arrangements students learn to deal with challenges and develop important life skills. During this transition, some students might need different support than others. This master's thesis focus on two dimensions of student diversity, which affect students' interaction with the built environment: neurodiversity (autism) and gender. Autistic people might experience challenges with shared living situations due to their difficulties with social interaction and differences in processing (sensory) information. Moreover, the built environment may embody gender stereotypes and influence how men and women are behaving therein. To gain insight into these dimensions of student diversity, this master's thesis explores how the built student accommodation plays, or can play, out in the lives of male/female autistic students, and how this relates to the social environment. Through a combination of semi-structured interviews with participative methods like photovoice and walk-along interviews, the stories of three autistic students were captured. A qualitative analysis and co-analysis (taking the initial findings back to the participants), resulted in four concepts that offer insight into their experience: independence, (not) feeling at home, shared versus individual space, and finding rest and avoiding stress. Related aspects, that affect their experience are linked to both the social environment and the built environment, and may be of value also for neurotypical students. For a comfortable student life experience, it may be important for autistic students to dare disclosing their differences, which may facilitate making a friend who can guide them. The student accommodation can be supportive by providing spaces that are shared by a limited number of people, and that afford diverse ways of social interaction, by offering opportunities for intensive personalisation, by allowing predictability related to people and the environment, and by ensuring acoustic comfort. Taking these findings back to participants allowed for some to broaden their view about how they would like to live.

Samenvatting

Aan de universiteit studeren is een cruciale overgangsfase op de weg naar onafhankelijkheid. Door het delen van ruimten leren studenten omgaan met uitdagingen en ontwikkelen ze belangrijke vaardigheden voor hun verdere leven. In deze fase hebben sommige andere ondersteuning nodig dan hun medestudenten. Deze masterproef focust op twee dimensies van diversiteit die een impact hebben op hoe studenten interageren met de gebouwde omgeving: neurodiversiteit (autisme) en gender. Studenten op het autismespectrum kunnen moeilijkheden ervaren met samenwonen omwille van hun moeilijkheden met sociale interactie en de manier waarop ze prikkels en informatie verwerken. De gebouwde omgeving kan gender stereotypen belichamen en zo het gedrag van mannen en vrouwen beïnvloeden. Om inzicht te krijgen in deze dimensies van diversiteit, onderzoekt deze masterproef welke rol de gebouwde kot-omgeving speelt of kan spelen in de levens van mannelijke en vrouwelijke studenten op het autismespectrum, en hoe deze zich verhoudt ten opzichte van de sociale omgeving. Door een combinatie van semigestructureerd interviews met participatieve methoden zoals photovoice en walk-along interviews, zijn de verhalen van drie studenten op het autismespectrum vastgelegd. Uit een kwalitatieve analyse en co-analyse (voorlopige resultaten voorleggen aan de deelnemers), komen vier concepten naar voor die inzicht bieden in hun ervaringen: onafhankelijkheid, zich (niet) thuis voelen, gedeelde versus individuele ruimte, en rust vinden en stress vermijden. Gerelateerde aspecten, die hun ervaring beïnvloeden zijn gelinkt aan zowel de sociale als aan de gebouwde omgeving, en soms ook relevant voor neuro-typische studenten. Voor een comfortabele kot-ervaring kan het belangrijk zijn dat studenten op het autismespectrum open durven zijn over hun verschillen zodat ze een vriend kunnen maken die hun begeleidt. De kot-omgeving, kan ondersteuning bieden in de vorm van ruimtes die gedeeld worden met een beperkt aantal mensen en verschillende manieren voor sociaal contact toelaten, mogelijkheden aanrijken voor uitgebreide personalisatie, voorspelbaarheid ondersteunen m.b.t. de omgeving en de menselijke activiteiten, en akoestische comfort bieden. De terugkoppeling van deze bevindingen naar de participanten, verruimde voor sommigen hun visie op het ideale kot-leven.

1. INTRODUCTION

1.1. PROBLEM STATEMENT

In your life you reach different milestones. This can be the first time you laugh, speak or walk. The first time your parents leave you at kindergarten. The first time you make a friend. The first day of preschool or the last day of high school. With each milestone you learn new things and you shape yourself. With graduating from high school a new process starts: becoming an adult. It is a time of making your own decisions, whether or not with the help of your parents or others to guide you in your choices. You decide whether you want to go to college or you want to start working right away. And you decide what you want to study or what work you want to do. These decisions help you shape your future and are first steps towards independence. Learning to become independent is important for many people. Helping you gain this independence, you decide if you continue to live at home or you move abroad. Many students and their parents agree that for developing oneself, living alone in a student accommodation could be an important step in learning to become independent.

The need for independence is also felt by people living with different kinds of impairments or conditions (a visual impairment, a physical impairment, a hearing impairment or a different neurological condition). Young adults and adults with a neurological condition or who are on the autism spectrum also want to be as independent as possible and want to contribute to society in a positive way (Dijkstra 2012). Because a larger number of children on the autism spectrum are able to receive a high school education, compared to before there was an inclusion of students with a disability, and because of the greater awareness of the importance of early intervention, a larger number of young people is better prepared for and interested in attending university (VanBergeijk, Klin, and Volkmar 2008). The autism spectrum consists of a variety of people with different abilities. When time comes, they also choose what they want to study and where, and whether living in a student accommodation is an option. When a student is attending university, different challenges in relation to education, student life and daily (independent) living arise (Van Hees, Moyson, and Roeyers 2015). Stress caused by these challenges can result in mental health problems (most commonly anxiety and depression) and the risk for this happening is higher for students on the autism spectrum. A good support system and preparations help in coping with these issues. This is the reason many students (on the spectrum) live still at home in the first year or take less classes, so that the adaptation to college life can happen gradually (Van Hees, Moyson, and Roeyers 2015).

People on the autism spectrum can have some difficulties with aspects that are linked to living together in a new environment. They may have difficulties with social interactions, may have limited interests and/or may have developed repetitive behaviour (Spek 2014). Living with others means interacting with others, which can be hard. Further autistic people also have a detailed way of processing the environment and they may perceive sensory stimuli differently from neurotypicals¹ (Spek 2014). Their neurological difference has an impact on their functioning in the everyday life. Sensory over- or understimulation, or internal interference can make their everyday experiences difficult and irritating (Kinnaer, Baumers, & Heylighen, 2016; Spek, 2014). The architectural context becomes an important part of the autistic person's life. With this in mind a study of the student

¹ Neurotypicals are people whose cognitive processes are considered typical (Owren & Stenhammer, 2013).

accommodation can give more insight into how architecture is playing and can play a role in autistic students' lives.

In society many different people are living together. This diversity exists in all aspects of life: in ethnicity, age, religion, ability, political believes, sexual preferences and gender. However our world is not (yet) tolerant to all these differences and many people are being treated badly and not to their capabilities. For example we still live in a world where your gender defines your wage, your interests, your value and contribution to society. The world seems to be designed for men by men and this is seen through all disciplines in society. The (white) male body is believed to be the standard, neutral body (Franck & Lepori, 2007). Scientific studies like studies concerning autism are often limited to male subjects (Cridland et al. 2013). Which may be a reason why only 1 woman is diagnosed with autism for every 4 men. Because of this diagnosing system which is based on these male characteristics (Cridland et al. 2013; Mandy and Lai 2017; Pearlman-Avnion, Shlain, & Lowinger, 2019) and because women have developed compensatory strategies and abilities to camouflage their differences (Kanfiszer et al. 2017), women get diagnosed later in life or not at all (Cridland et al. 2013; Mandy and Lai 2017; Pearlman-Avnion, Shlain, & Lowinger, 2019) . The result is that autistic women experience more difficulties later on in life (Dean et al. 2017; Kanfiszer et al. 2017; Mandy and Lai 2017). Through approaching male and female students this research acknowledges the complexity of gender and how your gender can also inflict upon your perception and experience of the world around you.

1.1.1. APPROACH TO DISABILITY

Throughout the 20th century disability was approached as divergence from the norm (Winance, 2007). For this master's thesis I choose to approach the concept of disability as something about differences and not about impairments. Approaching disability as divergence from the norm aligns with an individual/medical model of disability (Heylighen, Van Doren, & Vermeersch, 2013). Disability is seen as an individual, physiological disorder, situated in the person, who has to be treated or cured. A rehabilitation of the 'handicapped' or stigmatised person is foreseen (Winance, 2007). Within this view the stigma of a person can be visible or invisible. People whose stigma is invisible will try to pass as what is seen 'normal'. For example people on the high-functioning end of the autism spectrum will hide their differences (Kanfiszer et al. 2017). Considering disability not as a divergence from the norm but as a result of an interaction between individual, social and physical factors (Winance, 2007) aligns with social/relational/hybrid model of disability (Heylighen, Van Doren, & Vermeersch, 2013). The body is thus seen in a socio-material context with complex interplay between a person's body and the environment or context of the person's actions. A context can then be enabling or disabling, by which the cause of disability is no longer found in an impairment of the person or solely in the disabling situation, but in the interaction between them. According to this idea participation of people in society can be improved by reducing environmental barriers (Owren & Stenhammer, 2013). For example when people in a wheelchair are confronted with a staircase, the problem is not caused by the impairment but by the encounter with the staircase. The aim should be to create a physical environment which is accessible (not only physical) to everyone. This is called universal or inclusive design. In this way an entire population gets addressed instead of a particular target group. By writing about differences the stigma about the disability is discarded. Autism is in this master's thesis approached as a neurological difference and not as a neurological disorder.

1.1.2. TALKING ABOUT AUTISM

Different ways exist to talk about disability or autism. When using particular expressions the semantics are important to consider. For instance, it is disrespectful to refer to disabled people as 'handicapped', 'retarded' or to autistic people as 'autist' (Pellicano, 2015). This contributes to a negative view of disabled or autistic people. A positive and inclusive way is to use a language that does not define people by their disability. A commonly used language is the person-first language, for example a person with autism/ a person who has autism. People use this to emphasize the worth and value of a person. This language describes what a person has and not what a person is. However, because this implies that a person can be separated from their autism, and that behind their autism a 'normal' person could exist, rather than a person whose life is partly defined by being autistic, people on the autism spectrum find this language dehumanising. Many autistic people (and other disabled people) prefer identity-first language, such as 'an autistic person'. In this way the individual's identity as an autistic person is recognised and validated and their autism is not seen as something that can be cured. It is accepting that the individual is different from neurotypical's. A clinically correct way to talk about autism is to refer to it as autism spectrum disorder (ASD), however this lays the emphasis on the disorder. Instead, we could also refer to autism as autism spectrum condition (ASC), implying that you can speak of a neurological difference instead of a neurological disorder. In a study (Kenny et al., 2016) autistic people and their proxies 2 (parents, professionals, family and friends) were asked which language they preferred to use. It showed that several different terms were used and that autism and a person on the autism spectrum were liked by all groups. Being autistic also showed to be highly used. For my master's thesis I choose to use a mix of these different terms to show this diversity in writing about autism.

'Autism is a way of being. It is not possible to separate the autism from the person – and if it were possible, the person you , would have left would not be the same person you started with' (Sinclair 1993, in Owren & Stenhammer, 2013)

1.2. MASTER'S THESIS GOALS & RESEARCH QUESTION

Through this master's thesis I seek to look into how autistic students experience their student accommodation. This research is relevant because more young adults on the autism spectrum will be able to go to college due to early diagnosis, greater awareness and solid interventions (by personal therapist, parents, schools) (VanBergeijk, Klin, & Volkmar, 2008). Looking into their student life allows mapping out, the needs, meaning a combination of social and spatial requirements, of the (autistic) students. Once this is known, it's possible to look into what this means for autistic students living in student accommodation.

To develop an understanding of what it is like for an autistic student to live away from home in student accommodation, I try to find an answer to the following two research questions, which each have their own sub questions.

- 1. What is the role of the built space of the student accommodation in the lives of male/female autistic students (and their housemates)?
 - How do male/female autistic students experience being 'op kot'? What is the role of the built student accommodation in this experience?

² A proxy is a person close to the participant who is impaired (Hendriks, Slegers, & Pieter, 2015).

- How do aspects of the built student accommodation affect social interactions?
- How do aspects of the built student accommodation affect different sensory challenges (over- and under-stimulation and interference)?

With this first research question the experience of the current living situation is looked into. The focus of this research is the experience of the autistic student, while also incorporating the experience of their housemates as well.

This question should bring forward the factors which play a role in living together and how they relate to the experience of 'op kot'. It also should give an answer to what living in student accommodation means and what influence it has on the growing independence of the students. The subquestions help focus on spatial aspects and address the link between the built and social environment.

- 2. How can the built space of the student accommodation play a role in the lives of autistic students (and their housemates)?
 - How can different environment address different sensory challenges (over- and understimulation and interference)?
 - How can aspects of the built student accommodation address social interaction?
 - How do the students describe their ideal shared living arrangements?
 - Show different possibilities for their living environment which work well for the participants and by this providing interesting ideas for others to apply to their own.

The knowledge gathered from the analysis of the first set of data, which is received by answering the first research question, is then implemented as a basis to develop an understanding about comfortable student accommodation for autistic students. The second research question will help in finding the needed information. The subquestions help focus on improvement and things the students like. The results can help autistic students reflect on the choice of their student accommodation and inform architects when designing a student accommodation.

1.2.1. ABOUT THE USED METHODS

A research question about the use of different methods arises. The aim of the research is to generate insights into the student accommodation experience of autistic students. However gaining this insight is not evident. Research about participation of autistic people is mainly focussed on low-functioning autistic people and children. However in this research, I work with higher functioning autistic students. They don't want to be treated differently from neurotypicals, but do experience more difficulties with social interaction and process information differently. On top of this, people have difficulties with expressing how they feel in the built environment. The combination of a) high functioning autistic students and b) the space of the student accommodation, in this qualitative research, made it useful to incorporate different methods when working with the participants.

How do participants experience the chosen methods?

Asking the participants feedback on the used methods and evaluating their interpretation of it, provides insight to formulate an answer for this research question. To obtain a better view on the matter, this research makes use of multi-informants, which gives multiple people's views on one situation. Reflecting on the different methods allows to gather information which could be useful for others in participative research.

1.3. MASTER'S THESIS STRUCTURE

This master's thesis consists of seven chapters which form a whole.

The introduction presents the relevance, the goals and the research questions of this master's thesis. It gives the reader a first impression of what to expect from the other parts of the thesis. The context explains the theoretical basis I started from and shows which concepts are used in the following parts of the research. The methodology explains how I tried to gain insight into how autistic students experience their student accommodation and how the field work unfolded itself. The findings reports on the content analysis of the fieldwork. The discussion chapter reflects on the results and links these to the concepts gathered from literature. The conclusion mentions what can be learned from this master's thesis. At the end the references and the appendix with extra materials can be found.

2 CONTEXT

For this master's thesis I gathered information from literature to gain an understanding of what autism is. The information I gathered serves as a background to my own research. It helped me to develop concepts I found useful when thinking about being 'op kot met autisme'. Because I am interested in the topic of gender, I also looked for literature which approached this from an autistic point of view. The literature is used to help formulate my research questions and to develop an approach to implement concepts in my own research.

This chapter contains following topics: 1) What is commonly understood by the autism spectrum, how this became the concept that it is today, and what characterises people on the autism spectrum, 2) How (autistic) people experience gender and sexes and how this develops in adolescence, 3) How (autistic) people experience college life and living in student accommodation, 4) How the architecture is experienced and what is defined as autism-friendly architecture.

2.1. UNDERSTANDING OF THE AUTISM SPECTRUM (AS)

Autism is a spectrum, meaning that a variety of people within different ranges of capabilities are autistic. Some autistic people will need life-long support, while others will reach for guidance in times of change, like going to college or living independently. Many people on the autism spectrum don't perceive autism as anything negative (Mcgee, 2012; Owren & Stenhammer, 2013). Plenty autistic people consider autism as a part of their identity and regard it as a difference which should be respected rather than a deficiency to be repaired (Owren & Stenhammer, 2013).

The common understanding, however, is that autism is a disorder. Since the introduction of DSM-5³, all autism disorders were redefined as the same, referred to as autism spectrum disorder (ASD) (Spek, 2014). This is a life-long neurobiological condition/ cognitive developmental disorder (Mostafa, 2010; Spek, 2014). Nowadays people are diagnosed on the basis of previously mentioned the DSM-5 (Mostafa, 2010; Spek, 2014). Characteristics are having difficulties with social communication, having limited interests, and repetitive behaviour. Autistic people also have a different sensory experience and have a detailed way of processing the information received from the environment.

2.1.1. HISTORY

Through time the conception about autism has shifted from an infantile psychosis (schizophrenia) to autism spectrum disorder (ASD), a DSM-5 **neurodevelopmental** disorder (Harris, 2018; Verhoeff, 2013). When the concept was mentioned by Leo Kanner in his paper Autistic disturbance of affective contact of 1943 in the Nervous Child journal, it was derived from the first time autism was used by Eugen Bleuler as a primary **symptom of schizophrenia** in 1910. In his paper, Kanner wrote about **children** born with the innate inability to form the usual, biologically provided contact with people. Based on observations of eleven children with 'autistic disturbance of affective contact', the **key features** he described included a lack of communicative use of language, preservation of sameness, restricted interest in activities, and stereotypical and repetitive patterns of behaviour, and he emphasised 'autistic aloneness' (Harris, 2018). In 1944 he introduced the diagnostic term 'early infantile autism' to describe children with features mentioned in his paper of 1943. These features

³ DSM-5 is the latest public version (2013) of the Diagnostic and Statistical Manual of Mental Disorders (DSM). The DSM is an American handbook which is used as standard in psychiatric diagnostics (Spek, 2014).

continued to remain core features of the disorder. In the following table (table 1) can be found how the conception of autism changed through time and how this was implemented in the DSM.

table 1 How autism changed through the different versions of the DSM

year	DSM	changes
1968	DSM-II	Autism classified as 'infantile psychosis' under childhood schizophrenia (Harris, 2018; Verhoeff, 2013)
		Rutter clarified the distinction between autism and schizophrenia in the 1970s (Harris, 2018; Verhoeff, 2013)
1980	DSM-III	New category 'early infantile autism' classified as a pervasive developmental disorder (Harris, 2018)
1987	DSM-III-R	Changing the term 'early infantile autism' into autistic disorder and broadening focus to a wider age range (Harris, 2018)
1994	DSM-IV	Dividing category of pervasive developmental disorder into four subgroups: autistic disorder, Rett disorder, childhood disintegrative disorder, and Asperger Syndrome ⁴ (Harris, 2018)
		Lorna Wing considering Asperger's syndrome as part of an autistic spectrum (Verhoeff, 2013)
2013	DSM-5	Elimination of sub-groups and introduction of autism spectrum disorder (ASD) as a neurodevelopmental disorder ⁵ (Harris, 2018; Spek, 2014; Verhoeff, 2013)

2.1.2. AS AN ASPECT OF DIVERSITY

Since the 1990s autistic people have cultivated the idea of autism as a **neurological difference** (Owren & Stenhammer, 2013). With the neurodiversity movement, autistic people reject that autism is a disorder and defend their right to be autistic. Adding the concept of **neurodiversity** to other existing categories of diversity like ethnicity, age, gender, and sexual orientation, extends the diversity in society (Mcgee, 2012). Studies on the neurobiology of autism have found more support for the hypothesis that people on the spectrum are just different than for the hypothesis that autism is a dysfunction (Owren & Stenhammer, 2013). Being autistic is a fundamental part of who someone is and therefore the differences should be recognised as part of human diversity, which makes autistic people a minority group that needs to be taken into account. An important step in including people in society is addressing environmental barriers. People on the spectrum have sensory sensitivity and processing issues and experience more difficulties when interacting with neurotypicals who fail to understand their needs and behaviours.

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⁴ Asperger syndrome, introduced by Lorna Wing as a new term for Hans Asperger's term autistic psychopathy, was used to describe higher functioning people with social communication deficits. In the same year as Kanner (1944), Asperger described four children with a normal intelligence but who were socially odd and had poor nonverbal communication skills and limited interests (Harris, 2018). He clearly distinguished the children he described from the children Kanner described because he viewed Kanner's early infantile autism as a form of infantile psychosis. However Wing considered Asperger's syndrome as part of an autistic spectrum (Verhoeff, 2013).

⁵ The diagnostic criteria were reduced to two criteria which refer to Kanner's key features 1) social communication deficits, and 2) repetitive patterns of behaviours and restricted activities or interests, while keeping in mind the sensory sensitivities of the people on the autism spectrum (Harris, 2018; Spek, 2014).

2.1.3. PREVAILING UNDERSTANDING

Despite the growing awareness for autism as a form of neurodiversity, a **proper way of diagnosing** autistic behaviour is still required to **ensure autistic people can access the appropriate assistance**. People on the autism spectrum today are diagnosed on the basis of behavioural characteristics through the DSM-5 (Spek, 2014). According to the DSM-5, five domains determine whether someone is autistic.

The five domains according to DSM-5 (Spek, 2014):

- Domain A: Deficits in social communication and social interaction across multiple contexts:
 - Deficits in social-emotional reciprocity
 - Deficits in nonverbal communication used for social interaction
 - Deficits in developing, maintaining and understanding social relations
- Domain B: Restricted, repetitive patterns of behaviour, interests, or activities:
 - Stereotyped or repetitive motor movements, use of objects, or speech
 - Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour
 - o Highly restricted, fixated interests that are abnormal in intensity or focus
 - Hyper- or hyposensitivity
- Domain C: Symptoms must be present in the early developmental period
- Domain D: Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning
- Domain E: These disturbances are not better explained by intellectual disability or global developmental delay.

A diagnosis can be made only if the person meets the three conditions of domain A (social communication) and two out of four conditions of domain B (limited interests and repetitive behaviour). Further criteria to be taken into account include the presence of the symptoms in an early stage of life (domain C), problems in everyday life (domain D) and the clear difference from an intellectual impairment or global developmental disorder (domain E). Additional, autism has a high comorbidity rate (70 to 80.9%) (Buck et al., 2014). This means that autistic people can be diagnosed with other conditions than ASD, for example an intellectual impairment, a language impairment, ADHD⁶ or mental health problems like depression and anxiety (Spek, 2014; Pearlman-Avnion, Shlain, & Lowinger, 2019).

On the spectrum, each domain can show different degrees of severity, which results in a variety of people with different capabilities. For example at two ends of the spectrum high (HF-AS) and low functioning (LF-AS) autistic people can be found (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Pearlman-Avnion, Shlain, & Lowinger, 2019). HF-AS people have cognitive skills within the same range as neurotypicals, enabling them to function in society almost like them. However they have difficulties with social communication, social norms and living up to society's expectations. This leads to difficulties in adolescence and adulthood because communication and interpersonal relationships are crucial aspects of adult life. HF-AS people are in risk of academic and job failure, are more vulnerable to rejection from peers and social isolation, and they experience difficulty when navigating in new and unpredictable (social) environments (Pearlman-Avnion, Shlain, & Lowinger, 2019). Even though these difficulties arise early in life, both children and adults can be diagnosed with ASD (Spek, 2014). Receiving an early diagnosis, however, is considered important for autistic individuals and their

⁶ ADHD (Attention Deficit Hyperactivity Disorder) is a neurodevelopmental disorder. It is characterized by difficulty in paying attention, excessive activity and acting without regards to consequences, which are otherwise not considered appropriate for a person's age.

family to gain access to appropriate support and early interventions so to better prepare them for later life (Cridland, Jones, Caputi, & Magee, 2013; Pearlman-Avnion, Shlain, & Lowinger, 2019; VanBergeijk, Klin, & Volkmar, 2008; Van Hees, Moyson, & Roeyers, 2015). Thanks to early diagnosis a greater number of autistic children are able to consider post-secondary education (VanBergeijk, Klin, & Volkmar, 2008).

Three theories linked to everyday life come up when interpreting these domains: 'Theory of Mind', sensory sensitivity and a detailed way of processing. Each theory explains symptoms of autistic people's daily life, referring to their interaction with other people and with the built environment.

People on the autism spectrum often have difficulties with 'Theory of Mind' (ToM) skills which cause **communication difficulties in everyday life** (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Scheeren, De Rosnay, Koot, & Begeer, 2013). ToM skills denote the ability to ascribe mental states to people and to explain and predict their behaviour in terms of underlying mental states (Varon-Cohen et al., 1985 in Scheeren, De Rosnay, Koot, & Begeer, 2013). HF-AS children and adolescents show a limited ability to infer mental states during social interactions occurring in everyday life, whereas in ToM tests they don't show differences from neurotypical peers. This can be explained because these test don't have the same complexity as there is in everyday social interactions.

Autistic people have a **unique sensory experience** (Kinnaer, Baumers, & Heylighen, 2016). They can be hyper- or hyposensitive or they may experience internal interference (Kinnaer, Baumers, & Heylighen, 2016; Spek, 2014). Hypersensitivity refers to a more intense experience of sensory input. In this case, a person's sensory networks are easily overloaded, which makes it difficult to function properly in sensory rich environments. To get rid of this overload they require a space or activity they may retreat to. Hyposensitivity indicates that a person does not or barely experience sensory input (Kinnaer, Baumers, & Heylighen, 2016). They miss important information their body is telling them. For example they don't feel hungry or thirsty, nor do they experience extreme temperatures. This can be a great danger for their health and safety. Internal interferences happens when sensory experiences get mixed together or a person losses the idea about the boundaries of their body (Grandin, 1995 in Kinnaer, Baumers, & Heylighen, 2016). For example after sitting on a chair for too long, the boundary between body and chair fades out. Another example of this is when they experience a cross-activation of the visual and audio sense, this happens when both sensory systems receive information while only one of them is activated (Robertson & Baron-Cohen, 2017).

The domains above are also linked to how autistic people process information from the environment (Spek, 2014). Their trouble with change is rooted in their **detailed way of processing information**. This analytical, instead of global, level of processing information is linked to a weak drive for central coherence (Jarrold & Russell, 1997). This means autistic people pay attention to things in a more detailed way instead of looking at the global picture. This can be both an advantage, being correct and accurate, and a disadvantage, having difficulties with constructing a global context. A weak central coherence in autism should be viewed as a preference for a particular cognitive style rather than a form of deficit (Frith and Happé, 1994 in Jarrold & Russell, 1997). **People on the AS are looking for predictability through overview and rest by developing routine behaviour and rituals** (Spek, 2014). By avoiding sudden changes they themselves did not implement, they keep control over the situation they are in. Anticipating sudden changes takes time and energy for autistic people.

When helping autistic people become independent, one may consult the following principles, which were developed based on the significant amount of professional experience and knowledge, accumulated over many years in the field (Atsmon, Yaakobi (Gorga), & Lowinger, 2019):

• Don't make assumptions about their daily life skills because gaps between different abilities are common, for example between social skills and motoric skills.

- Use clear communication and clarify situations, so they can prepare themselves in advance and have certainty. This allows them to better understand others despite their social communication deficits.
- Autistic people will need help with planning tasks during their entire life because it is seen that their ability to plan decreases with age. It can help to dismantle a task into smaller parts.
- Encourage their independence by finding the minimum level of necessary support.
- Accept their difference.

2.2. DIFFERENCE BASED ON SEX AND GENDER

I am interested in gender and how the built environment addresses the issue of gender (in)equality. This made me wonder how gender and sex are expressed within the AS and what effect this has on autistic women and girls.

2.2.1. GENDER ROLE & GENDER IDENTITY

People approach sex and gender in different ways. In 1955 John Money and his colleagues made the distinction between biological sex and gender as a role (Muehlenhard & Peterson, 2011). This idea received both support and criticism. Today it is difficult to know what people mean when they write about these two concepts. Biological sex refers to an individual's physical characteristics and gender refers to an individual's psychological characteristics and behaviour. Money introduced the concepts of gender identity and gender role, the first being the private, individual experience of a gender role, the second being the public expression of one's gender identity, everything a person does or says to disclose oneself as a specific sex (Money and Ehrhardt, 1972 in Muehlenhard & Peterson, 2011). These concepts have been developed further since Money's work. According to Gayle Rubin sex is the biological body and gender is the social role imposed on the sexes (Muehlenhard & Peterson, 2011). Rubin's interpretation is visible in the view of social constructivism. Social constructivists advocate that society imposes gender roles and pressures people to conform to the genders they may biologically represent (Muehlenhard & Peterson, 2011; Zahrai, 2015). How people experience gender issues depends heavily on the society, culture or community they live in. Most societies (e.g. Western society) traditionally have a binary gender model representing masculinity and femininity. However according to social constructivism these concepts are artificially imposed (Zahrai, 2015). Developments within the LGBTQ+7 suggest that gender is much more complex and is not limited to this binary gender approach.

Cultures represent gender roles by stereotypical views about masculinity and femininity, which are socially constructed by institutions based on assumptions and sex based patterns (Muehlenhard & Peterson, 2011; Zahrai, 2015). Masculine characteristics are assumed to be rational and action-orientated and are about achieving success through social status, physical look, anti-femininity and intellectual and emotional stigmas. Feminine characteristics are being emotional and caring resulting in conflicts between work and family because of assumptions about motherhood, housekeeping, relations and interaction, and having an attractive appearance. People will automatically compare themselves to these expectations of 'real' men and women (Zahrai, 2015). However some (or even many) people might find out that they don't (want to) fit into these categories and start to question their gender identity based on these gender roles in a more elaborated way. These gender roles remain

⁷ LGBTQ+ is an acronym for *lesbian, gay, bisexual, transgender, queer/questioning and the plus stands for other categories of sexual orientation and gender identity.*

real as long as people keep recognising their existence and they will keep influencing people's gender identity and the way they represent themselves in society. For example, to reflect the stereotypes about dominance and subordination, many women have developed defensive behavioural strategies like representing themselves more feminine, working behind the scenes, mask problems, or developing mothering skills (Zahrai, 2015).

2.2.2. DIFFERENCES WITHIN THE AUTISM SPECTRUM

Women and girls are less often diagnosed with autism than men (Cridland, Jones, Caputi, & Magee, 2013; Kanfiszer, Davies, & Collins, 2017; Pearlman-Avnion, Shlain, & Lowinger, 2019; Spek, 2014). Across the whole spectrum only one woman is diagnosed for every four men. The gap between the sexes at the HF-AS end is bigger than that at the LF-AS end. Women on the AS are also less represented in research, resulting in a conventional male representation of traits within the AS (Cridland, Jones, Caputi, & Magee, 2013; Pearlman-Avnion, Shlain, & Lowinger, 2019). This difference between the sexes leads to two hypotheses: 1) there are fewer autistic women, 2) women are less frequently diagnosed with HF-AS (Pearlman-Avnion, Shlain, & Lowinger, 2019). The first hypothesis suggests that women are biologically protected, that they have better social skills which protect them from traits related to autism, and that women on the AS are more likely to end up at the low functioning end. The second hypothesis suggests that women a) are less likely to be diagnosed, are underdiagnosed or receive an alternative diagnosis for their symptoms, and b) are usually diagnosed later on in life than most men. This is explainable because i) they are less likely to conform to expected traits of ASD (which are based on the male phenotype), and ii) HF-AS women may have developed coping strategies to hide that they are autistic. These two hypotheses show why it is difficult to diagnose (high functioning) autistic girls/women properly (Cridland, Jones, Caputi, & Magee, 2013). Often they are diagnosed after entering adolescence because their coping strategies from childhood aren't sufficient for adolescence interaction.

To address the differences between autistic men and women and recognise both phenotypes, a suggestion can be made to add sub-categories to the current diagnostic tools (Pearlman-Avnion, Shlain, & Lowinger, 2019). Additional characteristics of women on the AS can be associated with gender issues, sensory sensitivity, use of imagination, social masking, imitation of characteristics and preoccupation with socially accepted behaviour and interests.

GENDER IDENTITY AND SOCIAL RELATIONSHIPS

This gender gap within the AS reflects the cultural and social expectations of how men and women socialise (Pearlman-Avnion, Shlain, & Lowinger, 2019). Women on the AS may feel like they don't fit in this stereotypical model of femininity. Autistic women may lose grip on their gender identity because they may feel like their interests lay closer to typically male interests, they may lack an attention to their appearance and they may not feel what would be thought of as feminine (Kanfiszer, Davies, & Collins, 2017; Mandy & Lai, 2017; Pearlman-Avnion, Shlain, & Lowinger, 2019).

To meet these social expectations (high functioning) women and girls have developed **coping or compensatory strategies** (Kanfiszer, Davies, & Collins, 2017; Pearlman-Avnion, Shlain, & Lowinger, 2019). From a young age autistic girls mask their symptoms through memorizing socially acceptable responses, mimicking the social behaviour of others or using linguistic camouflage to gain access to peer groups (Dean, Harwood, & Kasari, 2017; Pearlman-Avnion, Shlain, & Lowinger, 2019). Through

camouflaging these symptoms, which is managed better with a high cognitive functioning (Pearlman-Avnion, Shlain, & Lowinger, 2019), their social interaction problems and difficulties become less obvious to perceive (Mandy & Lai, 2017). That makes autistic girls unnoticed and unable to receive the assistance they need to develop (Cridland, Jones, Caputi, & Magee, 2013; Dean, Harwood, & Kasari 2017).

Qualitative differences in how boys and girls socialize are widely recognized (Dean, Harwood, and Kasari 2017). The way these social interactions happen changes with maturation (Kanfiszer, Davies, and Collins 2017). Looking into how children play, the difference between the interaction of small groups of girls and larger groups of boys shows that boys and girls experience different social environments (Dean, Harwood, and Kasari 2017). Boys form large stable groups where the main activity is doing something and playing games. This makes it easy to notice if someone doesn't play along or is being isolated. Girls, on the other hand, form multiple smaller groups between which they change. In these groups the interaction happens through conversation and intimacy. With aging the complexity of social relationships increases (Cridland, Jones, Caputi, & Magee, 2013). Especially female relationships become more complex trough intimate social communication, where certain skills are expected like reciprocal sharing, emotional support and social problem solving. It is at this moment the autistic girls' deviation from social expectation and non-typical social development (lack of complex social skills) becomes apparent (Pearlman-Avnion, Shlain, & Lowinger, 2019).

Because social interaction issues interfere with communication and not with play and activities, autistic women have a disadvantage compared to their male counterparts in relation to the development and maintenance of friendships (Cridland, Jones, Caputi, & Magee, 2013). They often have limited social connections and most of them have contact only with their family members. They will **avoid social situations, close themselves off and have difficulties with trusting people** (Pearlman-Avnion, Shlain, & Lowinger, 2019). The obstacles in social contact may result in negative experiences, a lack of confidence, possible sexual victimization and the feeling of being perceived as odd or strange (Kanfiszer, Davies, & Collins, 2017). This can effect autistic women's emotional well-being.

Due to coping strategies which make it possible to 1) come close to social expectations about femininity and 2) interact in complex female social interaction, autistic woman experience greater emotional difficulties such as introversion, anxiety, depression and identity confusion (Pearlman-Avnion, Shlain, & Lowinger, 2019). They also experience a higher risk for comorbid psychiatric disorders like mental health problems of anxiety and depression (Cridland, Jones, Caputi, & Magee, 2013; Pearlman-Avnion, Shlain, & Lowinger, 2019).

ADOLESCENCE

Adolescence is a **critical period** for young adults on the spectrum, especially for girls, and their parents (Cridland, Jones, Caputi, & Magee, 2013). It seems like autistic girls don't fit anywhere because, on one side, they are not accepted by neurotypical peers and, on the other side, they are part of a predominantly male autistic world where activities are arranged around the interests of boys. However, many of these girls experience being surrounded by boys as positive because they find them easier to get along with and they may share some common interests.

Parents of autistic girls and boys experience similar difficulties when raising their young adult (Cridland, Jones, Caputi, & Magee, 2013). Times of transition are challenging and when their child reaches

adolescence, their role as parent and guide increases (Cridland, Jones, Caputi, & Magee, 2013; Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). They have to explicitly teach their child the increase in hygiene routines a grown up body needs, what personal boundaries are, and how to protect oneself against sexual vulnerability (Cridland, Jones, Caputi, & Magee, 2013). On top of this parents of adolescent girls have to help develop and maintain friendships and teach them about sex-related issues. This last issue is mostly handled well by autistic girls because they approach it as something logical and practical. However they need to be taught how to be discrete about private issues. Adolescence enhances the bond between parent and child and even stronger between mother and daughter due to the adolescents' willingness to discuss difficulties they experience.

2.3. COLLEGE LIFE

Many young people **leave the parental home** for the first time when they are starting post-secondary courses (Rugg, Ford, & Burrows, 2004). This event of moving to an unfamiliar location defines the transition to adulthood and is an important step in becoming independent. Some degree of support in this phase will have benefits for their further growth. The presence of university campuses, student accommodation established by both the university (residences) and the private market and student leisure have recreated city centres (Rugg, Ford, & Burrows, 2004). In Belgium, cities as Leuven and Gent are referred to as student cities because of the larger number of students living there. **Student life develops around studying** (going to classes, studying independently (in the library)) **and leisure** (for example, going out, sports, culture and student associations) (KU Leuven, 2020a). The university supports this student life by offering different services.

Students live in their student accommodation during the week/semester, and typically return back to the parental home during weekends and/or holidays (Rugg, Ford, & Burrows, 2004; Thomsen, 2007). They live in two places, both may be referred to as home, with different living qualities (Thomsen, 2007). A student's satisfaction, and thus comfort and happiness, is influenced by the degree of feeling at home in student accommodation. According to Gifford (2002, in Thomsen, 2007) the home is defined as a 'haven, order, identity, and connectedness, warmth and physical suitability', it goes beyond the physical structure of a house. It is a place to which people attach a cultural, demographic or psychological meaning (Thomsen, 2007). The home is significant for all people, also for students in temporary situations. A sense of home can be created by allowing individual to adapt the space so that it becomes an expression of self-identity. However this might be challenging to achieve in student accommodation due to the difficulty to form an attachment to space in a temporary dwelling (Thomsen & Tjora, 2013). The place where someone lives is an individual space to where one can escape from outside and can be seen as the primary site for identity expression (Holton, 2016). This place, the home, can then become a material and meaningful space. Student housing plays a role in the personal development to independent adult living and the notions of what a home should be (Thomsen, 2007).

Going to college and living in student accommodation, leads to students experiencing some **challenges** like navigating on campus, adjusting to housemates, developing a study routine, making new friends and dealing with homesickness (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). For young people who have left the parental home it is important to have friends with whom they can share these challenges (Thomsen & Tjora, 2013).

2.3.1. STUDENT ACCOMMODATION

Little research has been done on housing arrangements for young people despite the fact that their stage in life comes with specific needs (Thomsen, 2007). Often their budget is restricted and the housing is temporary. For students this temporary character results in **shared living arrangements** within a student accommodation (Verhetsel, Kessels, Zijlstra, & Bavel, 2017). Contemporary cohousing initiatives find their roots in student housing, which traditionally includes shared living. For this type of shared living, aspects of **social behaviour and relationships within the built environment** are relevant to look at (Thomsen, 2007).

The student accommodation is a dynamic place where multiple, disconnected identities live together in shared spaces where they have to **deal with boundaries** (Holton, 2016). This living away from the parental home together with strangers and becoming involved in new relations is seen as an aspect of being a student at university (Card & Thomas, 2018; Thomsen & Tjora, 2013). The student accommodation is a domestic space, where student transfer life skills learned at home into the student accommodation (Holton, 2016). Every housemate has their own view on living, so being able to compromise is needed to avoid tension and conflicts in relation to hygiene, noise and thoughtlessness (Card & Thomas, 2018; Holton, 2016). Through taking each other's activities into account, living in student accommodation becomes **a social way of living** (Thomsen & Tjora, 2013). In student accommodation students have the possibility to learn from each other (Card & Thomas, 2018). It is a learning space wherein students can make mistakes without it having serious consequences (Rugg, Ford, & Burrows, 2004).

Often due to a lack of shared spaces available, a re-occurring phenomenon in student accommodation is the **prioritisation of the bed-space** over communal areas (Holton, 2016). This means that students do every simple activity - like eating, studying and socialising with friends - in the private bedroom. The private room becomes a place to study and relax, making that in a student accommodation a less rigid structure exists about where the activities of the daily life are conducted (Card & Thomas, 2018). Students have the possibility to experiment with different ways to organise life, blurring out the line between public and private spaces. This asks for **flexibility in use of space** (Thomsen & Tjora, 2013).

When searching for student accommodation, students and their parents pay attention to certain aspects. Through time students' expectations towards student accommodation increased (Verhetsel, Kessels, Zijlstra, & Bavel, 2017). Possible points of attention are the following:

- How close the student accommodation is to campus (Card & Thomas, 2018). They also take
 into account the walking and cycling distance to the city centre, the train station and other
 students (Verhetsel, Kessels, Zijlstra, & Bavel, 2017).
- With whom they are sharing space in the student accommodation (Card & Thomas, 2018).
- The financial aspect of living in student accommodation: how much rent they have to pay (Verhetsel, Kessels, Zijlstra, & Bavel, 2017). The rent is most of the time covered by the parents (Rugg, Ford, & Burrows, 2004).
- Aspects related to the housing type (Card & Thomas, 2018; Verhetsel, Kessels, Zijlstra, & Bavel, 2017). In Leuven there are several different types of student accommodation with possibilities on the private market or housing offered by the university (KU Leuven, 2020b): classic student housing, student residences, community housing, the landlord living at the same address, 'op

- kot met engagement'⁸ and 'omkaderd wonen'⁹. There is also the possibility to live in an apartment or house which is not a typical student accommodation.
- Aspects related to the kind of private room (Verhetsel, Kessels, Zijlstra, & Bavel, 2017).
 Students can choose between rooms with private facilities or rooms with shared facilities, choosing for a private/ shared kitchen and/or private/shared sanitary. A flexibility is offered in kind of social interaction with housemates.
- Also the quality of the room is taken into account (Card & Thomas, 2018; Thomsen, 2007; Verhetsel, Kessels, Zijlstra, & Bavel, 2017). Aspects such as the size and layout of the rooms, furniture (included or not), materiality, physical comfort and warmth, cleanliness and noise play a role in choosing a student accommodation. It is recommended to have better sound insulation in shared housing (Thomsen & Tjora, 2013).
- The **possibility for personalisation** can be an important factor and it allows students to feel more at home in their student accommodation (Thomsen, 2007).

2.3.2. AUTISTIC PEOPLE GOING TO COLLEGE

Young adults on (the high functioning end of) the autism spectrum are also attending college, yet, are said to run a higher risk for failure; only a few (5-40%) of them would succeed in completing college¹⁰ (Levy & Perry, 2011; Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). In reality, however this doesn't differ much from the total success rate (36,38% in 2017) of all people who completed postsecondary education in Belgium (Trading economics, 2020). The first semester at university is a critical time of transition (VanBergeijk, Klin, & Volkmar, 2008). This transition is a long, adaptive process (Van Hees, Moyson, & Roeyers, 2015). To ease the transition, some live at home the first year of college or take on a less intensive course package (Van Hees, Moyson, & Roeyers, 2015). Attending college and living in a student accommodation asks for a) a strong motivation of the autistic student (and their housemates) in addressing life skills (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; VanBergeijk, Klin, & Volkmar, 2008) and b) a careful preparation, guidance, counselling and support for challenging aspects of their student life (VanBergeijk, Klin, & Volkmar, 2008; Van Hees, Moyson, & Roeyers, 2015). Support on a daily basis from their parents (and family) is crucial for their success (Lowinger, 2019). At the same time the parents also look for support and information to understand the university environment. On site visits of the campus with their soon to be student are recommended. The intense involvement results in families expressing stress in emotional, financial and physiological issues from parenting an autistic young adult (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017).

For autistic students, the parental home is the most familiar and safest place, it is the place they know best (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). The transition to living in a student accommodation possibly in a new city, leads to additional, unique and complex challenges for them (Lowinger, 2019; Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017; Van Hees, Moyson, & Roeyers, 2015). This as a result of the increased demands of higher education (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017; Van Hees, Moyson, & Roeyers, 2015) to adjust and self-advocate within this novel and complex environment (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). These challenges

⁸ 'Op kot met engagement' is living in a student accommodation (in a residence or on the private market) where the social aspect is the primary factor (KU Leuven, 2020c).

⁹ 'Omkaderd wonen' is a 'kot'-formule where student who are (physically) impaired and students who are not impaired live together in a group of ten to fifteen students in a KU Leuven residence (KU Leuven, 2020d).

¹⁰ Based on several longtime studies mentioned in Levy & Perry, 2011.

manifest themselves on three domains: 1) education, 2) student life and 3) daily (independent) living (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015).

- 1) Educational challenges can be linked to autistic people's detailed way of processing information and thus their poor ability to understand abstract concepts, but also to a short attention span, weak organisation skills, time management issues and possible hypersensitivity to sound, smell and light (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). This sensory overload can cause stress and fatigue (Van Hees, Moyson, & Roeyers, 2015).
- 2) Challenges in student life are linked to their social communication deficits (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017; Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). They experience difficulties with social relationships (Van Hees, Moyson, & Roeyers, 2015), due to having difficulties with ToM and understanding body language (Lowinger, 2019). Although they are in need of social contact and want to join the social aspects of campus life, they feel hindered by their limited social skills. The lack of friends and social contact causes feelings of loneliness and social isolation.
- 3) Challenges for daily (independent) living manifest themselves in new situations, unexpected changes and sensory issues (Van Hees, Moyson, & Roeyers, 2015). Because their family involvement is limited they have to advocate for themselves and solve things on their own (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). However when help is needed, they will contact their parents to ask them for help with solving the problem.

These challenges result in a need for **individual academic and non-academic support** (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). Autistic students also have a higher risk for comorbid psychiatric disorders (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017; Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). Due to living independently (and thus alone) they risk to experience mental health issues as loneliness (and isolation), anxiety, depression, stress and they also may express being tired (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). This results in a reduced self-care and more support of the parents is needed (Van Hees, Moyson, & Roeyers, 2015). However autistic students also experience benefits from their differences (Van Hees, Moyson, & Roeyers, 2015): academically they have a strong memory, are precise, have dedication, strong analytical skills and a power for observation. Socially they are sincere, impartial and have a will to listen to others, they are open and honest in their communication, all characteristics which are highly valued by family and friends.

Young adults on the AS, especially the ones who can easily mask their differences, have **doubts about disclosing their autism** (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). They feel that exposing themselves would lead to setting them apart from neurotypical peers and thus think it is better that people are not aware of their differences (Lowinger, 2019). This out of fear to be perceived as different (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). However **disclosure could help to receive the needed (non-)academic support** (Van Hees, Moyson, & Roeyers, 2015).

This support is helpful for HF-AS students who are intellectually capable of succeeding in post-secondary education but are hindered through the different challenges they face (VanBergeijk, Klin, & Volkmar, 2008). Support and interventions are available for different individual needs: academic

needs, independent living, social and vocational issues, counselling. With the right support autistic students can transition into greater independence.

Through going to college, experiencing student life and living independently, autistic students experience improvements in their way of living (VanBergeijk, Klin, & Volkmar, 2008). They experience a greater independence, become better at communication, learn more about their personal challenges, learn to develop habits and learn to clean (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). They learn how to behave in public, and they experience an improvement in organisation skills, learn their job interests and understand their differences better.

Successfully completing post-secondary education requires a right fit between institution and individual student (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). Institutions can enhance their effectiveness for all college students by insuring accessibility, employing universal design for learning, and providing professional development for faculty and staff on disability issues (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). In this way students are better prepared to become a productive member of society (VanBergeijk, Klin, & Volkmar, 2008). Finding a residential place which suits the individual best can make them more comfortable in living on their own (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). Autistic people are also **searching for a sense of belonging and a supportive social environment**. They seek changes for gaining growth, independence, new skills and to escape social isolation.

2.4. INTERACTION WITH THE BUILT ENVIRONMENT

The built environment influences people physically and emotionally (Franck & Lepori, 2007). People use their body to experience the different scales in which they live. Our bodies are our focus for our perception of the world (Franck & Lepori, 2007; Pallasmaa, 2007). Through occupying space, people create an inside and an outside (Franck & Lepori, 2007). The inside is a physical location, for example one's personal space, that is separated from the rest of the world physically and symbolically. This means the built environment stands in relation to people (Baumers & Heylighen, 2014). This understanding can be found in an ecological approach where the relation between human beings and their environment shape the meaning of an environment (Sanders, 1996 in Baumers & Heylighen, 2014). A fundamental concept in this approach is affordance, introduced by Gibson. The term is used 'to describe what an object offers to an actor, 'what it provides or furnishes, either for good or for ill." (Gibson, 1979 in Baumers & Heylighen, 2015). It indicates the basic (functional and emotional) relation between people and the environment in an architectural context (Baumers & Heylighen, 2015; Gaudion, Hall, Myerson, & Pellicano, 2015). It is linked to the physical characteristics of the environment (the artefact) and to the actor and its capabilities (the user) (Baumers & Heylighen, 2014). Affordance is about 'what actions the user perceives to be possible' (Norman, 1999 in Baumers & Heylighen, 2014)

The built environment can extend and enhance human capacities by providing a shelter for human activities that protects the body from the surroundings (Franck & Lepori, 2007). However it can also disable human capabilities (Heylighen, Van Doren, & Vermeersch, 2013). **Enabling and disabling contexts arise because of the interaction between a person and their environment** (Baumers & Heylighen, 2010; Heylighen, Van Doren, & Vermeersch, 2013). The built environment provides people primordial experiences through sensations of comfort, protection and a feeling of home (Pallasmaa, 2007). Interactions with the built environment have a verb form rather than a noun form (Franck &

Lepori, 2007; Pallasmaa, 2007). For example people experience the space around them through doing activities, as washing the dishes or cooking, theirin.

2.4.1. USING THE BODY

The human body (and it sources of sensation) is **the center of the human experience**, perception and actions (Franck & Lepori, 2007). The body is the navel of the world and a locus of reference for memories, imagination and integration (Pallasmaa, 2007). It is used to orientate ourselves in the world and everything is in relation to it (Franck & Lepori, 2007). Our measurements are derived from the body, putting it into relation with the built environment. The body is taking in and producing sensations and information, it is open to objects, the surroundings and relationships.

The human body is **open and inclusive** towards the environment (Franck & Lepori, 2007). The body has **boundaries** (the skin) which make it an independent entity. However it is incomplete by itself. The body is porous, permeable and thus deeply connected with its surroundings. There is a continuous exchange between inner and outer (Franck & Lepori, 2007; Pallasmaa, 2007). For example the body is constantly exchanging air with its environment (Franck & Lepori, 2007). Through interacting with objects and other bodies people learn what their bodies are capable of. The body depends on the surrounding to know where one is and where one goes. Our bodies are moving, making spaces, and they are a continuous process.

The environment is experienced through the senses (Franck & Lepori, 2007; Pallasmaa, 2007). Originally, following the Greek view, Western culture focused on the visible, with sight being the dominant sense (Pallasmaa, 2007). Increasingly the experience of the built environment is understood no longer as a one-sense experience, but as a **multi-sensory experience** (Franck & Lepori, 2007; Pallasmaa, 2007; Steele & Ahrentzen, 2016). The qualities of space, matter and scale are measured equally by all senses of the body (Pallasmaa, 2007). This multi-sensory experience developed from Gibson's five-sensory system (Pallasmaa, 2007) into the eight sensory systems to process information for daily living by Anna Jean Ayres (Sensory integration education, 2020). These eight systems contribute to the experience of a space, on which a designer can anticipate when designing the built environment (Steele & Ahrentzen, 2016). The eight sensory systems are (Sensory integration education, 2020):

- Sight
- Hearing
- Smell
- Touch
- Taste
- Proprioception. This helps to define the boundaries of the body and its location in space. It is
 used to coordinate the body.
- Balance or vestibular sense. Better known as the inner balance mechanism. It is used to maintain balance.
- Interoception. The internal operation of our body, like experiencing hunger, thirst and temperature. This is the way in which the body tells what is happening inside of it.

The body is **not only physical**, it is enriched by memories, dreams, the past and the future (Pallasmaa, 2007). It is through interaction with our memories and not only sensory elements, that we experience

places. The experience of home for example is structured by distinct activities as cooking, eating, socializing, reading, storing and sleeping. Further the body is also shaped by culture and social events (Franck & Lepori, 2007). A two-way relationship between body and culture exists: Bodies' needs are cultural and cultures are shaped by people.

When people interact with the built environment they are taking in spaces (Franck and Lepori 2007). In this way a space can become a possession, **a personal space**. This can be for a short period of time, when someone leaves their belongings on a chair, or for a longer period of time, like the place where someone lives. 'The place where we live becomes the most intimate and visible extension of our bodies/ ourselves' (Franck and Lepori 2007). The home is an expression of intimacy (Pallasmaa, 2007).

2.4.2. DESIGNING ARCHITECTURE

When designing architecture, architects keep in mind people's desires, sensory experiences and everyday actions (Franck and Lepori 2007). As designers, architects ask questions, watch, and listen to other people's opinions. They rely on their own experience and those of others. From an inclusive or universal design approach architects use the view of disabled persons to open their eyes to different experiences of the built environment (Baumers & Heylighen, 2010). Inclusive design seeks to address the needs of the widest possible audience, irrespective of age and ability, in order to consider human differences (Bianchin & Heylighen, 2018; Kinnaer, Baumers, & Heylighen, 2014). This diversity is present in mental and physical capabilities across the population and over the length of a lifetime. As mentioned above 11 disability arises from interaction with the environment (Bianchin & Heylighen, 2018). Originally inclusive design research focused on physical accessibility and less on sensory difficulties, making it difficult to take autistic people into account (Kinnaer, Baumers, & Heylighen, 2016). Designers have to make choices in which they keep the space usable for everybody while respecting the diversity in human capacities (Bianchin & Heylighen, 2018). This is the paradox of inclusive design. However this might be dealt with by shifting the concept of usability from creating an artefact which is useable by everyone in the same way (for example everyone uses the same elevator), to an overall distribution of usability within a relevant social context (for example people can choose, according to their preferences, to use an elevator, ramp or stairs, which are all three designed with the same care). With this idea participation of users in the design process is encouraged.

The built environment is not limited to its visual appearance, the body and all its senses are addressed as well (Kinnaer, Baumers, & Heylighen, 2016). When designing, an architect focusses on their memories and works with their own experiences and that of others (Franck and Lepori 2007). Architects provide opportunities for users to experience emotions, they can control the physical appearance but not the use of a space (Baumers & Heylighen, 2015). In this way an architect's vision may differ from the experience of the users. They design a space with the intention that it is experienced in a certain way, however they cannot control how different people in different contexts are actually going to interpret it (Crilly, Maier, & Clarkson, 2008). By tuning in with all people and aspects involved in the design process they might succeed in creating a meaningful, non-arbitrary space for everyone (Franck and Lepori 2007). According to Frank and Lepori (2007) designing architecture, can be approached from the outside or from the inside.

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¹¹ See 1.1.1 approach to disability

When designing from the outside, architects are occupied with designing forms and manipulating materials (Franck and Lepori 2007). Space is seen as a concept instead of something that is inhabited by people and the architecture is based on the body's functional needs. The body is seen as a universal body with standard measurements, it is motionless, male, white, not young nor old, but strong and healthy. It can be represented by the Vitruvian man of Leonardo da Vinci. The body is seen as an object without culture, lifestyle and personality. No attention is paid to its religion, customs, family structure, gender or cultural relationships. Vision is seen as the only sense to experience architecture.

Designing from the inside means creating architecture to house and organise human activities, to support and enhance daily life (Franck and Lepori 2007). First there is human activity, then a space is designed to support this. The human body is diverse. It is alive, moving, changing, acting and is constantly engaging with the surroundings. Architectural design responds to a body's position, gestures and belongings. It is given life and spirit by all the qualities that touch the human senses and soul. These qualities can be light, colour, sound, texture, expansion and compression of space, view and prospect. By designing from the inside an intimacy is created by working with all senses.

According to autistic designer Roland, feelings and experiences are a fundamental principle of his design approach (Baumers & Heylighen, 2015). He finds inspiration in the work 'A Pattern Language' of Christopher Alexander. In this work Alexander links experience to form and function and by doing this his aim is to create beautiful places. In this way designers should think about what interactions their designs should afford.

2.4.3. THE BUILT ENVIRONMENT ACCORDING TO AUTISTIC PEOPLE

Due to their differences, their sensory modality and more detailed perception, autistic people across the spectrum have different perceptions of the world (Robertson & Baron-Cohen, 2017). They live in a mentally challenging world and might perceive reality as chaotic and unpredictable due to human actions (Kinnaer, Baumers, & Heylighen, 2014; Kinnaer, Baumers, & Heylighen, 2016). Dealing with the world and the people in it becomes difficult because they may be easily misunderstood, stressed and anxious (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). A difference can be made between autistic spaces and spaces for autistic people (Sinclair, 2010). Autistic spaces are spaces where autistic people are in charge and where attention is payed to the diversity on the spectrum. Space for autistic people are spaces which are shaped by neurotypicals based on their perception of what autistic people need. Autistic people are often more comfortable in cyberspaces because there they can better deal with communication pitfalls, than in the physical, shared space. When entering the shared space they try to modify their behaviour to fit in with the world of neurotypicals (Baumers & Heylighen, 2010; Sinclair, 2010).

Because understanding other people is difficult for people on the spectrum the built environment needs to be predictable, consistent, compatible and controllable (Kinnaer, Baumers, & Heylighen, 2016). That results in them having a greater attachment to the built environment (Baumers & Heylighen, 2010). Some autistic people have less developed orientation and navigating skills (Kinnaer, Baumers, & Heylighen, 2016). They need elements to orientate themselves with in a city or building. The built environment offers them things they can hold on to, which gives them a feeling of continuity and comfort. Familiarity and literally something they can hold on to, like a bike, offers them grip on their position in space, which is needed due to possible body unawareness. They are looking for **anchors** in the physical world (Baumers & Heylighen, 2010). For this reason their home plays an

important role: a) it is the easiest place to meet new people because they know this place best and can then focus on the interaction (Kinnaer, Baumers, & Heylighen, 2016) and b) it is their anchor, the place where they have everything under control (Kinnaer, Baumers, & Heylighen, 2014). Autistic people can be themselves in their own private space, where they can refuge from stress, be in control and are free to arrange the environment (Sinclair, 2010). In their private home, structures, made by others, decrease, which makes that they have to give structure to their lives themselves. Autistic people will often receive assistance in this.

2.4.4. AUTISM-FRIENDLY ARCHITECTURE

Autistic people also have an opinion about how they would like to life. However, they may have difficulties with life skills - like cooking, eating healthy, shopping, cleaning, maintaining hygiene, a sleeping schedule and a budget, driving and using public transport - which are needed when living independently (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). These difficulties affect a person's ability to build a social network. People on the autism spectrum will require a certain kind of support when living independently depending on their needs, which are divergent across the spectrum. HF-AS people may need only minimum and temporary assistance, for example to cope with challenges, while other people on the spectrum need intensive lifelong support. Autistic young adults are more likely to remain living at home or with another responsible adult.

When designing autism-friendly architecture architects have to understand that they are designing for individuals (Kinnaer, Baumers, & Heylighen, 2014; Steele & Ahrentzen, 2009). These individuals may experience particular design features differently (Steele & Ahrentzen, 2016). When designing their house, the goal is to find the balance between what the individual needs and how they want their house to look (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). What is crucial for one autistic person might be irrelevant for another (Steele & Ahrentzen, 2009). Autism-friendly architecture is about designing the most comfortable living situation based on the person's own preferences for different architectural aspects going from the neighbourhood to furniture layout (Kinnaer, Baumers, & Heylighen, 2014). Autistic people might live in situations that are not considered as acceptable living situations from a neurotypical point of view.

Steele and Ahrentzen (2016) have developed **ten quality of life design goals** to keep in mind when designing for (autistic) people. These design goals and corresponding guidelines are research informed which means they are based on the empirical work of professional researchers, reflective practitioners, and autistic adults themselves (Steele & Ahrentzen, 2009). How these goals should be met and what they mean for people on the spectrum may be different and unexpected compared to how they would be implemented for neurotypical people. For example students on the autism spectrum will value a place where they can sit quietly in the same room as others but where they don't have to interact. This is a different kind of social behaviour than one would expect from young residents in student accommodation. In *At Home With Autism: designing housing for the spectrum* Steele and Ahrentzen provide a range of options so that individual circumstances, needs and inclinations can be met. The ten design goals found in the work of Steele and Ahrentzen (2016) resonate with what is found in other work and these goals are the following:

 Ensure safety and security, the first priority in any home (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Mostafa, 2010; Steele & Ahrentzen, 2016). This through selecting materials, furnishings and design features that minimalize falls, slips and imbalance and reduce the injury

- if this might occur (Steele & Ahrentzen, 2016). For housing for autistic people these are greater than standard measures (Steele & Ahrentzen, 2009).
- 2. Maximize **familiarity**, **stability**, **predictability** and **clarity** (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Steele & Ahrentzen, 2016). This to address potential overload and different interpretations of the environment (Steele & Ahrentzen, 2016). Scale of space, type and style of furnishing are used as clarifying environmental messages.
- 3. Enhance sensory balance (Steele & Ahrentzen, 2016). This is provided by having multiple spaces with different sensory stimulation. The zoning in the house should be sensory and not functional, however these two are related to each other (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Mostafa, 2010; Steele & Ahrentzen, 2009). Different sensory needs are addressed through the use of sensory rooms and escape spaces (Kinnaer, Baumers, & Heylighen, 2014; Kinnaer, Baumers, & Heylighen, 2016). A sensory room is a multi-sensory space. An escape space is a small, sensory neutral space which is easily assessable (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). Different gradations exist in how closed off an escape space is. For example this can be a completely isolated room or it can be just a visual barrier. Such rooms are necessary to gain a sense of control and safety (Kinnaer, Baumers, & Heylighen, 2016). Autism-friendly architecture keeps in mind the sensory differences (Robertson & Baron-Cohen, 2017)
- 4. Offer multiple opportunities for controlling **social interaction and privacy** (Steele & Ahrentzen, 2009; Steele & Ahrentzen, 2016). This can be established by providing a range of spaces to retreat to if things get overwhelming (places which are too crowded or too plain) (Kinnaer, Baumers, & Heylighen, 2016). The desired levels of privacy and sociality depends on the control the autistic individual has in regulating boundaries (Steele & Ahrentzen, 2016). In shared residences control over their own boundaries depends on the number of housemates and their visitors. This control can be ensured by providing enough boundaries between private and shared space (Steele & Ahrentzen, 2009).
- 5. Provide adequate **choice and independence** (Steele & Ahrentzen, 2009; Steele & Ahrentzen, 2016). People's sense of independence and self-worth is often shaped by their ability and opportunity to make choices, having control over events and environments and having a level of independence (Steele & Ahrentzen, 2016). Technological devices can support autistic people and help them in controlling the environment on their own.
- 6. Foster **health and wellness** is important for everyone (Steele & Ahrentzen, 2016). However many autistic adults experience different health issues, so a sustainable house with a high-quality indoor environment could enhance their health.
- 7. Enhance one's **dignity** (Steele & Ahrentzen, 2009; Steele & Ahrentzen, 2016). Having an outer facade that blends in with the neighbourhood shows the autistic person fitting in with society. Providing room for personalisation and creating visual and auditory privacy, helps in creating intimacy and a sense of dignity.
- 8. Ensure **durability** (Steele & Ahrentzen, 2009; Steele & Ahrentzen, 2016). Some autistic individuals are well-coordinated, while others experience problems with gross motor skills and coordination. Delivering a robust environment which is resistant to unintended use, homelike (by using warm, non-commercial material), maintainable in cost and easy to restore, is essential for the residents safety and well-being (Kinnaer, Baumers, & Heylighen, 2016; Steele & Ahrentzen, 2016).

- 9. Achieve **affordability** without reducing the building's quality, which would have a negative effect on the health and well-being of the residents (Steele & Ahrentzen, 2009; Steele & Ahrentzen, 2016).
- 10. Ensure accessibility and support in the surrounding neighbourhood (Steele & Ahrentzen, 2009; Steele & Ahrentzen, 2016). A location in close proximity to services, retail and public transport makes it easier to live independently. A supportive and helping community can be helpful to get a feeling of social inclusion.

These design goals can be linked to design guidelines to keep in mind an individual's preferences and needs about their living situation (Steele & Ahrentzen, 2016). The goals mentioned above can be matched to different aspects of the home: the overall home (1, 3, 5, 6, 7, 9, 10), outdoor space (2, 3, 4, 5, 6, 8, 10), floorplan strategies (1, 2, 3, 4, 6). They can also be matched to the different rooms in the house: entry (2, 3, 4, 6), living room (1, 3, 5, 6), dining areas (3, 5), kitchen (1, 2, 3, 5, 6, 8), hallways (1, 2, 3, 4, 6), bedrooms (1, 2, 4, 5, 6, 7, 8), bathrooms (1, 2, 3, 5, 6, 8), multi-sensory environments (3), and storage (2, 3, 5). In group homes it is possible that there is an office of a support provider, also for this space design goal 6 can be thought of.

These design goals can also be applied to more technical aspects which address the sensory experience (Steele & Ahrentzen, 2016). Criteria for technical aspects are also mentioned in other works and can be linked to the **sensory design model** of Mostafa (2010) in which the built environment is put in relation to diverse autistic needs, through design criteria about safety, spatial quality, spatial organisation, spatial orientation and spatial integration. These criteria are suggestions, they won't be wanted or necessary for every autistic person. This sensory design model is based on the voluntary participation of primary caregivers and teachers of autistic children through a questionnaire (Mostafa, 2008) and has been applied in a case study for a work home for autistic adults (Mostafa, 2010).

- **Safety** precautions that need to be taken into account depend on the age and life skills of the autistic person (Mostafa, 2010). Placing of safety devices can be necessary.
- The **spatial quality** is measured through different sensory elements (Mostafa, 2010).
 - The haptic environment, which depends on texture and sensory areas like escape spaces (Mostafa, 2010).
 - The acoustic environment, which depends on the external and internal sounds, the spatial geometry, spatial organisation and zoning (Mostafa, 2010). The quality of acoustic environments for autistic people should be higher than the standard recommendations (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). Design goal 3 can be taken into consideration (Steele & Ahrentzen, 2016).
 - Illumination, which is best natural and indirect (Mostafa, 2010). Attention can be paid to design goals 1, 2, 3, 6 and 8 (Steele & Ahrentzen, 2016).
 - The individual preference of the autistic resident in regard to colours and patterns (Mostafa, 2010). White and pale tones and no patterns seem to be the most comfortable. In regard to these and other materials design goals 1, 2, 3, 5, 6, 7, 8 and 9 can be applied (Steele & Ahrentzen, 2016).
- The **spatial organisation** depends on how people use space (Mostafa, 2010).
 - Navigating and wayfinding elements need to be straight forward for autistic people to understand (Mostafa, 2010). Through adding enough transitional spaces abrupt (sensory) changes can be avoided (Atsmon, Yaakobi (Gorga), & Lowinger, 2019).

- Autistic people function best when they have a routine, this manifests itself through defining one activity for each space and avoiding multi-functionality (Mostafa, 2010). By integration of (physical and visual) boundaries and compartmentation the focus on one activity can be enhanced, for example by grouping furniture in a specific way. Compartmentation allows for single activities with a smaller number of people (Atsmon, Yaakobi (Gorga), & Lowinger, 2019).
- To help with following the daily routine and form a structure in space and time, activities can be linked to places and objects through spatial sequencing (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Baumers & Heylighen, 2015; Kinnaer, Baumers, & Heylighen, 2016). This gives a feeling of being in control, having personal space (Atsmon, Yaakobi (Gorga), & Lowinger, 2019) and being more comfortable because an intimacy gradient is created (Baumers & Heylighen, 2015).
- Spatial orientation depends on regulating climate through proper ventilation, natural lighting, visual access and views to outside (Mostafa, 2010). It is possible that outside views might distract the autistic person.
- **Spatial integration** is accomplished through incorporating the landscape with attention to sensory balance (Mostafa, 2010). Gardening and doing outdoor activities seem to work therapeutically.

When implementing these criteria into a design, if possible, it is important to listen to the needs and wishes of the individual person for whom the design is meant (Steele & Ahrentzen, 2016). In situations where this is not possible, for example student accommodation, as much personalisation options as possible should be offered. Through active participation of people, who are impaired, in the design process a richer environment can be created (Vermeersch, Schijlen, & Heylighen, 2018).

METHODOLOGY

3.1. START RESEARCH

3.1.1. ABOUT THE RESEARCHER

I'm a female student, who has been living in the same student accommodation for the past five years. I'm a fifth year architectural engineering student. During my college career I became more aware of the inequalities in society and how these can be handled. Through studying architecture I learned that space also has an influence on this, which sparked my interest in the way that space does this.

When choosing this topic for my master's thesis, my own interest in equality was of influence. Because of this interest I chose two elective courses which in their own way both highlight how the built environment is not equal for all. *Inclusive Design* gave insight into how the built environment can enable or disable people's movements. *Architectuurtheorie, capita selecta: Macht, diversiteit en gender* gave insight in how inequality between men and women is supported through the built environment. This sparked my interest to research a) the different effects of the built environment on people on the autism spectrum and b) whether this effect differs depending on a person's sex. In my thesis this space is defined as the student accommodation. As a student living in a student accommodation, I can use my own experience and take a critical point of view.

3.1.2. INSIGHTS FROM ELECTIVE COURSES

The elective courses emphasized the role of the built space in the experience of a person's daily life. Each person is different and these differences can be supported or suppressed by the built space. Both courses mentioned that a space should no longer be designed for a universal or standard body, but rather for all different body types.

The course of *Inclusive design* taught me how people, with an impairment experience public spaces. The testimony of a father with an autistic son showed that it can be exhausting to live with an autistic person and that a change in lifestyle is necessary to make this work. The course contained different exercises to look into the inclusivity of buildings. One of these exercises was a visit to *Alma 3* in Heverlee. The students were divided in groups of two and were assigned a user/expert who showed them around in *Alma 3*. The user/expert shared how the experience was to them. I was assigned an autistic student who also studies architecture. From that visit and the other experiences from the KU Leuven autistic students, I learned that these students prefer less crowded areas. They are drawn to places that are connected to the outside and they dislike loud places. They are in need of clear signs and logical planning to understand the building. The autistic female user/experts don't like to be alone in unfamiliar places and they all need a place where they can find some peace and quiet, a place which functions as an escape space.

¹² A user/expert can be anyone who has developed natural experiences in dealing with the challenges of our built environment (Ostroff, 1997)

3.1.3. INSIGHTS FROM LIVING IN STUDENT ACCOMMODATION

My own insight in living in student is based on my experience of living in a student accommodation and on observing the situations of my friends who are also living in a student accommodation. Some of them were not allowed by their parents to live in student accommodation during their first year of college. They had to commute every day to campus, which had a negative impact on their social life. For me, going to college in Leuven also meant finding a new place to stay during the week.

My parents and I searched on *Kotwijs* (the student accommodation website of KU Leuven), to find a student accommodation. For this decision, we focused on location, a private bathroom and a nice atmosphere. My father found my student accommodation and when we visited it, I immediately felt that this was the place where I wanted to live for the next years, because of all the greenery around the house. I feel comfortable in my student accommodation because I like the consistency, the atmosphere of the house and that I could make my room my own. This are reasons why I didn't change of accommodation during my five years of studying in Leuven. Even though I had the opportunity to live with some of my friends, I chose to stay where I was, with guidance of my parents, because the other accommodations wouldn't have suited me as well as the one I am living in now.

My student accommodation is close to the campus Arenberg in Heverlee. During the week I live there, on weekends I go home unless there is an important deadline for my design course. We, as students, live on the top floor which has room for six students. The rest of the house is dwelled by the landlord and his wife. Living in with the landlord has the advantage of him always being available if necessary. Out of the six students, two students have a private bathroom, one student has a private kitchen. That results into the other five sharing a kitchen and four of them sharing a bathroom.

My housemates have changed frequently over the years. With the arrival and departure of new students every year, the atmosphere in the student accommodation changed constantly and my experience was different every year. In my first year four new students moved in, three of us were freshmen (two boys and me) and one girl who was friends with the girl already living there. The girl who already lived there pinned up some ground rules for the communal parts which we should follow, because the boys and I were freshmen, she felt like she had to teach us the basics. I had a small group of friends who would come cook and chill in my room in the evening. In the second year, two students had left and one new girl moved into the room next to me. Because it was my second year I had a bigger group of friends who would come for dinner and chilling before going out, making the noise sometimes a problem for my older housemate. In the third year the new girl left and a new boy and my sister, both freshmen, moved in. I was no longer the youngest and I could spend some time with my sister, which was not easy because she has a different rhythm and lifestyle than I do because of the differences in our studies. The fourth year my sister and the older student moved out and two new boys moved in, one of them is a close friend of mine with whom I did design during my third year of college. Up until that year the interaction with my housemates was very limited. My lifestyle changed again and was now getting intertwined with my friend's lifestyle. Now I was one of the oldest and the only girl, so the dynamics in our student accommodation changed. I felt more at ease because I felt like I wouldn't disturb as much as before. This year, my fifth year in student accommodation, a new boy moved in but nobody moved out. This has benefits for our social interaction and some of us started to do things together more often, in our student accommodation and outside. Student house activities, which we tried to do twice a year, became more fun.

When looking at the living situation of my friends, I see much variety in the way they are living. One of my friends lives with her family in a house where they share the kitchen, a living room and the bathroom. Another friend lives in an all-girls student accommodation where they also share the kitchen and the bathroom but don't have a living room. One of my sisters moved into a house where every student has their own studio and they only have a shared hallway. My other sister lives in a residence where they share a big kitchen with 27 students but all have private bathrooms. Other friends who study architectural engineering live together in an apartment and in a house. Some of my friends live in a KU Leuven residence with *Omkaderd wonen*, which means they share their communal areas with students with a physical impairment and/or psychological vulnerability. These cases show some living possibilities for students in Leuven and it also shows that your independent lifestyle and choice of accommodation affects the dynamic between you and your housemates. For example when my friend became my housemate, we became friends with another housemate and our relationship changed from acquaintances to friends. Because I can rely on my own experience when thinking about the data, this may have an impact on the research.

3.2. FIELD WORK

3.2.1. APPROACH

To answer the research questions a qualitative research is conducted with autistic students, who are living away from the parental home during the week. To accomplish this, participative methods, supported by traditional interviews, are used. The participative methods that are used are photovoice, walk-along and co-analysis. These methods are used to look into how participants experience living in a student accommodation, and what the role of the built space is therein. Three different cases are studied. Differences and similarities in experience across the cases are examined.

Through different methods (interview, photo-voice and walk-along), the students are invited to talk about their experiences of their student accommodations, in different ways. This makes it possible to collect extensive data on their experience. Data collected with one method can also (partly) overlap with data collected through another method. In this way the data becomes more reliable. In qualitative research looking at the same subject from different angles allows gaining a better understanding of it.

All communication with the participants happened in Dutch, as this is their and my native language. In this way, the participant's knowledge of English had no impact on the data. All meetings were audiotaped through my personal device which proved to be of good quality.

3.2.2. ORIGINAL PLAN

The original plan was thought of in a symmetrical way on two levels: a) the difference between female and male students on the AS across different student accommodations and b) the difference between the autistic student and the neurotypical student within their student accommodation. In this way each of the participants would have accomplished exactly the same kind and number of meetings and the voices of the autistic student and the neurotypical student would be equally represented and both students would be treated in the same way. Through setting up the process in this way I aimed to incorporate the following themes which should help in answering the research question:

- 1. The student life of the autistic student and the student life of the neurotypical student
- 2. The student's ideal living situation
- 3. The role of built space in how the students experiences their current living situation
- 4. Improvements for the current living situation
- 5. An analysis and reflection of the results of the process.

Using the different methods in different consecutive meetings should allow to address these themes and thus give an answer to the research questions. For each student accommodation the plan was to follow the schedule below:

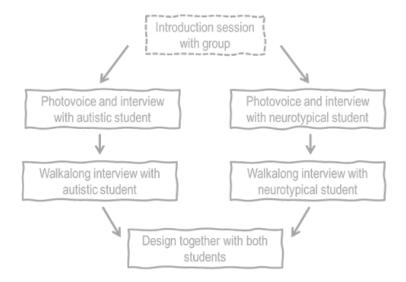


fig. 1 Schedule to follow with the participants

The first meeting was intended as an introduction of the research to the participants and of the student accommodation to me. During the meeting I would mention the kind and number of meetings and would explain how the following meetings would go.

The following two kinds of meetings focussed on the current living situation of the participants.

The second kind of meeting would be conducted twice for each student accommodation: once with the autistic student and once with the neurotypical student. This meeting would consist of two kinds of interviews: a) A photovoice interview and b) an additional face-to-face interview which was planned to be semi-structured. The meeting was intended like a conversation through which some topics get handled.

The third kind of meeting would be conducted twice as well for each student accommodation: once with the autistic student and once with the neurotypical student. It would consist of a walk-along interview through the student accommodation. The student would guide me through their student accommodation while explaining elements that they thought were interesting. I would ask additional questions from a topic list to obtain information that the student didn't bring up.

The last meeting would focus on improvements and the ideal living situation through co-design.

The fourth meeting would be a group design where the autistic student, the neurotypical student and I would reflect together on the information gathered from the previous meetings. The idea is that participants would come up with aspects they perceived as key elements within the student accommodation and how their student accommodation may become more inclusive and appropriate to them by talking and drawing. This session would be designed after the other sessions were conducted so it would be possible to incorporate everything that was gathered so far.

3.2.3. FINDING PARTICIPANTS

For this study, the choice was made to work with a limited number of participants, so their experience of living in student accommodation could be looked into in a more detailed way. This approach was suitable because, meeting multiple times allows the participants to become more comfortable with me and the research itself. It allows them to express themselves more openly. This research starts from the autistic students themselves. By giving the students a strong voice, the individual, around who the research is developed, doesn't disappear to the background. When this would happen others (like stakeholders or parents) would decide what is best for them. By letting the autistic students actively participate the research is focused on their experience and the results are depending on their participation.

Three different cases are studied: a female student in student accommodation (Eline), a male student (Victor) and one of his housemates (Koen) in co-housing, and a female student (Ellen) in student accommodation and the insights from her mother (Tessa).

The students who were contacted all had participated as user/experts in the course of *inclusive design*. In total, three autistic students were contacted. The used names are pseudonyms to respect the privacy of the participants. According to the original plan, one female student and one male student were contacted. Both were contacted through e-mail. Because I already had contact with the male student, Victor, the user/expert I collaborated with for the *inclusive design* course, I sent him the e-mail myself. However the e-mail to the female student, Eline was sent by supervisor Ann Heylighen to maintain her privacy in case she did not want to respond. The e-mail contained the following topics:

- a) why this research needs their participation
- b) a brief summary of what the research is about
- c) what is expected from them during the meetings, and
- d) the request to contact a housemate and a request for planning the meetings.

Eline replied that she didn't want to participate because she hasn't told her housemates that she is autistic and prefers her environment not to know about, in her words, her disability, because people have preconceptions about ASD. She did mention that she experienced difficulties living in student

accommodation and after asking if she wanted to talk about it she agreed to meet once, at the condition that her housemates would not be involved.

Since people are quick to judge people with ASD, I prefer that my environment is not aware of my impairment.¹³ (Eline in her e-mail on January 27th, 2020)

After I received this e-mail from Eline, a second female autistic student was contacted this same way. This student, Ellen, replied that she would like to participate. However she also hadn't told her housemates that she is autistic and would also like to keep it this way because she also doesn't want to be prejudged. She suggested that her mother could fill in the place of the housemate as a second participant. After consultation with the supervisor and assistant, we thought this could give some interesting perspectives on her living situation. After meeting with Ellen and her mother Tessa for the first time, I learned that Ellen's brother also is autistic and lived in student accommodation. This made Tessa a very interesting source in this research to compare the experience of her two children, however the focus during the meetings is on Ellen's experience.

Victor said upfront, during a meeting for the *Inclusive design* course, that he was interested in participating in this research. He mentioned that he was co-housing with two friends. After receiving the e-mail he mentioned that Koen would be the second participant. Victor is not living with other students in student accommodation but is actually living together with Koen and his husband Paul in their house.

3.2.4. METHODS AND THEIR IMPLEMENTATION

In this master's thesis the active involvement of the participants is wanted through the whole process of collecting and analysing data. Through relying on participative methods from literature, the involvement of the user/experts becomes valuable. These user/experts are the autistic students living in student accommodation and one of their proxies. In this way the information gathered for this thesis relies on multi-informants: the autistic student, their proxy and myself (Gaudion, Hall, Myerson, & Pellicano, 2015). The involvement of multi-informants can enrich the understanding of how, in this case, a student accommodation can become inclusive for an autistic student (Vermeersch, Schijlen, & Heylighen, 2018). This research is based on a participatory design approach where participants' involvement is incorporated through a) gaining insights through participatory methods where the knowledge is gathered from doing things and b) co-interpreting the results together with the researcher (Spinuzzi, 2005).

People in general have difficulties with expressing how the built environment influences their daily experiences, this is due to a lack of conversational skills, a lack of vocabulary when talking about space and the complexity of the experience (Annemans, Van Audenhove, Vermolen, & Heylighen, 2012). To address the involvement of the built environment in their experience, alternative interview techniques were developed. Because the built environment is approached through the senses according to Pallasmaa (2007), these techniques can be described as sensory methods which help people document their experience through for example photographs, drawings and stories (Annemans, Van Audenhove,

¹³ Original: "Aangezien mensen nogal snel een oordeel klaar hebben over mensen met ASS verkies ik dat mijn omgeving niet op de hoogte is van mijn functiebeperking."

Vermolen, & Heylighen, 2012). In this thesis photovoice and walk-along interviews are used to address these issues.

Hendriks, Slegers, & Pieter (2015) mention that taking people with an impairment into account in the research process means that this process should be individually adapted to the participants. So in this way they feel empowered by anticipating. However this, may also be relevant to people without an impairment¹⁴. Working together with autistic people makes that the approach should be strength-based, meaning that there is attention for the individuals sensory preferences, special interests and different action capabilities. (Gaudion, Hall, Myerson, & Pellicano, 2015). This approach ensures that meaningful and enjoyable information can be developed.

PHOTOVOICE

Photovoice was chosen because past research showed the value that it could bring. Photovoice allows participants, in this case the (autistic) student, to bring particular topics and their own voice to the interview (Jellema, Annemans, & Heylighen, 2018). It allows the researcher to question which spaces are considered. By collecting empirical material the participants could be inspired to talk about specific aspects of the building (Annemans, Van Audenhove, Vermolen, & Heylighen, 2012). Using photographs to facilitate the interviews allows to gain an understanding of what is made (in)visible in the photographs, how this is made (in)visible and why (Annemans, Van Audenhove, Vermolen, & Heylighen, 2012; Radley, 2010). However a photograph only acquires meaning when it is considered together with the narratives of the participant. The **combination of photograph and story** shows that a photograph can have a multi-layered explanation (Annemans, Van Audenhove, Vermolen, & Heylighen, 2012; Warren, 2002). The photographs have the ability to add additional information about the scenery and facilitate the dialogue, because questions can be formed around them (Wang & Burris, 1997; Warren, 2002).

Photovoice may give a voice to people who are stigmatized because of health conditions or social status (Wang & Burris, 1997). The photographs give people the possibility to share their expertise and knowledge. These notions can be seen in the three stage process of the photovoice method: 1) selecting photographs to discuss, 2) contextualising the photographs through telling stories: giving a voice to the individual or collective experiences, and 3) codifying by identifying themes, issues and theories: giving multiple meaning to the photographs. The photographs show the atmosphere of the environment and not the reality (Warren, 2002). In this way, it is possible that the photographs together with the story avoid an over-emphasise on the role of the visual and have the capacity to help visualise the invisible of the sensory stimuli like sound and smell and of the events and feeling within a certain setting.

When one asks people to photograph their experience it can be useful to give them some written guidelines to follow (Radley, 2010). These guidelines can include the number of photographs they can take and that they may include positive and negative elements. A brief description with each photograph can help understand what the participants want to show. When talking about the photographs, the researcher can look into their selection of photographs and ask: what they like and dislike, and what they think is the most significant photograph they took. The approach shows to be

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¹⁴ In line with the diversity approach, being autistic is not considered the same as having an impairment. Someone is autistic because of a neurological difference and not a defect.

flexible in use but a balance between freedom and guidance should be maintained (Annemans, Van Audenhove, Vermolen, & Heylighen, 2012).

I implemented the knowledge from literature into my own photovoice exercise for the participants. During the introduction meeting each participant received the same instructions on a piece of paper. The instruction was tested in a pilot study with my housemate and necessary changes were made. The instructions that were given to the participants can be found in the appendix under 8.1.1 Instructions photovoice.

My housemate made six photographs, highlighting different aspects of what it was like for him to live in our student accommodation. He found that six photographs were enough to illustrate what he wanted to say and he added a short sentence to each photograph. The results can be found in the appendix under 8.1.2 Pilotstudy with housemate.

The participants followed the instructions and put the photographs in a Word document. After receiving the photographs I could develop questions around them. It turned out to be difficult to find meaningful questions for each individual photograph beforehand. So I thought of two general questions which I could ask for each photograph and additional questions were asked during the interview. I also developed questions which were directed to all the photographs. Because I was interested in how the students experienced this exercise, I asked questions about this as well. The questions around the photographs that were thought of upfront can be found in the appendix under 8.1.3 Questions around the photographs. They were not shared with the participants beforehand.

The Word documents of the participants were printed and used during the interviews. Having the photographs on paper proved to be useful when talking about them because it made it easy to go through them and look at them all at once.

WALK-ALONG

Because it was interesting and pleasant to do the guided visit to Alma 3 with an autistic student during the *Inclusive Design* course and because of past research on walk-along interviews (Carpiano 2009; Jellema, Annemans, & Heylighen 2019; Baumers & Heylighen, 2014), I found this method to be useful as well. In a walk-along interview, the interview is conducted while the researcher receives a tour which is guided by the participant (Carpiano 2009; Jellema, Annemans, & Heylighen 2019). The researcher is walked through the participant's lived experience (Carpiano, 2009). An interview like this is well suited to illuminate **the influence of the built environment and social setting on a person's experience**. It gives the opportunity to observe 'how the physical, social and mental dimensions of place and space interact within and across time for individuals' (Carpiano, 2009). It is also a way to examine how the participants interpret their context while the researcher experiences it. The movement of people through and around buildings reveals their performance of this space or their performance of knowledge about the space (Baumers & Heylighen, 2014).

The method increases the participation due to the participant being the 'tour guide' and taking control (Carpiano, 2009). It has the advantage that the task of showing people around and discussing things while doing this, is intuitive. Most people won't need much guidance in terms of talking, pointing and giving an opinion about the things surrounding them. The walk-along interview makes it possible to

ask the participants about their own experience as well as how they perceive others would experience it (Jellema, Annemans, & Heylighen, 2019). Difficulties that may be encountered with this way of interviewing for this particular research lay in using the right equipment to audio-record and in the way the information can be analysed. The information given through the tour is linked to a specific place. Making notes and mentioning where you are in space while recording may help to address the right information to the right place (Carpiano 2009).

It can be helpful to have plans of the building and collect photographs which specify and situate certain elements spoken of (Jellema, Annemans, & Heylighen, 2019). To help the analysis the researcher can hand the participants a piece of paper at the end of the tour to map out different spaces (Carpiano 2009). This is a flexible method (Carpiano, 2009). It can be open-ended, where the participant talks about anything they want or it can be semi-structed, where conversation during the tour is supported by a prepared topic list and set of questions.

I implemented the knowledge from literature into preparations for the walk-along interviews¹⁵. I planned the tour to be open-ended so the participants could be in control. During this interview I would also ask for clarifications about subjects handled in the photovoice meeting. After the tour I planned to ask the participants to map out a few things on paper: 1) which place was their favourite spot and why, 2) which spaces they find comfortable and uncomfortable and why, and 3) what they enjoy doing and where and why that is the case.

SEMI-STRUCTURED INTERVIEW

Because this is my first time interviewing people, I read in *Handboek kwalitatieve onderzoeksmethoden* (Mortelmans, 2013) about different kinds of interviews, content of interviews and interview techniques. I chose to work with a semi-structured interview which is conducted in the same meeting as the photovoice.

When preparing the interview, which were face-to-face, I first thought to construct an unstructured interview with a topic list, which contained the following topics: a) study field and student life b) living in student accommodation c) autism d) life after living in student accommodation. But I was concerned that this method would not collect enough data, because some people might find it difficult to talk extensively about a topic without having clear questions. This is why I developed questions for each topic. These questions follow the order of a structured interview with five phases (leading to the mentioned order of the topics above). However I also asked additional questions depending on their answers, which make my interviews semi-structured:

- 1) opening questions about study field, interests and student life
- 2) an introductory question by asking about a typical day
- 3) transition questions which ask about concrete behaviour and experiences about needs for student accommodation and relation to housemates
- 4) key questions about living in student accommodation, what is (dis)liked, difficulties and advantages

¹⁵ Due to Covid-19 it became impossible to do guided tours because of the measures of the government. However the method and suggested implementation of the walk-along interview is still mentioned in the thesis because a spontaneous walk-along interview with Eline was done.

5) concluding questions about autism and meaning of their student accommodation

The full set of questions (in Dutch) for each participant can be found in the appendix under 8.2 8.2 Semi-structured interview guides.

Before the start of the interview I asked permission to record the interview, so it could be transcribed, analysed and codified later. The first interview was recorded with my personal device as well as a professional recorder. Because the recording on both devices was of equal quality, I only used my personal device to record the following interviews because it was easier to transcribe the interviews. I stressed that the interviews would be pseudonymised.

While interviewing I kept notice of the following interview techniques (Mortelmans, 2013): a) my position in the interview is that of the listener, not the talker b) the researcher has an open and kind attitude towards the participant, making the participant feel at ease by being sensitive to what is said c) don't make use of technical terms and ask clear questions d) enjoy while interviewing. In the interview with Eline the research was briefly explained, for the others this was not necessary because it was already explained in the introduction meeting.

CO-ANALYSING

In participatory design or research the part of co-interpretation by the researcher and participant is an essential part of the process (Spinuzzi, 2005). The knowledge gathered through the participatory process tends to be tacit knowledge, which is knowledge people have without being able to articulate it. Through introducing an analysing meeting, the participants are made aware of this knowledge and can feel empowered.

After I gathered data from the first meetings, the approach of the last meeting changed: The situation ¹⁶ didn't allow for a co-design scenario. The meeting became an analysing meeting which was twofold: a) a reflection on the insights gained from both participants b) a comparison with insights gained from the other student accommodations. This was intended/expected to make the participants more aware of their own living situation and gave additional insights.

The last meeting planned with the participants had two purposes: a) gathering and confirming information about the students living situation in the student accommodation b) giving information back to the participant. This meeting is conducted in a small group of three people of skype: myself and two participants a) Victor and Koen or b) Ellen and her mother Tessa. The meeting consisted of the following two parts:



fig. 2 Content analysing meeting

In the **first part** the previous meeting and its analysis is discussed. I made the analysis of all the interviews under guidance of the supervisor and assistant. These analyses were transformed into concepts I could talk about with the participants, while using the photographs and made schemes as

¹⁶ Due to 1) the female participants who didn't want to involve their housemates and 2) the measures to limit the spread of COVID-19.

support in this. The participants were invited to give feedback on my interpretation of their experience. This allowed to discuss, 1) what would be an ideal living situation and 2) aspects of living in a student accommodation.

In the **second part** I showed the participants a comparison with the other cases. The intention of this part of the meeting is to make the participants aware of how other autistic students are living, what the differences and similarities are with their own living situation and maybe what they can learn from the others' living situations.

I made for each group of participants a ppt presentation, which we discussed through skype ¹⁷. The first part about their own living situation, I had sent upfront to the participants so they could discuss this beforehand. This part contained my analysis of our previous meeting, structured under four themes. I also asked them to think about what would be an ideal living situation. I suggested to think about people, type of room and student accommodation, who would use the (shared) space, kind of spaces, light, view and other sensory qualities. They were asked to think about changing their living situation according to the four themes. During the meeting they could comment and address mistakes and we discussed their idea of an ideal living situation. The second part, where the different living situations of the autistic students are compared across the same four themes, I did not sent upfront. During the meeting they had the opportunity to comment and ask questions where they felt it was needed. At the end of the meeting I asked them if they had something to added and whether and how their idea of an ideal living situation had changed.

3.2.5. ELABORATION SESSIONS

The situations of the participants required some alteration in the foreseen schedule, making that each case is approached in a slightly different way.

When I first met the participants, they were again orally informed about the research, their role in it and what the foreseen schedule would be. Again they had the option to suggest other ways of conducting this research. The participants who would participate in more than one meeting later received an informed consent form which they could fill in. The consent form handled following topics: "Content of research", "Approach", "What is happening with this information", "Why participating is interesting", "Where can you ask your questions", "How to participate" and was written in Dutch. They received it the second time meeting and could give it back to the researcher at any time they wanted.

Giving the participants as much information as possible before meeting ensured that they were well informed. Through meeting a first time in an informal way, the participants would get to know me and be more comfortable in the following meetings. In this way being more comfortable can lead to better results.

ELINE LIVING IN STUDENT ACCOMMODATION

Eline is in her seventh and last year of study. She has a degree in Law and is now doing a two-year study in notary. She spent her first two years of college at KULAK, so she could still live at home. In her third year, she came to campus Leuven and started living in student accommodation during the week.

 $^{^{17}}$ Due to the measures of the government to limit the spread of the virus, covid-19 this meeting could not be held physically.

Her student accommodation is a big baroque house situated in the city centre which is located close to her campus and the train station. This year, the house has 15 students living in it. At the time of the visit the building was under construction while students were still living there.

Eline and I decided on meeting once at her student accommodation at a moment Eline chose. The communication with Eline happened through e-mail. I had prepared a set of questions in the form of a structured interview with topics about study field and student life, living in student accommodation, autism and life after college. Eline did like to have the questions in advance to be more efficient, so the questions were sent to her through e-mail. She also expected to do a guided tour around her student accommodation to focus on the architectural aspect like was done with the exercise for *the Inclusive Design* course. The researcher prepared herself according to this possibility by refreshing what she had prepared for the walk-along interview.

The meeting went as follows. Eline and I met in public in the evening and walked to the student accommodation where we found a quiet place to talk. An audio recording of the whole meeting was made with my personal device and a professional recorder, after receiving Eline's consent. After the structured interview Eline suggested to show me around in the house. This walk-along tour was openended and Eline gave information where she thought this would be interesting and useful. According to the places shown, the researcher asked questions about it. At the end of the tour, I asked if she could also send some photographs. These pictures where received through e-mail.

VICTOR AND KOEN CO-HOUSING

Victor is studying architectural engineering and is a third year student. He has been living with Koen and Paul since August 2019 and used to live with his mother before moving here. He doesn't go back home and lives permanently with Koen and Paul. Koen is an IT teacher and consultant and was already a friend of Victor's prior to them living together. Paul and Koen had been living in their house for two years when they started renovating it. Before Victor moved in Koen had also given shelter to a student of his until he graduated. Victor, Koen and Paul are co-housing, which means that everyone's voice is equally important in this household. However Koen and Paul are the owners of the house, because (for now) Victor is not contributing financially. The house is located in Wilsele, which is further away from campus Arenberg than a regular student accommodation.

The number of meetings did not change compared to the original plan. However Koen isn't a fellow student. He is an adult and he is in a different phase of his life than Victor. Because they are living together and are experiencing living together the intended meetings can stay the same. The following schedule was followed:

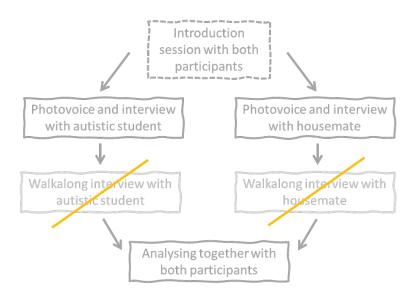


fig. 3 Schedule of meetings with Victor and Koen

The communication with Victor and Koen happened through a group chat on *Facebook* after the introduction session. For this session, I went to their home and we talked in the living room about the content of the next session and we had some small-talk. They were given the photovoice instruction on paper and had the opportunity to ask questions. We planned when the next meeting would be and decided to send the questions of the structured interviews upfront.

I received the photographs made for the photovoice meeting two days before the meeting. I tried to prepare questions linked to each photograph, which proved to be difficult. What participants explained about the photographs during the meeting allowed to ask better questions. The photovoice meeting did not happen in their house.

The photovoice interview with Victor was conducted in my private room in my student accommodation. When seated the informed consent form was handed over and the meeting was audio-recorded with my personal device. We decided to discuss the photographs first, to then continue with the structured interview. The topics discussed with Victor were study field and student life, living in co-housing, autism and life after college.

The photovoice interview with Koen was conducted in the conference room at the high school in the city centre of Leuven, where Koen was working that day. When seated the informed consent form was handed over and the meeting was audio-recorded with my personal device. Again we decided to first discuss the photographs and then directly continue with the structured interview. The topics discussed with Koen were job and living with an autistic person, living in co-housing, autism and life after living in co-housing. After the interview Koen showed me the chapel of the school which was equipped as a quiet room to study.

The analysing meeting happened through skype¹⁸ with both of them. The meeting was recorded with my personal device and the audio recorder on my laptop. The proposed order was followed. The topics discussed in this meeting where 'independence', ' (not) feeling at home', 'shared versus individual space' and 'finding rest and avoiding stress'.

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 $^{^{\}rm 18}$ Due to the measures of the government to limit the spread of the virus, covid-19.

ELLEN LIVING IN STUDENT ACCOMMODATION AND MOTHER TESSA

Ellen is studying bio-engineering and is a fourth year student. She has been living in student accommodation since she started college because it was impossible to live at home due to the distance. Her student accommodation is the KU Leuven residence Arenberg in Heverlee, where she stays during the week. The student accommodation is surrounded by green and is close to her campus. In Ellen's corridor live 10 people, there are more corridors in the building. Tessa is Ellen's mother and is currently unemployed. She learned from her experience with her son how to guide Ellen in living in student accommodation.

The meetings changed compared to the original plan because of the participants' mother-daughter relationship. There was no second participant who was also living in the student accommodation. For Ellen the kind and number of meetings stayed the same as was originally planned. Because it would not be useful nor manageable to let Tessa do the same exercises, her involvement became an extra view on the experience of Ellen. In this way the researcher thought it would be interesting to let Tessa discuss the photographs Ellen made. This translated itself into the following schedule:

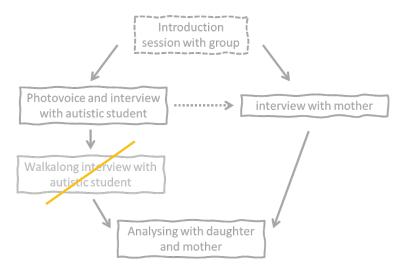


fig. 4 Schedule of meetings with Ellen and her mother

The communication with Ellen and Tessa happened via Ellen. Initially through e-mail but after the photovoice meeting we switched to *Facebook*. For the introduction session, I met both participants at Ellen's student accommodation. We - Ellen, Tessa, Tessa's boyfriend, and I - , talked in the communal kitchen of Ellen's corridor about the content of the next sessions and we had some small-talk. Ellen was given the photovoice instruction on paper and they had the opportunity to ask questions. We decided to send the questions of the structured interviews upfront so Ellen would be more comfortable.

I received the photographs that were made for the photovoice meeting two days before the meeting. I tried to prepare questions linked to each photograph, which proved to be difficult. What participants explained about the photographs during the meeting allowed to ask better questions. The photovoice meeting did not happen in their house.

The photovoice interview with Ellen was conducted in the communal kitchen of her student accommodation. When seated the informed consent form for her and her mother was handed over and the meeting was audio-recorded with the personal device of the researcher. We chose to first

discuss the photographs and then directly continue with the structured interview. The topics discussed with Ellen were study field and student life, living in student accommodation, autism and life after college.

The meeting with Tessa happened through *Skype*¹⁹. When the conversation started, the meeting was audio-recorded with my personal device and the audio recorder of my laptop. We decided to first discuss the photographs and then directly continue with the structured interview. The topics discussed with Tessa were study field and student life, living in student accommodation, autism and finishing questions.

The analysing meeting happened through skype²⁰ with both of them. The meeting was recorded with my personal device and the audio recorder on my laptop. The proposed order was followed. The topics discussed in this meeting where 'independence', '(not) feeling at home', 'shared versus individual space' and 'finding rest and avoiding stress'.

3.3. DATA ANALYSIS

3.3.1. QUALITATIVE ANALYSIS

To analyse the interviews, I roughly followed the *Qualitative Analysis Guide Of Leuven* (QUAGOL). This analysing method consists of 2 phases with each 5 stages, allowing the researcher to dig deeper with every step (Dierckx de Casterlé, Gastmans, Bryon, & Denier, 2012). The first phase is a thoughtful preparation of the coding process which is done with paper and pencil. This part is crucial to prepare the framework for the actual coding. The second phase is the actual coding and is typically done with a qualitative software program. It is said that a qualitative analysis is a team effort, in this case the knowledge and help of the supervisor and assistant were useful in this master thesis. I analysed the interviews alone, but asked the supervisor and assistant for feedback. In the analysing meeting the participants also anticipated on the findings.

After each interview was conducted I transcribed it and started the first phase of the analysis. The analysis and fieldwork ran in parallel. I chose to do the complete analysis by hand because for the number of interviews conducted, learning a new software program would be a big effort.

The first stage is thorough (re)reading the transcribed interviews. I read the interview and underlined and wrote comments in pencil on the printed interviews.

The second stage is drafting a narrative interview report. The interview was reread and some key words were marked. Then the interview was put aside and I tried to capture the essence of the interviewee's story in answer to the research question in about one page.

The third stage is making a conceptual interview scheme which will provide insight into the research topic. The most important data were filtered and clustered allowing to replace the concrete experiences with abstract concepts. These concepts were placed in a topic list for each individual interview. The topic lists of the interview with Eline and photovoice meetings with Victor, Koen, Ellen

¹⁹ This due to 1) it would be too much trouble for travelling to Leuven 2) the measures of the government to limit the spread of the virus, covid-19.

²⁰ Due to the measures of the government to limit the spread of the virus, covid-19.

and Tessa can be found in the appendix under 8.3 Topic lists interviews. The conceptual interview schemes and topic lists were read and commented on by the supervisor and assistant of this master's thesis. For the interview with Eline the supervisor also drafted a conceptual interview scheme and a topic list, so I had a reference on how this is normally done. The suggestions were taken into account and the topic lists were adapted accordingly.

The fourth stage is a fitting test of the conceptual interview schemes. In this step two questions are asked and answered by going back to the interview data: a) whether the concept schemes reflect the most important concepts in answer to the research question and whether no concepts are forgotten, and b) how the conceptual interview scheme is linked to the interview data. This was done by cutting up the interviews and placing the fragments under the corresponding topics. The topic lists were adapted to fit better to the data of the interviews.

The fifth stage is a constant comparison process. In this stage the interviews are compared to each other and concepts and hypotheses are checked. I compared the topic lists of newly analysed interviews with the ones I had made before, in this way I added topics which didn't come up first to the topic lists.

The sixth stage, drawing up a list of concepts, of the actual coding process happened in parallel with stage three. The seventh stage, which is the coding process happened in parallel with stage four.

The eighth stage consists of analysing and descripting the concepts. It is a cross-case analysis of the concepts. To do this I approached the concepts in different ways. I started from the research question and ordered the concepts per participant from most important to least according to their emphasis on it during the interviews. Next I compared the different concepts across the cases and linked them together through colour coding when they mention the same aspects. This can be found in the appendix under 8.4.1 ordering and comparing concepts within and across cases. Next I compared differences and similarities of mentioned concepts by a) the autistic students and their proxies, and b) the people in co-housing and the students in a student accommodation. Then I went more thorough by comparing the differences and similarities of the different cases one by one: Eline and Ellen (from her and her mother's perspective), Eline and Victor (from his and his housemates perspective), Ellen and Victor (also from all perspectives) and Ellen and her brother from Ellen's mother's perspective. This can be found in the appendix under 8.4.2 Differences and similarities. Then I linked the concepts to the subquestions of the first research question for each participant. This can be found in the appendix under 8.4.3 Link concepts and research question.

The ninth stage is the stage where the essential structure gets extracted. The concepts are integrated in a conceptual framework in a meaningful way. I started with linking the concepts to the conceptual interview schemes and combined these two together. Next I summarized every participants story in three to four sentences, highlighting the key elements of each interview. I finished this stage with a conceptual framework which can be found in the appendix under 8.5 Stage nine of the analysis: conceptual framework.

This conceptual framework I used to go back to the participants. When thinking about how I would return this information to them, I wanted to use a comprehensible structure which was the same for all participants. This resulted in developing four concepts (about living in a student accommodation) to talk about with them. Under these concepts the different elements of their stories which are

represented by the topic lists, could be discussed. After I had analysed everything on my own and developed the analysing meetings, I went back to the participants and told them what I had found. Their contribution in this stage of the analysis made that I could check with them whether I had interpreted their story correctly and it allowed me to make changes where needed. After this meeting I could finish my analysis with stage ten, a description of my findings which can be found under 4. *Findings*.

3.3.2. RELIABILITY

To increase the reliability of this research, constant feedback of the supervisor and assistant was received on different aspect: research question, methods, approach, paths that could be taken, analysis, findings, pieces of writing and structure of the master's thesis. The joint meetings with the researcher group also proved to be of help in this. Each comment was carefully taken into account and implemented in the further elaboration of this master's thesis. The reliability is also increased because of the last meeting with the participants. In this analysing meeting, misconception were cleared out and further explanation to certain concepts were brought up. Through using different interview technics, topics get covered from different angles, making the outcome more reliable.

4 FINDINGS

Due to the diversity within the autism spectrum, findings for one particular autistic student living in a student accommodation may not be representative for how others might feel in their student accommodation. The aim of my master's thesis was not to give a general solution for living 'op kot' as an autistic student, but to show how different autistic students live in their student accommodation, how they experience this and how the built space of the building plays a role in this.

4.1. PERSONAL EXPERIENCES OF LIVING IN STUDENT ACCOMMODATION

To gain insight into how autistic people experience living in a student accommodation I talked with autistic students and their proxies. During the interviews, attention was payed to the built environment and how social interactions are linked with this. The findings for each of the three participants are structured under the following four concepts which I came up with during the analysis: independence, (not) feeling at home, shared versus individual space, and finding rest and avoiding stress. I choose these concepts because they are all relevant to living in shared housing and thus student accommodation (as an autistic student). However, I am aware that some aspects might also fit under multiple concepts. The separation of the findings is thus artificial because the concepts might overlap at different points.

The first concept is **independence**, which is an important step towards adulthood. When living in a student accommodation a person has to manage their daily life on their own. This concept underlines how the participants approach this responsibility to do things on their own. The second concept is **(not) feeling at home**. Living in a student accommodation is different from living at the parental home, however this doesn't mean that a student can't feel comfortable or even at home in their student accommodation. This concept covers whether the participants feel at home in their accommodation and what aspects of their living situation affect that. The third concept, **shared versus individual space**, is relevant to look at in terms of shared living. In a shared accommodation multiple spaces - the living spaces, kitchens and bathrooms - are used by multiple residents. All residents also have a private room, which is their space to express themselves freely. This concept addresses how the participants use spaces shared with others and how they look at it. The last concept is **finding rest and avoiding stress**. College life can be stressful. A place to come to rest and to relax is needed, especially for autistic students, after a long day of going to classes, commuting and interacting. This concept serves to show how the participants try to achieve this in their accommodation, but not always succeed.

4.1.1. ELINE LIVING IN A STUDENT ACCOMMODATION

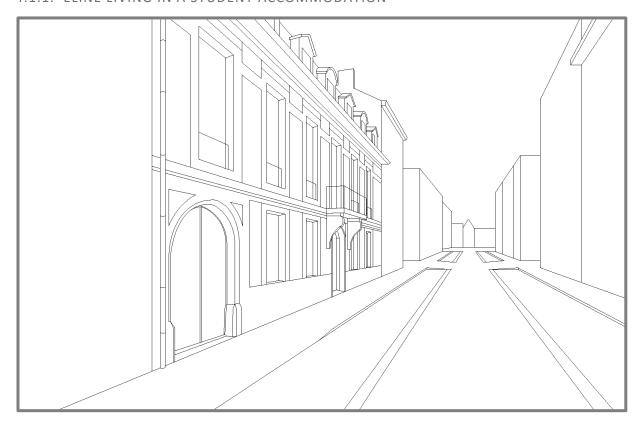


fig. 5 Type of student accommodation: A large student house in the centre of Leuven

Eline is an autistic student living in a student house. This is not an accommodation of the university itself but, as she says, is associated to it. The student house (fig. 5) is located in the centre of Leuven, which she finds convenient because it is close to her campus and the train station. In this house she lives with 14 other (female) students, none of whom knows that she is autistic. The building can house 20 students but because of ongoing construction works, the capacity is lower. She says she doesn't tell anyone that she is autistic and she believes that it is not something she needs to share because 1) she is afraid of prejudices: 'People know autism because of movies like *ben X* and others, and that' s not the reality' and 2) 'I don't want to be treated differently, that people have other ideas about me' and the looks at her autism, she says: '[I do see it] as an obstacle, I think that there are only a few [people] who take advantage of this, actually I don't think that someone takes an advantage of this, it's a disability' 3. Eline received her diagnosis during her adolescence, when she was already 15 years old.

Independence

Before she lived in a student accommodation in Leuven, she chose to study in Kortrijk to be able to keep living at home, which she thought would be nice. To finish her studies she had to go to Leuven and live in a student accommodation because the distance made living at home no longer achievable. When choosing her student accommodation, she was particularly looking for one with some form of

²¹ Original: 'Mensen kennen zo autisme denk dan aan zo die films als ben X en zo en dat is niet de realiteit.'

²² Original: 'Ik wil ook niet anders behandeld worden, dat mensen andere ideeën over mij hebben.'

²³ Original: '[ik zie het] als een belemmering toch wel, ik denk dat er weinig [mensen] zijn die daar een voordeel uithalen, ik denk eigenlijk niet dat er bijna iemand een voordeel uithaalt, het is een beperking.'

social engagement. As she puts it: 'I am a bit shy and I won't start a conversation with someone that fast, so I was looking for a student accommodation where the housemates also would be more socially'²⁴.

Initially this was one communal meal a week and she thought 'that it might be good and that it's a moment in which you get to know everybody, just in a little bit looser atmosphere'²⁵. However this turned out different than she had anticipated. It changed from one communal meal a week to four (all included in the rent). Because these communal meals are prepared for them and they aren't allowed to cook for themselves²⁶, the normal social 'kot' experience of cooking together with housemates or friends is taken away. She said this is sad because she likes cooking. Because of this she misses the opportunity to develop a vital life skill for independent living and she says that it is the reason why many of her previous housemates changed of student accommodation. She also explains that 'four times a week is really too much for me and sometimes two times a week as well, it's often very stressful'²⁷ due to her noisy housemates. She mentions that just like her housemates she doesn't eat every day in her student accommodation together with the others, sometimes she eats later because of classes or sports.

What really bothers her is that the landlord is not treating them as adults and doesn't communicate clearly to them. She feels like her landlord doesn't pay attention to the opinions of the students who are living there although they all pay rent and thus, according to her, deserve to know what is happening in the building. By way of example she says the following: 'With Christmas and New Year they closed our 'kot', [...], it would have been convenient if I could have stayed to study and then it was imposed from one side' ²⁸. She feels like she and her housemates **don't have a voice** when decisions are made.

Eline mentions that she had received GON-assistance²⁹ in high school, but that she felt that this was a waste of time and she only did it because other people insisted she needed it. She says that she didn't have any other kind of **assistance** and that she only uses the limited facilities the university provides during an exam. 'I sit in the front row for the exams and I receive more time for an exam and that's it actually'³⁰. She doesn't seek support from her parents and only counts on them for practical issues. While living 'op kot' she expects that her housemates are open for social interaction, although this is not always the case.

²⁴ Original: 'Ik ben zo een beetje verlegen en ik ga dus niet snel zo een gesprek aanknopen met iemand dus ik zocht meer een kot waar dat de kotgenoten ook wat socialer zouden zijn.'

²⁵ Original: 'Dat is dan misschien wel goed en is dat zo een moment waarop dat je iedereen zo wat leert kennen, zo een beetje in een losse sfeer.'

²⁶ She didn't give a reason why they were not allowed to cook for themselves anymore.

²⁷ Original: 'Vier keer per week is echt teveel voor mij en twee keer per week soms ook, het is vaak erg stresserend.'

²⁸ Original: '[...] met kerst en nieuwjaar was het kot gesloten, [...], het zou wel handig zijn, moest ik hier kunnen blijven om te studeren en dat wordt zo eenzijdig opgelegd.'

²⁹ GON stands for 'Geïntegreerd ONderwijs' or Integrated Education. It is a collaboration between ordinary and special education. This term is no longer applicable since 2017 and has been replaced by a 'support model' for students with specific educational needs (Het Vlaams Ministerie van Onderwijs en Vorming, 2020a).

³⁰ Original: 'Ik zit op de eerste rij voor de examens en ik krijg meer tijd voor een examen en ja dat is het eigenlijk.'

(Not) feeling at home

When I asked her if she **feels at home** in her student accommodation, her answer was ambiguous. On one side she started to experience 'this place as a home'³¹, a second home because she has lived in this particular student accommodation for almost 5 years and she knew a few of her housemates because they have also lived there for a while. For a shorter period of time Eline also lived in another student accommodation. There she didn't feel good at all because she didn't had any form of contact with her housemates and she didn't want to live like that anymore. Living in this student accommodation, she thinks that the barrier to talk with housemates is lower than somewhere else. From her perspective, being forced into a form of social contact (with the communal meals) is an advantage of this student accommodation. She feels that in this way she has at least some form of contact with her housemates. On the other side Eline doesn't feel at home because of her relationship with her housemates. She refers to this relationship as (almost) not existing. She feels left out and sees that her housemates all have a closer bond and do activities together. She feels different from her housemates which results in her feeling like she doesn't belong there.

Specific to a student accommodation is that almost every year the combination of people living with you **changes**. This can make it difficult to connect with housemates. 'There has been a year that was extremely difficult, now there are some [housemates] with whom I have an okay contact'³². Every year there are some exchange students, Eline experiences this as something very positive: they are, according to her, more social and open towards her because they are looking for a substitute family. While Eline was guiding me through the student house, she showed me a hobby room in the basement. She says: 'The space was also used by someone who likes to craft [...]. [I don't use this space], a friend of my used to work here often and I still think it' s strange to be here because she has moved to Spain and it feels like it's Mila's bureau'³³. The following figure (fig. 6) shows in a conceptual way the layout of the rooms in Eline's student accommodation.

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³¹ Original: 'Je begint dat dan zo een beetje als een thuis te ervaren.'

³² Original: 'het is nog een jaar geweest dat het heel moeilijk liep en nu zijn er wel een aantal waar dat ik nog wel een oke contact mee heb.'

³³ Original: 'De ruimte die ook wel gebruikt werd door iemand die zo wel graag knutselde [...] [ik zit hier zelf niet], een vriendin van mij werkte hier vaak en ik vind dat nog altijd vreemd om hier zo te zitten want die is verhuist naar Spanje en dat voelt als Mila's bureau.'

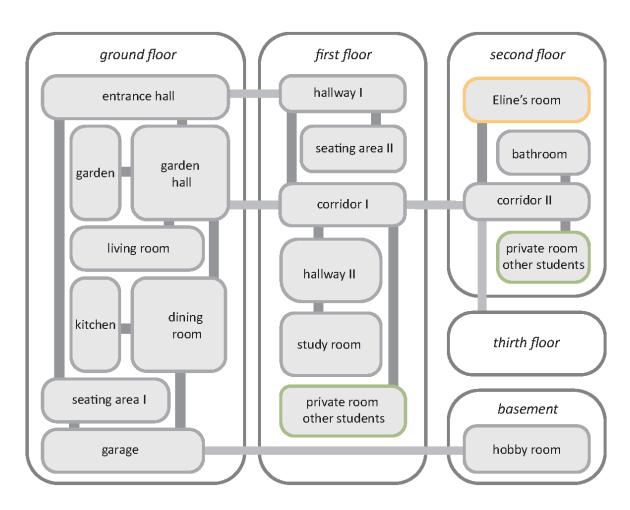


fig. 6 Conceptual scheme of Eline's student accommodation based on the guiding tour

Another aspect which has an influence on her experience is **communication**. With her housemates she communicates through $WhatsApp^{34}$ and they also have a bulletin board (fig. 7) to pin notes to in the hallway at the garden side of the house or they slide notes under someone's door. Open and clear communication is appreciated by her, but she feels that the landlord is not providing her this.



fig. 7 Picture Eline took, which shows the garden hall and it's staircase to corridor I. The bulletin board is on the left.

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³⁴ WhatsApp is a mobile app for messaging on a smartphone.

'I have a little bit of a different **biorhythm** [than my housemates] and I experience this as a disadvantage because I am rather calm and quiet and they are the total opposite and they become more active in the evening. My housemates are all extremely active and noisy and they are evening people'³⁵. Having a different lifestyle than her housemates also has an influence on the way she is feeling in her student accommodation. When asked whether she thought it would be helpful to know one of her housemates upfront, she said: 'On the one hand yes, but on the other hand that makes it more difficult to develop new contacts'³⁶.

Shared versus individual space

As mentioned above she chose this student accommodation because of the forced social aspect (of the communal meals). This is also the reason why **she didn't wanted a studio**, which has its own kitchen and bathroom, but a standard private room with shared kitchen and bathroom. 'You share toilet, shower, kitchen, you cross each other more often than if you wouldn't have that'³⁷. Her private room on the second floor is, as she says, not luxurious, which she doesn't need. On one side of the room she has a closet, covering the whole wall, in which the sink is integrated. Her desk stands parallel with this and her bed and a small bookshelf stand in the opposite corner and against the wall with the door. She has a window with view to the garden (fig. 8 and fig. 9).

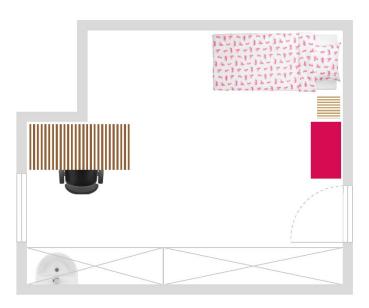


fig. 8 Schematic representation of Eline's room

³⁵ Original: 'Ik heb zo een beetje een ander bioritme [dan mijn kotgenoten] en dat vind ik wel een nadeel omdat ik ben zo eerder rustig en stil en die zijn zo totaal het andere uiterste en die worden dan zo actiever 's avonds. Mijn kotgenoten zijn allemaal zo heel actief en luidruchtig en da zijn zo avondmensen.'

³⁶ Original: 'Enerzijds wel maar langs de andere kant is dat dan ook moeilijker om nieuwe contacten te leggen.'

³⁷ Original: 'Je deelt toilet, douche, keuken, je komt elkaar sowieso meer tegen dan moest je dat niet hebben.'



fig. 9 Picture Eline took to show her bedroom

In the building there are many **different kinds of shared spaces for social interaction**, most of them she barely uses now and some of them she used in the past but not anymore. A representation of her use of the spaces in the student accommodation is shown in fig. 10. For example, the living room is often used by her housemates, but barely by herself. 'If there is a Christmas party or something else then we sit here, there are some who come here to read or crochet'³⁸. In the past she made use of the smaller seating areas in the building ³⁹. These were more secluded which she likes. She appreciates that the shared spaces are cleaned by someone professional and that there is no discussion about this among the housemates.

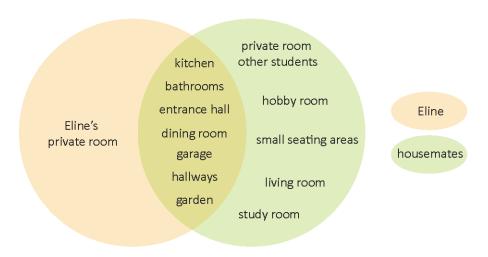


fig. 10 Gradient in social contact through use of space: how Eline uses the spaces in her student accommodation

Finding rest & avoiding stress

The study room on the first floor she had used in the past, but she prefers to study in the university library. There she gets less distracted by other people, like her housemates, because she can ignore the people in the library. On top of this it helps her to see other people study and there she can be

³⁸ Original: 'Als er zo een kerstfeestje ofzo is dan zitten we hier wel, er zijn er hier die komen lezen of haken ofzo.'

³⁹ Why she stopped using them is not clear, perhaps she didn't have a friend with whom she could share this space.

more anonymous. Another reason why she doesn't like to sit in the study room is because when seated her back would be facing the door and she would hear noises and movements behind her. This space doesn't give her an **overview** which she might need to feel comfortable.

She asked for a room with garden view because she thought that in this way she would experience less street noise, but unfortunately she had noisy neighbours, who would often have parties, for some years. However she still finds it peaceful to look onto some greenery instead of cars. In summer she goes into the garden and enjoys the sun while drinking a cup of tea and eating a biscuit.



fig. 11 Picture Eline took of the garden view from her room which she enjoys

Living in this student accommodation is experienced as stressful by Eline because there are many (sensory) stimuli. 'These communal meals where everyone is very hyper and active, the noise in the building, because [in my private room] I am located next to the staircase (fig. 7) and you can hear everything and then from the corridor I also hear a lot and when the person in the room next to me even plugs in her adaptor I hear it at my place' ⁴⁰. She experiences the **sound stimuli**, and thus noise from others, as the most difficult, but she does like listening to music. She blames the thin walls in the student accommodation for her hearing everything. Small details like a) bad insulation of the outer walls and old windows, which makes it very hot in the summer and cold in the winter, b) thin inside walls, c) thin curtains which don't keep out light or heat, and d) things that stop working as no longer having hot water in her private room, make living (with other people) more stressful.

After a busy day at her internship she wants to come to rest in her student accommodation, and she feels like that is not possible there. 'I think because we know each other, you always have the feeling that you're being controlled, I don't know, you can't be anonymous and sometimes I need that'⁴¹. **Balancing** the need for social contact and the search for rest and being on her own is one of the main difficulties she encounters from living in her student accommodation. From living in a student accommodation she learned to be more open to other people and cultures, and that she sometimes will have to talk the first step to interact with someone.

⁴⁰ Original: 'Dit kot maaltijden waar iedereen zo hyper en actief is, lawaai van in het gebouw want ja ik zit aan de traphal en je hoort alles en dan op de gang hoor ik ook heel veel en als degene naast mij zelfs maar haar stekker in haar stopcontact steekt dan hoor ik dat tot bij mij.'

⁴¹ Original: 'Ik denk omdat we elkaar kennen, heb je zo altijd het gevoel dat je wat gecontroleerd wordt, ik weet het niet, je kan niet anoniem zijn en soms heb ik dat wel nodig.'

4.1.2. VICTOR AND KOEN IN CO-HOUSING

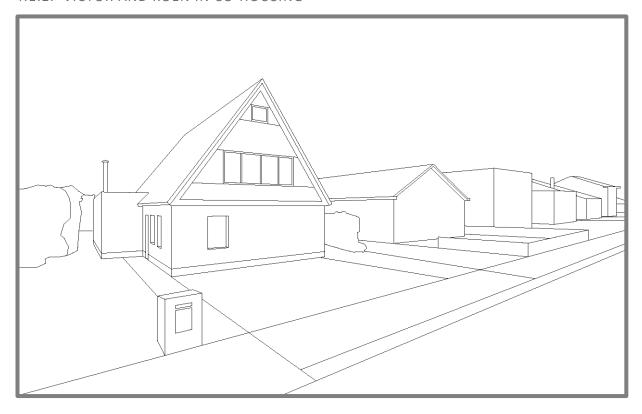


fig. 12 Type of student accommodation: Co-housing in Wilsele, a neighbourhood close to Leuven

Victor recently⁴², at the end of his second year of college, moved out of his parental home and when he needed a place to stay, his friend, Koen, offered him a room in his home (fig. 12) to stay during the summer. In this way Victor had a comfortable place to study for the re-examination in august. Victor never left since that moment and from then Koen, his husband Paul and Victor are living together in what they call a co-housing situation⁴³. When he moved in, Koen and Paul were still renovating the house. Before they started living together Koen knew that Victor is autistic, and recently Paul and Victor talked about this as well. Victor is very open about being autistic and, according to Koen, because of his intelligence he can communicate about it clearly. Koen mentions that Victor chooses his friends according to how open they are to get to know him. Victor does not only see disadvantages of being autistic and tries to pass over 'the label'. 'The fact that I'm different is already something negative, the positive elements, in my case, cancel out the negative elements to something neutral [...]. Because I know it, I don't think I'm disadvantaged or favoured'44. Victor was first diagnosed with high intelligence and when they did more tests he also received the diagnosis of autism around the age of 12. He does not think his autism is the reason for his problems, he only thinks about it when he is around too many people, when there are too many (sensory) stimuli or when he feels tired. He quickly notices details, which, as he says, is an advantage when revising a paper. Koen is very open towards Victor and has a positive view on autism and sees that autistic people might have a strength due to their eye for detail.

⁴² When the research was conducted Victor only lived for half a year with Koen and Paul.

⁴³ All of their names are on the mailbox, making them all equal. However (for now) Victor is not paying anything. He hopes that he can pay them back when he is able to.

⁴⁴ Original: 'Het feit dat ik anders ben is al iets negatief, de positieve elementen daarvan, in mijn geval, maken de negatieve elementen allemaal neutraal, [...]. Omdat ik het ken, vind ik mij niet benadeeld of bevoordeeld.'

Independence

This form of living together was new to all of them, so they had to figure out together how this could work and where the boundaries are. 'From in the beginning I required, not out of myself, but just out of the situation that I was in, a lot of attention. [...] I know, that was not easy for Paul'⁴⁵. Arrangements around living together developed when issues presented themselves and they solved it together. An important agreement was that Victor would stay at least one year. Koen mentioned that Victor even changed his domicile to this address. A **mutual commitment**, in time, from all of them is made, giving certainty to Victor that he always has a place to stay. Koen would really enjoy it if Victor would stay even after college and also talked about this with Victor.

For Victor the **people with whom he is living and the organisation of his day are key** features of how he is living. Because he is studying architectural engineering, he spends most of his time at the campus of Arenberg. Almost every day, he is there from 8u30 till often 19u00 or later. Much of his time is spent in the Arenberg castle because this is the place where the design courses are held⁴⁶. Koen says they try to keep the same rhythm every day, even during the weekend. Victor likes the **routine** in the house, he especially likes the mornings when they eat together at the kitchen counter (fig. 13). For lunch and dinner they eat at the dining table.





fig. 13 Picture made by Victor to show that they have a routine, and fig. 14 Picture made by Koen to show how technology eases Victor's life, according to him

Victor can **rely on** Koen to help him organise his day and for domestic support. Koen supports Victor by waking him up in the morning, making his lunch, driving with him to university by bike or car and picking him up again and cooking dinner on a daily basis. Victor can also rely on Koen for emotional support because they are good friends. When Victor has a deadline and needs to work till late, Koen will work and stay up as well so Victor doesn't feel alone. When Victor has been working with friends he can rely on Koen to come and pick him up at night. Sometimes Koen feels that his role is that of a mother because he helps Victor in studying, cooking and planning. The last one he stresses as important because Victor tends to schedule meeting multiple people at the same time and makes too

⁴⁵ Original: 'Van in 't begin eiste ik, niet vanuit mezelf, ma gewoon vanuit de positie waarin ik zat, veel aandacht [...]. Ik weet wel, dat was niet makkelijk voor Paul.'

⁴⁶ Architectural engineering students in Leuven get design courses in the Arenberg castle and this is also open for them to use as a study place. Many of these students, including Victor and myself, experience the castle as a kind of second home because they spend so much time there.

many plans because he wants to do good for everybody. Koen tries to help him in this by keeping an eye on it. He guided Victor in what kind of signals he was sending out to other people. Victor is friendly to everyone and shows a big interest in people but when he doesn't show that he doesn't have the same interests, it brings him in situations he would rather not be in.

Koen supports Victor in different aspects of his daily life as much as he can. He says that if something goes wrong Victor could always come to him for help. If Koen is away for work, he says that Paul has to take over his role so the organisation of Victor's day stays the same. For example since Victor moved in they have google home pods (fig. 14) in different spaces in the house. Koen says he can see that it is useful for Victor to help him find rest by using it as a way to organise his calendar. Koen likes that the way they are living is becoming automated, which is also convenient. Victor also thinks it is useful but doesn't stress it as necessary.

They have divided the tasks in the house, however this arrangement is flexible if Victor is to occupied with university: Koen cooks and does the shopping, Paul does the laundry, Victor folds the laundry and takes care of the plants (because he likes that) and they all clean.

Victor received much **assistance** when he was younger, but he says that he didn't see the value of it at that time because he felt like he didn't had problems although he knew he was different. 'I had a period in which I wanted to call for a lot of assistance myself, also to facilities of the university itself. This has been very useful. A lot of extremely understanding [people] and people with knowledge about it, and it was like that, I feel more comfortable and supported. Hilde⁴⁷, amazing, she helped, I think without her that it all would have been more difficult'⁴⁸. He also went to a psychologist but stopped that. He knows if he has a problem he can count on his friends.

(Not) feeling at home

Victor tried living with his partner in different gradations of commitment but it never succeeded. He says: 'I'm a difficult person to live with, I think, because I notice everything and I find it's very hard to cope with things'⁴⁹. That made him think how he wanted to live. Living with Koen and Paul is very different because their relationship developed through living together. They are all very close and both Victor and Koen describe themselves as a **family** of extremely close friends. They have a deep, open connection. Victor likes that nothing changes when they are around other people.

According to Koen **communication is key** when living together with others, otherwise you'll get frustrated. The main communication happens through a shared agenda, making that the three of them are very open towards each other. If they experienced a problem it was because of poor communication, for example when Victor forgot to mention he was not coming home for dinner. Koen helps Victor in maintaining his agenda, which Victor likes. Their digital agenda is very elaborated. Victor finds this extremely useful because he can check for himself what his housemates are up to without bothering them and they can plan things in for each other. For other communication they use a

⁴⁷ Hilde is the student counselor for student who are studying architectural engineering at the KU Leuven.

⁴⁸ Original: 'dan heb ik een periode gehad waarin dat ik zelf heel veel hulp wou inschakelen, ook naar faciliteiten van de universiteit zelf. Dat is heel nuttig geweest. Heel veel begripvolle [mensen] en mensen met kennis daarover, en dat was het ook wel zo, ik voel mij meer op mijn gemak en ondersteund. Hilde, geweldig, dat helpt wel, ik denk zonder haar dat dat moeilijker was geweest allemaal.'

⁴⁹ Original: 'Ik ben een moeilijk persoon om mee te leven, vind ik zelf, omdat ik net zo alles opmerk en ik vind het moeilijk om dingen te verkroppen.'

messenger group on *Facebook*. During breakfast they run over the planning of Victor's day to avoid mistakes. Koen is the mediator in the house, he makes sure that both Victor and Paul are happy with the situation.

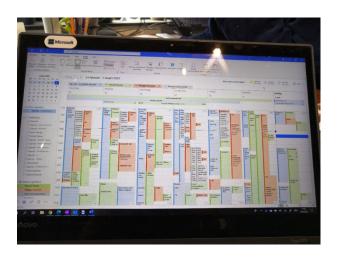


fig. 15 Picture of Koen to show the fundament of living together: the shared agenda

Koen makes Victor feel welcome through **encouraging him in adapting the house** together. 'We are going to give him *carte blanche* for the garden and he is going to build the wellness with us and stuff like that'⁵⁰. When Victor started living here possibilities, which he didn't had when living with his mother, showed themselves through property, freedom, relationships and use of space. The faith they have in Victor made him more open to comfort and people. However Victor is still guarded in making changes for the shared spaces because he is not used to being allowed to do this, although Koen wants to see Victor's personality in every space of the house. In this way Victor is given **a voice** to express how he likes to live. Because he was used to do everything in his room and because he felt more comfortable in limiting his contribution to his own room, they started with personalising this space. Victor, with the help of his housemates, thought of a way to hang up mirrors to the ceiling. He did everything himself, so it all would be correct and the result made him proud of what he did. Both Koen and Victor like that he could express himself in this way and has, as Koen puts it, a safe place in the house (fig. 16).

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⁵⁰ Original: 'We gaan dan de tuin hem volledig carte blanche geven, de wellness gaat hij mee bouwen en zo.'



fig. 16 Picture of Victor which shows his mirror project for his room

Also the office space, which is used by Victor and Koen, is completely furnished together, from choosing the flooring and wall-papers to Victor suggesting to place a hanging chair. Under Victor's influence more plants found a place in the house (fig. 17). The office space is Victor's favourite place in the house 'because I really made it my own'⁵¹. To anticipate Koen and Victor's interest in technology, they added sensors to take better care of the plants. Because of Victor, the piano got moved from a dark corner of the living area to a more prominent space in the house and is now a place where they enjoy each other's company.





fig. 17 Pictures Koen took to show Victor's contributions in the house

Victor first studied architecture in Australia, which he thought was too easy. He also felt lonely there and thus came back to Belgium. When living with Koen and Paul, Victor feels comfortable, he is supported and feels that he is part of a family, which, he says, he didn't really feel at any time before. Victor feels at **home**. He refers to the house as his home base because of the people who are living there with him. Koen says: 'My house has become my home, because I am there with the people that I like, because it is a place to come to rest and a **place to be yourself**. [...] Your home is a place where

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⁵¹ Original: 'Omdat ik het echt mijn eigen heb gemaakt.'

you don't have to wear a mask because of society, but where you can truly be yourself'⁵². Victor appreciates that it is okay to be himself, that everything is possible in the house. For example he enjoys to just play the piano and look outside while doing nothing special or to play together with Koen and talk about things that are happening in their lives (fig. 18). What he likes about the piano is that it doesn't take a lot to make a space and that when you are not using it, it becomes thin. It feels like 'his' furniture is not taking up too much space, so that he doesn't feel pushy.





fig. 18 Picture Victor took to show how he is comfortable in the house and enjoys the atmosphere, and fig. 19 Picture Koen took to show the importance of the living area for being together

According to Koen the home and living together is also about making arrangements. 'Living together means **taking each other into account**. [...] That in everything you do.'⁵³ Victor and Koen both mention that the three of them are in need of relaxing activities in the house like watching tv together in the evening because all of them have active lives. 'You also want **to be together**, obviously'⁵⁴, Victor says. It is about making time for each other and doing things together, Koen says. He also really appreciates a third person in the house because now he is never alone. Koen's favourite space in the house is the living area, because this is the place where they all have fun together (, and fig. 19). This is why he also likes the office space because he can spent more time with Victor and they can motivate each other to work efficiently.

Although they have a different **rhythm** of living due to Victor being a college student and Koen and Paul who are both working, them living together works really well. They tried living on Victors rhythm but it was too heavy, then they tried to live on Koen's rhythm but that was not what Victor wanted, so they all adapted their rhythms to each other and since then there have been no issues. For example when the exams start, they all live according to a study-schedule they made up to support Victor.

⁵² Original: 'Mijn woning is thuis geworden, omdat ik daar ben bij die mensen die ik graag heb, omdat dat een plaats is om tot rust te komen en een plaats om uzelf te zijn. [...] U thuis is een plek waar dat je geen masker moet dragen van de maatschappij, waar je volledig uzelf kan zijn.'

⁵³ Original: 'Het samenwonen is dat je rekening houdt met elkaar.[...] Dat is gewoon in alles wat je doet'

⁵⁴ Original: 'Je wilt ook wel samen zijn natuurlijk.'

Shared versus individual space

'It became interesting to see what everybody's boundary was'⁵⁵ and 'we really had to flip through that ourselves, everybody had his own degree of how much privacy he wanted'⁵⁶, Victor says. Originally Koen and Paul had planned to have a second living room, so they could separately use the space, if for example they wanted to see different things on tv or one of them had friends over, the other could retreat to the other room. However this room became Victor's room and nobody in the house misses the second living room. The possibility to avoid each other and go to different rooms exists in the house because there is enough space but both Victor and Koen experience that they constantly look each other up. Koen says: 'The house facilitates this.'⁵⁷ 'But if we had to live in a small apartment with the three of us that would give constant friction, constant being unpleasant, then we maybe would have said, Victor you can't live here'⁵⁸.

The spaces enable different kinds of possibilities for social interaction with the housemates which is represented in fig. 20. Recently they crossed a new issue. Victor had invited a friend back home and they were talking in the living area about a private issue. But it was unclear to Paul that he better not interfered and joined the conversation. To avoid these kind of situations they decided that for private conversations they go to one of the office spaces or their private bedroom, if this is not the case all of them can join the conversation in the living area. The living area is the continuous space of kitchen, dining room and living room which the three of them use on a daily basis. There are two office spaces in the house. One of them is used by Paul, the other, bigger one is simultaneously used by Victor and Koen. Where Victor sits on one side of the desk and Koen on the other, according to who needs to use the most computer screens. There is one bathroom they all share and one guest toilet. A negative element about the house they both experienced is that it is cold in the hallway and the guest toilet. They often finish their days with a little conversation at the entrance of Victor's private room. A social gradient between collective space and private space is present in the house, which makes living there comfortable. Victor says: 'The social [aspect], I like it because you can decide for yourself the gradation therein, there's nothing wrong with retreating yourself after a day or so, I think that there's a lot of buffer and possibilities for that'59. For him, this buffer is also tolerating each other and keeping each other into account when deciding something.

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⁵⁵ Original: 'Het was wel interessant om te zien wat de grens was voor iedereen.'

⁵⁶ Original: 'Dat hebben we echt zelf moeten aftasten, iedereen had zo zijn graad van hoeveel privé dat hij wil hebben.'

⁵⁷ Original: 'Dat faciliteert de woning.'

⁵⁸ Original: 'Moesten we met ons alle drie op een klein appartementje wonen dat zou constant wrijvingen geven, constant niet aangenaam zijn, dan zouden we ook misschien gezegd hebben van Victor je kan bij ons niet terecht.'

⁵⁹ Original: 'Het sociale [aspect], ik vind dat wel fijn want je bepaald zelf de gradatie daar in, 't niet fout om u even terug te trekken na een dag ofzo, dat kan allemaal. Ik vind dat er heel veel buffer en mogelijkheden zijn daartoe.'



fig. 20 Gradient in social contact through use of space: how they use the spaces in the house

Since Victor is living with them, their lives and the spaces within the house got more **structured**. The functions got separated more clearly over the different rooms which results in **every room having it specific function**. However in every room the space can be **used flexible**. Victor used to study in his bedroom but that quickly changed after Koen suggested they could share the office space. From that moment on, his bedroom is only used for sleeping and relaxing and the office space of Victor and Koen is strictly used for studying and working. However the different kind of chairs in the bureau allow different kinds of working methods (fig. 21). When Victor doesn't needs much space and only his laptop, he uses the hanging chair (fig. 17). A fixed place for activities he experiences as useful because it helps him focus. Also Koen experiences this flexibility as something positive because now he works more efficiently and he likes the flexibility in the bureau as well. The living area is versatile to Victor but every zone has its own function which he likes. The space, in front of the piano, where these zones come together can be used in a flexible way. They both experienced that the spaces are not that well acoustically separated, sometimes the noise from another room, like snoring, is hearable. They say that if the spaces are functionally separated from each other, they also should be sealed acoustically.





fig. 21 Picture victor took to show that he has a specific space to work in, and fig. 22 Victor took a picture of the light above the guest toilet to show he likes predictability

With , and fig. 22 Victor wanted to show clarity and less interference. He doesn't like it when someone knocks on the toilet door and here it is not needed because you can clearly see if someone is on the toilet. He likes that this is understandable for everybody and says that this is what architecture should do. He says that this kind of light would also be useful for a study room. 'If someone is focusing or studying than this would be generally known, without having an interruption' ⁶⁰. He likes the **predictability** and logic of this element.

Finding rest & avoiding stress

Victor always studies at home, in the office space because this is the place where he gets the least distracted. If he studies in another room, which he doesn't know, he says, he has more difficulties focusing, this not only because of the people or (sensory) stimuli but also because of the space itself. Routine and a place he knows are important in this. What he likes about the office space in the house is that he has enough space to keep his things insight, because he says he is a chaotic person. The large desk in the bureau offers him the **overview** he wants and needs (fig. 21). Victor has an eye for **details**, he directly notices if things aren't done properly as the finishing of the ceiling, an unclean connection between floor and wall or the wallpaper that doesn't correctly align (fig. 23). Victor likes the pattern of the wallpaper, which he helped choosing, because it is geometrical. Koen also noticed Victor is very sensitive to details. For example when hanging up the mirrors, Victor was very precise and was measuring everything onto the millimeter, which made that he took very long to finish hanging them. Only after they hung in place Victor said that you don't see the millimeter differences. Koen makes a reference to *The Big Bang Theory* where Lennard is wearing a woolen pull and his skin gets completely irritated, which is a physical representation of how his friend Sheldon, who seems to be autistic, feels all the time.

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 $^{^{60}}$ Original: 'Als iemand aan 't focussen of aan 't studeren is dat dat algemeen geweten wordt zonder onderbreking.'



fig. 23 Picture Victor took to show he pays attention to details

Koen tries to take away any stress Victor might experience, so that Victor can focus on his studies. The spaces in the house each try to facilitate rest in their own specific way. For Koen himself finding rest at home is also important. When he comes home from work he takes half an hour for himself to relax in the couch. He likes to come to rest at home and is planning on adding a wellness and sauna in the garden. He sees that Victor also needs to find rest. The spaces which facilities this the best is the bathroom (fig. 24). Koen calls it a relaxing space. It is a peaceful room which is very **spacious and where the windows can be fully opened, the lights can be dimmed, plants are present and music can be played**.





fig. 24 Pictures Koen took to show the peacefulness of the bathroom

The spatial feeling created in the bathroom is liked by Victor and it is also there in the living area. Here all the windows can be opened as well and **contact with the garden**, **outside** can be made. This is a positive aspect of the house for Victor. Koen mentions that Victor feels that the ceiling in the living area is too low. Victor himself says that he thinks the tv corner is a bit dark. The two skylights in the ceiling (fig. 25) however add the spatial dimension and light Victor likes in the living room. Also in his own room Victor tried to bring the **natural light** further into the room with the mirrors. The connection with outside, and especially the morning view from the bathroom (fig. 25), has for Victor also a more, as he puts it, philosophical meaning: 'It doesn't matter what you do, eventually everything stays the same. It's a kind of a relativization of everything that will happen. This stays tomorrow whatever

happens, so it gives a kind of rest, actually'⁶¹. He enjoys the view and likes to peacefully wake up to it. Closeness to nature, thus outdoor greenery and plants, is important for Victor the find rest in his living situation: it implies less (sensory) stimuli, less distractions and plants are just fun to look at.





fig. 25 Picture Victor took to show the importance of the connection with outside, and fig. 26 Picture Victor took to show how he comes to rest in the evening

Koen sees that after a day with many (sensory) stimuli Victor is **physically exhausted**. This was new for him when Victor moved in and he tries to keep this in mind. The light in fig. 26 represents for Victor the opposite of stimulation. The light completely changes the atmosphere of the room and brings him in a restful mood. 'I think red is a soothing colour, because it radiates rest' 62.

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⁶¹ Original: 'Het maakt niet uit wat je doet, uiteindelijk blijft het allemaal hetzelfde. Het is een soort van relativatie van alles wat er gaat gebeuren, dit blijft morgen wat er ook nog gebeurt.'

⁶² Original: 'Ik vind rood een aangename kleur, omdat het zo rust uitstraalt.'

4.1.3. ELLEN LIVING IN A STUDENT ACCOMMODATION AND MOTHER TESSA

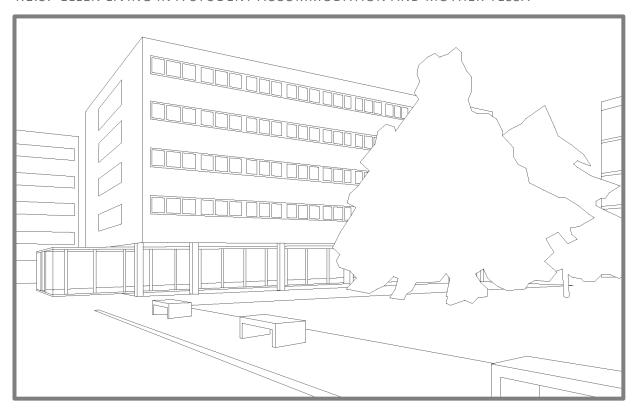


fig. 27 Type of student accommodation: KU Leuven residence in Heverlee

Ellen is an autistic student living at a KU Leuven residence in Heverlee (fig. 27). The rent of her room in this student accommodation is determined on the basis of her family income. The building Ellen lives in is one of the newer blocks and she rents a private room on the second floor in a corridor with nine other people, none of whom knows that she is autistic. She doesn't tell anyone that she is autistic for two reasons. 1) People don't know what autism is and they have prejudices. 'In high school it was like, someone was being aggressive, and then they said like "autist" or something, and then I wanted to say, "that person isn't autistic, it's not linked to each other". Thus I thought it was pretty annoying when people made such kind of remarks, and you then sit there with them, people don't know I'm autistic, I will just stay quiet'63. Her mother agrees that this is a big issue and that people even know less about high functioning autism. She argues that autism is still used too often as a swear word: 'autist' and that it can really hurt her children but that people don't realise that it hurts. 2) Ellen wants to be treated in a normal way. When I asked if it wouldn't be easier if she told someone, she said that it would be difficult because if you tell it to the wrong person, everybody might know. Her brother, who also lived in a student accommodation, only told his neighbour after this neighbour was open to him about his own autism. By the time Ellen was four, Tessa's colleagues asked her whether Ellen was autistic. Tessa didn't know what autism was, but noticed that her child was different from other

⁶³ Original: 'In 't middelbaar was dat dan, iemand die zo agressief deed, en dat ze dan zeiden van die autist ofzo en daar wou ik dan van zeggen, die heeft niet autisme, 't is niet gelinkt aan elkaar ofzo. Dus dat vond ik dan wel ambetant als mensen een opmerking zoals dat maken, en je zit daar zo bij, mensen weten niet dat ik autisme heb, ik ga maar zwijgen dan.'

children and consulted the CLB⁶⁴. They didn't mention anything about autism. It was only six years later, at the age of 10, that Ellen received her diagnosis. It took a long time between noticing that Ellen was different and her actually receiving a diagnosis. One year later, her brother, who always seemed down, would be diagnosed as well.

'Most people don't know I'm autistic, because you can't really see it. [...] It was probably like I was just the so-called weirdo'⁶⁵. Her mother says that in high school peers didn't treat her right although she was smart enough to hide her autism. However you could still see that she was different. Ellen thinks it is good that she had an opportunity to start over at university where nobody knows her because, according to her mother, Ellen could see that she was not treated well by peers. She doesn't have problems with her being autistic because she doesn't know what life is without it. 'When we were younger, my brother and I always thought we were smarter because of our autism, while actually it had nothing to do with it'⁶⁶. Her mother had told them this as comfort to deal with their diagnosis. Tessa tells that the way they expressed their autism was very different: Ellen was more aggressive while her brother was often very sad. Now Ellen is a sweet young adult. When her brother learned about his diagnosis, Tessa says, he felt relieved because the way he was feeling in certain situations started to make sense to him. According to Ellen, it might be an advantage that autistic people think in another way; some problems, other people struggle with, might be logic to solve. However, it might also be a disadvantage to think differently than other people. It really depends on the way you look at it.

Independence

Ellen started living in her student accommodation from the moment she went to college. Her mother believed this was best after advice from the CLB. They said this would be better than first going to college in Kortrijk, which was closer to home, but where she still had to be 'op kot'. The reasoning behind this was that 1) she only had to adapt to a new situation once and 2) her brother studied in Leuven as well and she could rely on him. Ellen also mentions that Gent could have been another option because it was closer to home but that Leuven eventually would suit her better because it is a more compact and less busy city, since there are no trams. Not losing valuable time to commuting, she thinks, has a positive effect on someone's grades, so living in a student accommodation is valuable. It is now her fourth year of living in her student accommodation. Ellen would have loved to live together with her brother, yet she didn't like the building he lived in and he didn't want to move because he was comfortable where he was. Tessa also didn't want them living in the same corridor because then Ellen would take advantage of her brother and not learn anything herself. Tessa mentions she learned much from her son going to college and how she could help Ellen better in this because she believes that Ellen would not have succeeded if she had been in the situation of her brother.

Tessa points out that, from the moment you are diagnosed with autism, you have access to the needed professional support. Ellen and her mother Tessa received different kinds of **assistance** while she was

⁶⁴ CLB is an abbreviation for Centrum voor leerlingenbegeleiding. Each school in Flanders works together with a CLB, which is approachable by students, parents and school boards for questions related to divers topics about health and studying (Het Vlaams Ministerie van Onderwijs en Vorming, 2020b).

⁶⁵ 'De meesten weten ook niet dat ik autisme heb, dus omdat je het niet echt kan zien. [...] Het was zo waarschijnlijk dat ik altijd de rare zogezegd was.'

⁶⁶ Original: 'Vroeger dachten wij, mijn broer en ik dachten altijd dat we door autisme slimmer waren, terwijl da er niet echt iets mee te maken had.'

growing up. They could rely on the CLB for multiple forms of assistance like the advice mentioned above. In primary school and at the beginning of high school Ellen received GON-assistance. When she looks back at it she thinks it was useful but that it did not have a big influence on her life. For choosing her study field they relied on the opinion of her head teacher from high school. They also received counselling from Raster⁶⁷ for three years in Leuven, these meetings were formed around specific problems Ellen might have experienced. Ellen however said that she didn't have problems to discuss and that she only asked help for course related issues. Eventually she was more stressed to go to these meetings than that they were helping so she stopped going and her mother received the counselling instead. The counselling also helped them to communicate better and Tessa said this was very useful for her to know how to handle practical elements.

Despite their high functioning, Tessa mentions that for autistic people succeeding in post-secondary education is difficult. That is why a proper **preparation** is very important. She guided Ellen in getting familiar with the setting of university life through a) visiting the auditoria with her so Ellen would not be overwhelmed the first time she had classes, b) taking her along when visiting her son, so she could get used to the environment, c) letting the counsellor take her to a printshop, d) showing her around in the store, making sure she had been there multiple times, e) looking up new buildings where Ellen has examinations f) staying over the first night of college life, 'so she was used to it, or that she could get used to it together with me. Actually that you don't leave her on her own'⁶⁸, and g) making sure she is settled in before it all starts by choosing her spot in the fridge and a cabinet in the kitchen. In fact, it means that Tessa is organising on Ellen's behalf.

Ellen relies on her mother for everything and at every moment of the day. If something happens she immediately tells her, and the other way around as well, as result of their close bond as mother and daughter. They call multiple times a day and text over messenger. This constant need of care weighs on Tessa. She supports Ellen in different ways. She tries to motivate Ellen to do different kind of activities, without success. However Ellen mentions that, in her first year, she did karate at the KU Leuven sports campus but she stopped because they were not professional enough. Tessa is there as emotional support and helped Ellen with her self-esteem when her father closed off all contact with them. Ellen has difficulties with organising, 'they need a lot of structure but making structure themselves they find hard'⁶⁹. Especially during this pandemic⁷⁰ it is important to keep structure. Tessa had noticed that Ellen was not eating properly while living on her own in student accommodation, because she forgot to eat or didn't think it was necessary. Now she makes sure Ellen has food from home for every day of the week. Ellen doesn't cook herself but just heats up the food her mother prepared. Tessa also makes sure that Ellen takes care of her personal hygiene. She was afraid that her children where not taking care of themselves because she felt their rooms were very unclean, however most students have a messy room.

⁶⁷ Raster vzw is one of the four organisation in Flanders around home assistance for autistic people (Het raster, 2020)

⁶⁸ Original: 'Zodanig dat ze dat gewoon was, of dat kon gewoon worden samen met mij. Dat is dan haar niet alleen laten eigenlijk.'

⁶⁹ Original: 'Ze hebben enorm veel structuur nodig maar zelf structuur maken vinden ze moeilijk.'

⁷⁰ Due to the measures of the university to meet the measures of the government to limit the spread of the virus, covid-19.

They also tried a **buddy**⁷¹ who could do things with Ellen like swimming or biking, but after meeting once Ellen didn't want to meet with her buddy again because she felt that they were too different. Her buddy had many friends, did scouts and went out while this didn't interest Ellen. She didn't feel the need to make an effort because her buddy is a stranger. Her mother said that she should at least try to get to know people because only then she would know if someone can maybe become a friend.

A positive aspect of living in a student accommodation, according to Tessa, is that Ellen is living on her own and that she can **learn to take care of herself**. Ellen also thinks that she became more independent and says she learned some things from living in student accommodation. She has to organise her daily life herself and does this through using a white board for writing down things she has to do and making lists (fig. 28). She implemented this herself and used this already in high school where she realised that this was very useful for her to order her mind. According to Tessa, this is her daughter's anchor, so she knows what she has to do. She mentions that Ellen has already taken many steps towards independence. She went to a *kot*-dinner for the first time in three years, she goes more often to the store, she looks up classrooms and buildings herself and as Ellen herself says: 'Maybe also that I now dare to address people more'⁷².



fig. 28 Picture Ellen took of her white board to show how she organises her life

(Not) feeling at home

Recently Ellen told her mother she doesn't feel good, that she already feels like this for several years and that she preferred to stop studying and going to Leuven. If it were possible she would like to be at home, but because she needs a degree she tries her best to keep going. Tessa tried to visit Ellen more often in Leuven so she would feel better. Ellen doesn't like living in a student accommodation in general and thinks that the student life is too much focussed on having fun instead of studying. In this respect, the COVID-19 pandemic is a blessing for them, they both find more rest thanks to Ellen being at home where she feels comfortable. Living in a student accommodation is only a necessity for Ellen

⁷¹ A buddy is a peer student who supports a student in need with different elements linked to college and student life (KU Leuven, 2020e).

⁷² Original: 'Misschien ook dat ik mensen nu meer durf aan te spreken.'

to study and not something she enjoys. She **doesn't feel at home** in her student accommodation and only remotely in her private room.

Ellen has difficulties trusting people, it takes a long time before she would call someone a friend. According to her mother, this is why she never really had a real friend in high school. This makes living in a student accommodation difficult because every year the people she is living with change. How comfortable she feels in her student accommodation depends on how the other students behave: 'Last semester there was someone else here as well and then it was, actually, constantly these three people who mostly talked and pulling the attention towards them [during a kot-dinner], and other people just sat there [...]'⁷³. She once had a neighbour who would play very loud music, she says, he got kicked out because he was not respecting his fellow housemates. The person who is now living next to her is also a bit shy and because her neighbour is more open towards her and asks things as how she is doing, it is easier for Ellen to also speak to her, when they cross each other. In these four years she is living in this corridor of her student accommodation, she has always been the youngest, she says, that it maybe would have been better if there was someone younger than her. According to her mother, she has one friend, whom she met online through a Pokémon game. He lives in India. When an exchange student from India moved in her building, she bonded with him but he misused her trust by letting her text something in Indonesian to her friend which was not friendly. Ellen broke all contact with him. She says: 'A friend, for me, is someone who is honest and kind and truly likes you'⁷⁴. Tessa found this unfortunate because she could see that Ellen was brightening up because she had someone to talk to.

Ellen only feels comfortable around her family because she considers them the only people she can fully trust. If her mother comes to Leuven they eat in the kitchen, while she normally eats in her room because she feels uncomfortable to be alone in the kitchen when other housemates, whom she doesn't know, also are there. Sometimes he brother came over and they would cook together. This was something she really liked but on her own she doesn't do that because as she puts it, it is just alone (fig. 29). She doesn't like to be alone but is it almost all the time. In the beginning she tried eating in the kitchen but in the morning there was no one so she gave up and eats in her private room. Due to the mentioned aspects, Ellen is **lonely** in her student accommodation. Both Ellen and her mother mention that it would be good for her to **have someone in the student accommodation who she can trust, pulls her along and makes her feel comfortable, a friend actually**. Ellen says: 'If it had to be with two, that I would be here, I maybe would do that more, because it also is more fun than being alone the entire time' 75. She also says that, if she had someone who pulled her along from the first week, everything might have been different.

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⁷³ Original: 'In 't vorig semester was iemand anders hier ook nog en dat was zo eigenlijk de hele tijd drie personen die voornamelijk praten [tijdens een kot-etentje] en de aandacht naar hen trokken en de andere zaten daar zo bij [...].'

⁷⁴ Original: 'Voor mij een vriend is [iemand] die eerlijk is en vriendelijk en u oprecht leuk vindt.'

⁷⁵ Original: 'Moest dat zo met twee zijn, dat ik hier zou zitten, zou ik misschien wel meer doen, omdat het ook, dat is leuker dan de hele tijd alleen.'





fig. 29 Picture Ellen took to show the kitchen which she almost never uses, and fig. 30 Picture Ellen took to show that everything see does develops around her computer and her bed

Social contact is difficult for Ellen. 'She doesn't dare to show her face to the people, she just dares to run to the microwave [...]'76, Tessa says. According to Ellen, she just says hello to her housemates but none of them starts a conversation with her. When two housemates are chatting in the shared kitchen and Ellen walks in, they stop talking until she leaves. This gives her the feeling that she is unwelcome. However she sometimes asks her housemates for things, when she needs something: one time she asked someone to print something for her and another time she asked for a stapler. She says her housemates could also count on her when they need something. Tessa says that having contact with her housemates is not felt as something necessary by Ellen, however if Ellen has put her mind to something she can and dares to interact with people. For example when there was a petition to retract the dismissal of the residence responsible, Ellen went with it from door to door so others would sign it because she believed the person had done a good job. The communication with her housemates happens through a Facebook group. They used to have a chalkboard in the kitchen on which they also could communicate. Ellen prefers the chalkboard over the Facebook group for two reasons: 1) it is less chaotic to arrange something because you could see immediately if something had to be done and 2) she could stay more anonymous when she puts something on it. She feels that with the chalkboard she wouldn't stick out as the weird one who says things as press the bottle flat before you recycle them. Being anonymous is very important for her.

Most of her time Ellen spends in her bed. She sleeps, eats, studies and relaxes there. It is the centre of her student life experience. Ellen attributes this to the fact that she has to do everything on her computer, which is connected to the internet through a cable since there is no Wi-Fi on her side of the building (, and fig. 30). She also says that it is just too exhausting to always move the computer from the desk (to study) to the bed (to watch series). She likes that she can just wake up, lay there and start the day on that spot. To make this way of living more comfortable they rearranged the furniture to the situation in fig. 31. Ellen likes that she could **personalise** her room in this way. She tells that she doesn't like sleeping with her head in the corner of the room so they moved a camping closet in that corner and turned the head end of the bed. Tessa tells that Ellen used to collect garbage at the end of her bed and that she was getting worried so she talked with the counsellor of *Raster*. The counsellor said that she did not have to worry and suggested to move the desk to behind the bed so Ellen could use this to place things on top. This was effective because now she had more space to place things on. They also

⁷⁶ Original: 'Ze durft gewoon niet onder de mensen te komen, ze durft juist nog naar de microgolf lopen [...].'

replaced the tall closet so that it could also serve as shielding when the closet door was open and Ellen was washing herself at the sink. They tried hanging up stuff but they never kept sticking to the wall because it is not allowed to drill holes in the wall.



fig. 31 Schematic representation of Eline's room

Ellen doesn't like living on her own, however she prefers this above living with someone she doesn't know. She would like to live with someone from her family, preferably her mother. In the first meeting Ellen said she doesn't think living with another autistic person would be a good idea because both of them would have trouble with reaching out to the other, although it might depend on the other person. 'Not every autistic person you're going to like and not every non autistic person you're going to [like]'⁷⁷. In the second meeting when comparing to the other participants Ellen and her mother agree that maybe this actually could be good. Tessa says: 'If I look at Eline's situation, then it would maybe not be so bad if different autistic people lived together in a hallway'⁷⁸. Ellen continues: 'Because I rather would be drawn to such people, who also feel left out, people who are not super social'⁷⁹. Tessa adds: 'That is maybe easier to form a connection with them'⁸⁰. She feels like she has nothing in common with her current housemates and that she doesn't know them. However, according to Tessa, she will only get to know them if she spends time with them, but Ellen doesn't see the value of this because they are just too different.

⁷⁷ Original: 'Niet elke persoon met autisme ga je leuk vinden en niet elke persoon zonder autisme ga je ook [leuk vinden].'

⁷⁸ Original: 'Wel als ik dat zie nu van die Eline zou het eigenlijk ook niet slecht zijn als verschillende mensen met autisme samen op een gang zitten.'

⁷⁹ Original: 'Want ik zou net meer trekken naar zo een mensen die zich ook buiten gesloten voelen, mensen die niet super sociaal zijn

⁸⁰ Original: 'Dat is misschien gemakkelijker om daarmee een band te hebben.'

Shared versus individual space

Ellen doesn't miss any particular space in her student accommodation and she says that her private room is big enough, although others might think it is small. It is what could be expected from a standard subsidised residence. 'There are multiple options to come in contact with people and I maybe rather avoid them'⁸¹ (fig. 32). She avoids the shared spaces because they are used also by people she doesn't know. She has a private room and shares the kitchen and bathrooms with the other nine students from her corridor. Tessa wants that Ellen uses the kitchen so she has at least some form of contact with her housemates because otherwise Ellen would be completely locked away in her own room. However ideally, all facilities would be private, but they cannot afford this luxury.

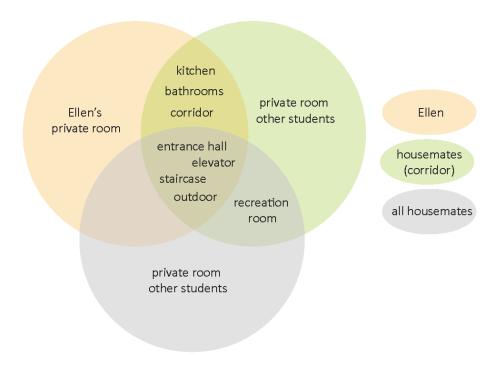


fig. 32 Gradient in social contact through use of space: how Ellen uses the spaces in her student accommodation

The recreation room on the ground floor she used a few times to do a group work for college, however otherwise she doesn't use the space because it might be too crowded there (fig. 33). She doesn't like that it is so open and people from outside could see what she is doing. Tessa tells that she herself thought this was a nice space and that it would be fun to use the table-tennis table if she was a student. She says that if the table-tennis table would be **closed off and thus not visible for others** that Ellen might make use of it (together with her). She also likes that her room is on the second floor so she has privacy from people outside, who aren't able to look inside. This need for **anonymity** and not wanting to stand out, makes that Ellen doesn't feel comfortable anywhere. She also doesn't like using the kitchen, for her, it is a functional space in which she doesn't feel comfortable to socialise. She doesn't like the dirty dishes people leave behind in the kitchen and thinks that her housemates should put it away directly after using.

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⁸¹ Original: 'Dat er verschillende mogelijkheden zijn om met andere mensen in contact te komen en dat ik die misschien eerder vermijd.'

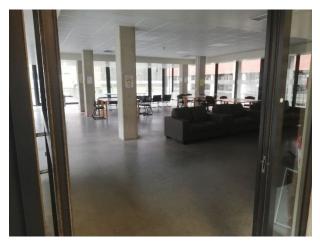




fig. 33 Picture Ellen took of the recreation room to show she is uncomfortable in open spaces, and fig. 34

Picture of Ellen to show that she is more comfortable when she is in her own room

Ellen mentions that the corridor on which she is living is the least social in the whole building, but she thinks this is an advantage because then she bumps into less people. She likes her privacy and always closes her door so she can be in her own world and wouldn't be disturbed by other people. In this way she feels the most comfortable (fig. 33, and fig. 34). She thinks it is uncomfortable when others leave their door open because she doesn't want to be rude when she walks by.

Finding rest & avoiding stress

When choosing her student accommodation, the key element was that it was close to her brother. When Tessa and her son went looking for a student accommodation, they spent a whole day looking. He didn't like any of the places they visited because it was either too loud, too old, or he just didn't feel good in any of the places in the centre of Leuven. He wanted something with more **greenery** and when they visited the buildings in Heverlee he was directly sold because of the environment. He didn't even care that the buildings were a bit older. He enjoyed the **peacefulness** that the environment, the greenery of Heverlee radiates. Ellen herself doesn't mention nature and the connection to outside as important. Tessa mentions that she likes the view from Ellen's room because it looks out on a peaceful little green square. Ellen also really wanted to live in the **new building** because this represents for her a more peaceful atmosphere. She also has bad knees so she needed a room, which is easily physical accessible. They first wanted to give her a room on the first floor in an old building but Tessa said that this would not be suitable for Ellen because, due to her autism, she would get too distracted by the people passing. For Ellen the fact that people could look inside was more bothering. It was a big relief for them that Ellen could live on the second floor in this new building (with elevator). It gave her a bit courage to start with college.

In the beginning Ellen really liked the kitchen (fig. 29) for two reasons: 1) it was more modern which made it look clean and thus more peaceful, although according to Tessa Ellen herself is not very clean in her own room. She says it might give Ellen rest. And 2) it was twice as big as the kitchen in her brother's student accommodation where she felt that the furniture stood too close to each other. A bigger space has more **air and light** and gives her **overview** and thus rest. That everybody has their own cabinet in the kitchen she thinks is good and clear. With fig. 35 she shows that everything in her room has a specific place so she can easily find the things she needs. Tessa says she added a camping

closet and an additional book shelf because there was not enough closet space. However, Ellen says that she would like even more closet space so everything could lay in sight.



fig. 35 Picture Ellen took of her closet to show she needs an overview

She says that the people on the first floor eat together every Thursday and that she is glad her corridor doesn't do that because it would be too much for her. However she also says that this regularity of eating together once a week in the kitchen instead of alone in their rooms, would be better for her than the spontaneous kot-evenings her corridor organises. Tessa thinks Ellen would like this, but would also look for ways to not go, because she might be afraid of what others think of her. Ellen doesn't often go to these events because she thinks they are not well put-up. '[If] it would be a bit more fixed, for example they did take away, that's like what [is it]? If it were Chinese for example than I only like to eat spring rolls and if they say we order everything and then everybody can eat of everything. But that would not be that fair, someone who eats everything and someone who only eats something small'82. She also doesn't drink alcohol and feels uncomfortable to say that she doesn't want to pay for it. That she doesn't know what it is going to cost also bothers her because 1) she believes they all should pay attention to what they spend due to living in a subsidised residence, and 2) she wants to like what she is paying for. When she does go she says that nobody is ever on time because for her 6 o'clock is 6 o'clock but none of her housemates are on time and in the beginning of such an event she feels awkward because nobody is really talking. She also says that if she is finished eating she would like to leave 'and then it also is difficult to leave, then you have to find an excuse so that you can go to your room'83. It would be best if there was a kind of predictability for these kinds of events, so she would be more comfortable. Tessa says: 'If something is already a little bit unclear than she gives up'84. For example if there were clear and elaborated instructions on when it is allowed to and how to use the table-tennis table and where the needed equipment can be found, Ellen might make (more) use of it.

⁸² Original: '[Als het] zo een beetje meer vaster ligt, zo bijvoorbeeld ze gingen iets gaan afhalen, dat is ook zo van wat [is het]? Als dat chinees is bijvoorbeeld dan eet ik bijvoorbeeld alleen maar de loempia's graag en ze dan zeggen we bestellen alles en dan mag iedereen nemen van alles, ma da zou niet eerlijk zijn, iemand die alles eet en iemand die eigenlijk enkel iets kleins eet.'

⁸³ Original: 'En dan ook is het zo moeilijk voor weg te gaan, dan moet je zo een excuus achtig iets vinden omdat je naar je kamer zou mogen gaan.'

⁸⁴ Original: 'Als der iets al een klein beetje niet duidelijk is dan geeft ze het op.'

Her **bed** is her favourite place in her student accommodation because it is very comfortable, she likes that she can just lay there and doesn't have to sit up straight all the time. Tessa says that Ellen might like it so much because it is warm, cosy and made of soft materials in contrast to a table and a chair which are hard. She mentions that a space where Ellen could come to rest by playing and listening to music, which she likes, and relaxing in a big pile of pillows could be interesting to implement. Ellen also asked for such kind of space at home but unfortunately they don't have the room for it.

Although Ellen doesn't like living in her student accommodation, she feels like this is at least better than in the centre of Leuven because here she isn't really bothered by her housemates. She mentions that she dislikes that she can hear clearly the noises that her housemates make. She hears when someone is moving in the room above her or is walking in the corridor. The noise people make in the kitchen in the evening, keep her awake. Tessa mentions that it is a problem of bad insulation of the rooms. It are the **small elements** like a smoke alarm that goes off in the middle of the night and not knowing how to turn it off, a bathroom door that closes in a way that she feels trapped and uncontrollably hot water in the shower, housemates who spill and don't clean it and bad cleaning of the shared spaces by the cleaner **that make it difficult to live in her student accommodation** every week.

4.2. ASPECTS OF LIVING IN A STUDENT ACCOMMODATION

The individual stories, analysed according to four themes, can now be compared. The similarities and differences might give a view on what aspects of living in a student accommodation might be points of attention for autistic students.

As the only one of the three, Victor told his friend and housemate about his autism. Neither Ellen nor Eline tell anyone that they are autistic because they are afraid of how people might react. This means that the people living with Victor can actually take him into account when doing things in the house, while Ellen and Eline's housemates can't do this properly because they don't know that they might need some attention. Tessa's son also told his neighbour after he had opened up to him. Eline looks at her autism from a negative point of view while the other two also see many positive aspects of being autistic, it is part of their lives.

Independence

Ellen is the only one of them who lived away from the parental home from her first year of college. Although this was and still is very difficult for her it was the right choice because her brother was there to help when something would go wrong and she didn't had to adapt twice to a new situation. She lives in a student accommodation where only students live, with a residence responsible she can contact. Eline choose to first live two years at home and study on a campus which was closer, before she had to move to Leuven to finish her studies. It seems that this was also the right choice for her because she could first get used to post-secondary education and then learn to live independently. Eline also lives in a student accommodation where only students live but meals are provided every day. Victor also moved out of his parental home (his mother's house) after two years of college, because of personal reasons and not for his education. He is the only one who lives with adults (who are not related to him). That his friend gave him the opportunity to live with him and his husband in a co-housing format turned out to be an ideal situation for both of them.

Eline says she doesn't rely on anyone for emotional support and only expects of her parents to do the practical work. She doesn't cook for herself although she would have liked this, because her student accommodation provides every meal. Eline knows that she has difficulties in making contact with people, so she forced herself into a living situation where this social engagement is implemented. Eline's situation on this aspect is very different from Ellen's and Victor's, who both have someone who guides them in everything. Ellen relies heavily on her mother, for every aspect of her life: even though she is not living with her during the week, they are in contact throughout the entire day. Her mother helped her prepare for college life by visiting places a student might need to visit. She is there for emotional support and to help Ellen organise her life. She makes sure Ellen takes care of herself and prepares food for the whole week. She also tries to engage Ellen into social contact because she is too uncomfortable to do this herself. Victor relies on Koen, with whom he is living, for many elements of his life. Koen stands by at every moment of the day and they support each other emotionally. Koen helps Victor maintain a calendar and organise his life. They have a routine that they follow every day and Koen prepares dinner for the household (of three). Victor is very social and open and Koen guided him a bit in what kind of signals he was sending out to others. None of them is actually preparing their own dinner and the girls are experiencing more socially related issues than Victor is. Tessa also told that her son is more independent than her daughter and that he was also more socially open. Eline and Ellen both learned to some extent to be more open towards others. Ellen also learned to do some things on her own which she has not done before living in a student accommodation.

(Not) Feeling at home

Victor is the only one who feels at home where he is living. This might be because of different aspects which are very different for him and the girls. The first aspect has to do with whom they are living with. Victor is living with his friends. They have an open communication and adapted their rhythms to one another in which Victor's student life and Koen and Paul's work life align well. Eline says she feels at home because she is living there for a longer period in time but due to the weak connection with her housemates and the bad communication with her landlord this feeling gets repressed. She has difficulties to connect with her housemates because they are, according to her, evening people who are loud and wild and she is the opposite. Ellen doesn't like living in a student accommodation and doesn't feel at home. She barely communicates with her housemates. In the last meeting she said that it could be interesting to live with other autistic students because they can relate to each other's issues and wish for peacefulness. She also feels that she would be more comfortable around other people who are shy and don't feel like they belong there. The three of them enjoy a more restful kind of student life instead of the 'typical' one of going out to party, to a cantus or a pub. Victor mentioned that he is a person who enjoys a fun evening at home with around five people while talking and playing cards. Parties with ten people are too much for him and a pub is also too loud. Ellen doesn't do any kind of activity when she is in Leuven and she says she thinks student life is constructed too much around going out instead of studying and that she is not interested in the things other students like. Eline sometimes does sports. It seems like both Ellen and Eline could use a friend in their student accommodation who is open, knows about their autism and can pull them along in activities.

A second aspect might be that the people Victor is living with will stay the same and that it is thus more easy to have and maintain a connection with them. For Ellen and Eline the people they are living with continuously **change**, which makes it hard to bond and maintain possible connections: if they made a friend, it isn't guaranteed that they would be living in the same student accommodation the next year.

Both Eline and Ellen don't expect much from their housemates. Eline would like that they talk to her and Ellen only contacts them when she is in desperate need for something.

A third aspect to feel at home might be the possibility to **personalise** the spaces they are living in. Victor had complete freedom in decorating his own room, because his housemates wanted him to feel at home and had the idea that he would stay for a longer while. He also is allowed and encouraged to add and change elements in the shared spaces and made the office space of him and Koen into the place he enjoys most. Victor gets the opportunity to express himself while Eline and Ellen don't have this. They are allowed to change things in their own private room but are restricted by rules as not drilling in the walls. Ellen liked that she could change the furniture layout so it would suit the way she likes to live (from her bed) in her student accommodation. Eline says that they, as students, are not well enough taken into account when decisions are made. She feels like she doesn't have a voice when it comes to her own living situation.

Shared versus individual space

None of the participating students have private facilities. Except for their own room they share every other space as the kitchen and bathroom(s) with their housemates. However they don't have the same kind of spaces in their accommodations. Victor and Eline also share a living space with their housemates and Eline shares a recreation room with her whole building but doesn't have a living room. Victor shares an office space with Koen and Eline has access to a common study room and smaller seating areas distributed through her student accommodation. Eline and Ellen live in a student accommodation where they might come in contact with respectively 14 and 9 other housemates on a daily basis while Victor's has only two housemates, who are always around. Eline deliberately didn't want a studio because sharing **spaces offer more opportunities for contact with other people**. This is the reason why Ellen would have preferred a studio, but which was financially impossible and her mother also thinks this would have been a bad idea because Ellen would be even more isolated. Victor and Koen enjoy the shared spaces because for them this represents the co-housing aspect. Eline and Ellen don't have a (good) bond with their housemates and don't feel comfortable in using the shared spaces together with their housemates. Victor, on the other hand, has a very close bond with them which makes he likes using the shared spaces together with them.

When they are using a shared space in their accommodation, this is always linked to a kind of social contact (fig. 10, fig. 20 and fig. 32). In the house where Victor is living, it is very easy to switch between having contact with his housemates to being on his own and moving away from any social situation. He also has different options: in the living room they can socialise all together, in the office space it is just him and Koen, more private conversation can happen at the door of his bedroom. In Victor's case a gradation of social contact is visible through the way he uses the space. Eline and Ellen don't have these different options. They have a choice between being alone in their private room without contact with their housemates or being in a shared space with (what they experience as) too many people, around whom they don't feel comfortable. Eline shares all spaces with the 14 other girls in her student accommodation. Ellen shares most of her spaces with her housemates who live in the same corridor. She also has opportunities to come in contact with other students in the building by going to the recreation room. However because she doesn't feel comfortable around other people she almost never does this. Spaces that are shared by less people could provide a gradient in social contact which could help them feel more comfortable around the people with whom they are sharing these spaces.

In the house Victor implemented that every space is assigned a different activity. The office space is meant for working, the bedroom for sleeping and the living area for relaxing. Ellen, on the other hand does everything - eating, sleeping, studying and relaxing - from her bed. She prefers to do everything from in her bed because then she can just start her day from there. Eline didn't mention any specific preferences about how she uses the spaces in her student accommodation.

Finding rest & avoiding stress

The idea of privacy, not standing out and **being anonymous** is an interesting issue to consider. Ellen and Eline both are fond of their privacy or, how they refer to it, anonymity. Ellen found this anonymity in her private room. The room is on the second floor and people from outside can't look into her private space. She always closes her door, so she can be comfortable and undisturbed in her own space. Spaces, like the recreation room with its big windows, which don't guarantee that she is not being observed in what she is doing, are uncomfortable for her and she avoids using them. If it was more shielded she might use the space. Eline experiences difficulties with balancing her need for social contact and her need for rest and being alone. She specifically chose a student accommodation with social engagement because she wants this social contact but because nobody is making an effort to get to know her and she experiences her housemates as too active and loud, these meals also become very stressful. She says that she can't find a place to rest in her student accommodation. Even in her private room she can't come to rest and be anonymous. Victor didn't mention this need for anonymity and is actually looking up his housemates to be around.

All three of them spoke, directly or indirectly, about needing or wanting an **overview**. Eline mentions she doesn't like sitting with her back to the door because she doesn't see what is happening behind her. Victor says he likes an open, well lit, spatial room such as the living area in his house and also likes that he has a large desk to place his stuff on. He pays much attention to details and says that he needs to know a room to be able to concentrate there. Ellen wanted to live in a new building because this looked cleaner. Originally she liked the kitchen in her building because of its spaciousness providing light and air, cleanness and modern look, it gave her rest. In her private room she has ample shelf space to place her belongings on, so she can easily find the things she needs. Victor and Ellen talk about **predictability**. Victor talks about elements that help to understand a space in a logical way, like the light above the guest toilet at his home. Ellen says that she would be more comfortable if there were clear agreements and a routine for social interactions like a *kot*-dinner.

A connection to outside, greenery and a peaceful, quiet environment seemed something they were all looking for. Eline mentions she explicitly asked for a room on the garden side of the building so she wouldn't hear the noise from the street. The spacious bathroom in Victor's home is designed to be a peaceful place with a strong connection to outside. Victor's enjoys the view in the morning. Ellen's brothers directly felt comfortable when he visited the student accommodations in Heverlee. Ellen agrees that he made a good choice because it would have probably been too loud in the centre of Leuven. A peaceful (green) environment provides less sensory stimulation and distraction. The sound from inside the accommodation seemed to bother them most. The noises from housemates is for the girls a difficult aspect of living in a student accommodation. Also Victor experiences this as annoying, however not to the same extend as Ellen and Eline. Ellen likes doing everything from inside her bed, her mother tries to explain this through referring to the haptic sense, in relation to the warmth and softness of the materials of the bed. Small (technical) issues within the building make living in their

student accommodation **more stressful** and difficult for Ellen and Eline. Student life can be very stressful and both Koen and Tessa try to take away as much stress as possible from Victor and Ellen so they can focus on their study and find rest.

4.2.1. IDEAL WAY OF LIVING

Victor and Koen

When talking about their living situation, Victor and Koen both describe it as ideal. They think everybody could benefit from a co-housing situations in which all housemates are extremely open to each other. Victor thinks it is an efficient way of using goods and really likes the shared spaces. Koen is also very happy with his living situation and doesn't know what could be changed to make it better. During the analysing meeting they repeated themselves by saying that they didn't wish to live in any other way. Victor says that he recognises his own experiences in Eline and Ellen's situation before he started living with Koen and Paul. He says he feels good there because he received the opportunity to 'make places his own' and show himself through the house and that this is a key feature of being comfortable where you live.

Ellen and her mother

Before seeing how other autistic students live, Ellen preferred to have a bigger private room with private facilities for three reasons: 1) the advantage of not sharing kitchen and bathroom with others is that you are not confronted with other people's dirty habits. 'If everything is yours, you don't always have to wear shoes, flipflops or something else. Then you can just move around on your socks, now it is a bit dirty'85, 2) she wouldn't have to interact with other people, and 3) it would be more sound prove. However, Ellen's preference of living in a studio is in conflict with her having difficulties of being alone. Living with another person, whom she'd know and chose herself, would be a solution for this solitude. Yet, this person should still respect her private space and time, because otherwise it would become too stressful. Ellen doesn't believe it is possible to find someone who could be this kind of person for her. In her residence, there is an example of a group of students, some of whom are impaired, who are there for each other. They are living on the first floor in 'omkaderd wonen'. Such situation could be interesting, Tessa says, because people living there are invested in each other, just like Victor, Koen and Paul are invested in their relationship. While thinking about 'omkaderd wonen', Tessa says that it would not be ideal if ten autistic students would live together in one corridor. However after the comparison with the other participants and seeing Eline struggling with the same issues as Ellen, she changes her mind and says that this could actually be good because they might understand each other's wish for rest.

After showing them how other autistic students live, **Ellen's vision on an ideal shared living situation completely changes**. She could recognise herself in Eline and said that living with other shy people would maybe benefit her. Victor's living situation intrigued them and Ellen says that she also would like to live in such a situation. Tessa mentions that people like Koen, who are open minded and are willing to do this, are needed. Having someone like him in her corridor would make it much easier.

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⁸⁵ Original: 'Als het allemaal jou deel is, moet je niet altijd zo schoenen, slippers of iets anders aandoen. Dan kan je gewoon op je kousen lopen, nu is dat een beetje vuil.'

Ellen says that she no longer would need private facilities (except an own bedroom) if she were living together with less people, who are open minded.

4.2.2. ADDITIONAL ISSUES

Due to the measures of the university to anticipate the measures of the government to limit the spread of the COVID-19 virus, the (autistic) students experienced more stress than usual. Ellen and her mother said that the amount of work she has do to is way more than when the courses were not held online. Victor says that the workload he is experiencing is partly due to himself because now he got more time to work for his design course due to everything else being cancelled. Eline e-mailed me on 13/04/2020 because she felt mistreated by her landlord. She wrote that she also has health issues, besides her autism, that requires that she regularly visits a doctor in Leuven. Due to the measures to limit the spread of COVID-19 all students were sent home, however for Eline it was indicated to stay in her student accommodation so she could go to the doctor. However her landlord didn't allow her to live in the student accommodation, even when she had two certificates from the doctor that said she was allowed to. Despite involvement of the housing agency, they could not solve it, resulting in a termination of her renting contract. She wanted to point out that people don't have any understanding for people with medical problems and probably even less for people who are impaired or autistic.

5 DISCUSSION

In this discussion I link the findings from the fieldwork to insights gained from literature, while formulating an answer to the research questions. I structure this discussion according to the four concepts I worked out during the analysis and I confront these with concepts from literature. The analysis was focused on how the built environment plays and can play a role in the participating students' experience of being 'op kot', how they dealt with social interactions and sensory challenges. This chapter discusses possible aspects, whether or not linked to the built environment, which make it harder or easier for autistic students to live in student accommodation.

5.1. BEING AUTISTIC IN A STUDENT ACCOMMODATION

Like many other autistic people, two out of three participants consider their autism as a part of their identity, of whom they are, and don't see it as a deficiency. One participant's housemate's vision on autism leans onto the idea of the neurodiversity movement that autism is a neurological difference. He supports his autistic students and his friend in showing their capabilities. He believes that his autistic students are the best programmers because of their eye for details. One participant follows the common understanding that autism is a disorder. She experiences her autism as an impairment (beperking) and she can't find an advantage in this.

Diagnosis

In this research I especially wanted to work with a male and a female student because I am interested in (gender) equality. Through reading literature I noticed that less autistic women are diagnosed and that they are underrepresented in research (Cridland, Jones, Caputi, & Magee, 2013; Kanfiszer, Davies, & Collins, 2017; Pearlman-Avnion, Shlain, & Lowinger, 2019; Spek, 2014). To explain this gender difference two hypothesis were introduced (Pearlman-Avnion, Shlain, & Lowinger, 2019). The first one implies that there are less autistic women because they are biologically protected and end up on the LF-AS end. In my research I worked with two HF-AS female students and HF-AS male student. The second hypothesis implies that they are often misdiagnosed or later on in live than men (Pearlman-Avnion, Shlain, & Lowinger, 2019). This could be due to that the diagnostic criteria are based on a male phenotype, while autism might present itself differently with men and women. Also HF-AS women (and men) might have developed coping strategies to hide their autism. These are developed in childhood and they make it less obvious to perceive girls' difficulties (Mandy & Lai, 2017). However these coping strategies are no longer sufficient in adolescent friendships because of the increased complexity in social interaction (Cridland, Jones, Caputi, & Magee, 2013; Pearlman-Avnion, Shlain, & Lowinger, 2019). Making that autistic women often are diagnosed after entering adolescence. The situation of the participants confirms to some extend what is found in literature. One girl was only diagnosed when she reached adolescence. The other two participants were diagnosed at the end of primary school, but one of them was first diagnosed with high intelligence and for the other it took six years between noticing she was different and actually receiving the diagnosis. Her brother was also diagnosed with autism but it represented itself in a very different way, which only shows the diversity across the spectrum.

Receiving an early diagnosis is important for having access to proper assistance, which guides autistic people in different stages in later life. The age at which the participants were diagnosed differs but is

relatively late. One participant⁸⁶ received many different forms of assistance for different aspects of her life. Another, when diagnosed, didn't really think he had issues but searched for different forms of assistance himself later in life. The other female participant felt that the limited assistance she had received was a waist of her time. The amount of assistance needed and wanted, depends on the autistic individuals themselves.

Many autistic people are often diagnosed with other mental health conditions than autism, (Buck et al., 2014). This risk is higher for autistic students (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017; Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015), and autistic women (Cridland, Jones, Caputi, & Magee, 2013; Pearlman-Avnion, Shlain, & Lowinger, 2019). But this seems not the case for the three students in this research. However, one participant⁸⁷ mentioned through e-mail that she also had other health issues, but she didn't specify if this were mental health issues. The other two didn't mention they have other (mental) health issues, but this was not directly asked so it may be the case. The female participants, one in particular⁸⁸, do feel lonely in their student accommodation.

Disclosure

Young autistic adults, especially the ones who masks their symptoms very well, have doubts about disclosing their autism (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). This out of fear to be considered different from neurotypical peers (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). For this reason, both female participants are very sceptical about opening up to other people about their autism. They also say that people have prejudices about autism. However by not telling anyone that they are autistic, they have problems to connect with their housemates. It becomes difficult for their housemates to take them into account and communicate with them. This is different from the male participant's situation who was very open about his autism from the start. His housemates can and want to take his needs into account, which gives him a place where he feels accepted. The brother of a female participant also opened up to his housemate after this person told him about his autism. To feel accepted autistic people will need people around them who are open and willing to take them into account.

⁸⁶ Ellen, independence, pp 69-70.

⁸⁷ Eline, p 83.

⁸⁸ Ellen, (not) feeling at home, p 72.

5.1.1. INDEPENDENCE

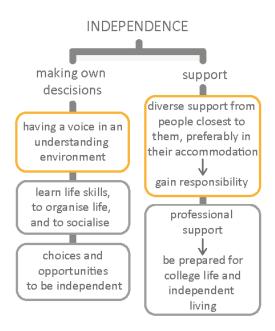


fig. 36 Aspects related to independence

Making one's own decisions

The students in this research are HF-AS young adults. For their post-secondary education they all choose a high quality education at the KU Leuven in which they are succeeding. Literature suggests that autistic people have a higher risk for failing higher education, but the three participants are all following the intended learning trajectory without major issues. Yet, due to COVID-19, students have to work from home, and the participants experience a greater workload, and one participant suddenly has difficulties with processing this amount of work.

Going to college and leaving the parental home is a critical transition period for all students (Rugg, Ford, & Burrows, 2004). However, autistic students might have more difficulties with this and the process needs to be thought through (VanBergeijk, Klin, & Volkmar, 2008). The transition of both female participants was handled carefully. One choose to first study two years closer to home so she could stay home, which eased her transition. For the other the best solution was to directly move to the compact city of Leuven, because then she needed to adapt to a whole new situation only once. The male participant moved out of his mother's home only because they were having problems. By going to college autistic students might experience a greater independence, become better at communication, learn more about their personal challenges, learn to develop habits and clean, learn how to behave in public and experience an improvement in organisation skills (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). They are also looking for a sense of belonging and a supportive social environment which allows growth, independence, learning new skills and escaping social isolation (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). Yet, their limited social skills can hinder their wish for the social aspects of college life. This is true for the participant ⁹⁰ who made a very clear choice in how she wanted to live. Because she knows that she has difficulties with communication, she choose for a student accommodation with social engagement. However the social engagement turned out to

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⁸⁹ Ellen, p 83.

⁹⁰ Eline, independence, pp 50-51.

be too much for her and the opportunity for developing an important life skill, cooking, was taken away during the years. On top of this she is disappointed in the relation with her landlord who is unable to proper communicate. The students have no voice when important issues need to be discussed. She points out that people are not understanding towards people who are living with an impairment. She learned to be more open to people and that she sometimes has to take the first step in interacting. The other female participant, on the other hand, let other people - and especially her mother - take care of finding her a student accommodation and making sure she ended up in the place she preferred (a private room, which was not on the first floor, in a new building). Living close to, but not in the same building as, her brother allows her to reach out for support when needed but also gives her the opportunity to take care of herself. She became more independent, learned to organise her daily life (through using her whiteboard) and tries engaging in social situations. The male participant ended up living with friends because one of them offered him a place to stay in times of need. In the house he received the opportunity to grow and his voice was equally important as that of the other housemates. Like for the male participant, independent living situations for autistic people should provide them choices and opportunities to develop their independence (Steele & Ahrentzen, 2016).

Support

HF-AS people might require a certain kind of support for living independently in the form of minimum or temporary assistance (Atsmon, Yaakobi (Gorga), & Lowinger, 2019). Autistic young adults are more likely to live a home or with another responsible adult. One participant doesn't have a support person but she hopes that her housemates will be there for social interaction. The two others rely (heavily) on the people around them for all kind of needs. By receiving diverse support from the people closest to them, they don't have to face the challenges in education, student life and daily (independent) living, alone. Autistic people can benefit from a clear communication, help with planning, and encouragement for independence. With going to college, their family involvement is limited and they will have to solve issues on their own (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). However when help is needed they will not hesitate to call their parents to help them solve the problem. The male participant lives together with two adults. One of them helps him in organising and planning his life through a digital calendar. This is very useful because he always had difficulties with planning and now he can make up his own calendar. He can also rely on his friend for domestic support (cooking and doing the groceries) and emotional support because they are good friends. He can reach out to his housemate on every moment of the day and he has responsibilities for household tasks, like taking care of the plants, folding up the laundry and helping with cleaning. One female participant doesn't feel good in her student accommodation, she feels very lonely, and rather would like live at home with her mother. At one point she wasn't even eating properly. This reduce in self-care may be the reason why she depends heavily on her mother. She relies on her mother for emotional support, helping her organise and structure her life, personal hygiene and preparing dinner. Her mother also tries to stimulate her in having social contact, but with little success because she doesn't trust anyone. This intense involvement also asks much from the mother, who is experiencing stress and the need for support herself. Having a person nearby in her student accommodation on who she can rely for these kinds of support could benefit an autistic student and their parents. All three students say they are capable of taking care of themselves.

These two participants⁹¹ also benefit from **professional support**. It helped one participant to be better prepared for living on her own in a student accommodation. According to the mother and Lowinger (2019), preparation and counselling is the key to success. The male participant mentions that his student counsellor of KU Leuven is very helpful, which shows that well educated staff can make a difference in the life of students.

5.1.2. (NOT) FEELING AT HOME

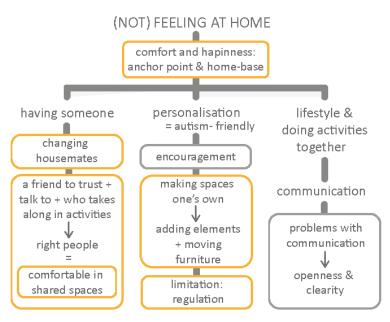


fig. 37 Aspects related to (not) feeling at home

Most of the time students live in student accommodation during the week/ semester, and typically go back to the parental home during weekends and/or holidays (Rugg, Ford, & Burrows, 2004; Thomsen, 2007). They live in two different places which they might call home. The female participants live in two places, but the male participant never goes back to his parents' houses. **The comfort and happiness of students in their student accommodation depends on them feeling at home** (Thomsen, 2007). Different aspects of their living situation make that the participants feel or don't feel at home. Ellen doesn't feel at home, Eline is ambiguous and Victor feels completely at home.

The home can take a central place in the lives of (autistic) people (Gifford, 2002 in Thomsen, 2007). It can become an **anchor point** in the physical world where they feel the most comfortable (Kinnaer, Baumers, & Heylighen, 2014). One participants' accommodation has this meaning for him. It is his **home-base**, which he uses to find rest and to reload his energy. Another participant refers to her bed as her central place when living in Leuven. The other female participant⁹² can't find rest in her student accommodation or her private room and didn't mention anything that could suggest that she sees her student accommodation as anchor point.

⁹¹ Ellen and Victor, independence, p 59 and pp 69-70.

⁹² Eline, finding rest and avoiding stress, p 56.

Having someone

All students, and maybe autistic students even more, might experience challenges like navigating on campus, adjusting to housemates, developing a study routine, making new friends and dealing with homesickness (Hendrickson, Woods-Groves, Rodgers, & Datchuk, 2017). Having a friend to share these challenges with is important. When living independently autistic people will benefit from having access to a supportive environment. However finding someone to face these challenges with may be difficult to find in a student accommodation because housemates change constantly. A lack of friends and social contact can cause feelings of loneliness and social isolation. The female students mention that it depends on the other people they are living with each year whether they feel comfortable in their student accommodation. One of them doesn't feel at home because she has difficulties trusting people and people are not making an effort to talk to her. But she also doesn't make the effort herself because she feels uncomfortable around other people. It would be best for her to have a friend who she can trust and talk to and who guides her through kot-activities, so she would be less lonely. The other is ambiguous about feeling at home. On one hand, she does feel at home because she is living there for a longer period of time. On the other hand she doesn't feel at home because of the poor relationship with her housemates. Because she doesn't want to be alone, she hoped that the (enforced) social engagement would foster a better connection with them. She is looking for people who are open towards her. The male participant is living permanently with his friends, they form a kind of family which makes that he is definitely feeling at home. Finding the right people to live with can make a **living situation more comfortable**. One of the participants, ⁹³ for example, would be more comfortable around other shy people, maybe autistic people, with whom it would be easier to connect. Living in their student accommodation with someone like the male participant's housemate, who is openminded and wants to help, would benefit the other autistic students as well.

Autistic women often have limited social connections, that are often restricted to their family (Cridland, Jones, Caputi, & Magee, 2013). This seems the case for one of the female participants, who has a good bond with her family. Her bond with her mother is especially strong and they talk to each other about everything thanks to them being able to bond when she was in high school. She **only feels comfortable in the shared spaces of her student accommodation when a person she trusts**, her mother or brother, **is around**. It takes a very long time before she can trust someone and feel comfortable around them. Often she gives up after meeting once because she feels she is just too different from the other person. She has one friend whom she met online. The other female participant doesn't really have a strong bond with her family but she did talk about some friends she has had. The male participant also has a weak bond with his parents but he seemed to have many friends he could and would count on. One participant's ⁹⁴ brother also has had it difficult in high school but at one point he got accepted and now he is still friends with these people from high school, while the participant doesn't have this.

⁹³ Ellen, (not) feeling at home, p 74.

⁹⁴ Ellen

Personalisation

A sense of home can be achieved through allowing personalisation (Thomsen, 2007). The place where someone is living, is in fact an extension of who they are. When choosing their student accommodation student and their parents keep in mind the quality of the room through size, layout, ((not-included)) furniture, materiality, comfort, warmth, cleanliness and noise (Verhetsel, Kessels, Zijlstra, & Bavel, 2017). They also pay attention to the financial aspect which might limit the possibilities. Independent living can be autism-friendly if there is room for personalisation. This is based on what is most comfortable for the individual depending on their own preferences for different architectural aspects (Kinnaer, Baumers, & Heylighen, 2014). However this can be hard to achieve in student accommodation because of regulations. One participant was encouraged to show his identity in the whole house and not only his private room. There were no limitations on what could be done which resulted in him being very proud of how his private room turned out to be. Together they furnished the office space and because he could make this space his own it is favourite space to be in. But he doesn't want to take in too much space in the shared spaces, and he feels like he succeeded in this. These possibilities to be himself and not needing to modify his behaviour to fit in with the world of neurotypicals give him a sense of home. The other participants couldn't change elements in the shared spaces, but had limited options for their private room. One of them likes that she could personalise her private room, by moving around the furniture, to how she wants to live (from her bed), however she couldn't pin things to the walls because of regulations. They made her room more comfortable and enjoyable to stay in, but the joy she gets from this is limited due to her loneliness. The other participant had few options for personalisation, her room is not luxurious but she says that she didn't needed it to be.

Lifestyle

One of the participants is living with people who appreciate the same kind of activities, which allows them to bond. Although their daily routines are different (he is a student, his housemates are working), them living together is not a problem for any of them because the steady (but busy) schedule of his housemates is actually helping him keep control over his own busy life. The people he is living with and with whom he is **doing activities together**, make him feel at home and make that living in the house is very pleasant. The girls don't have this luck. They experience that they are very different from their housemates and that they don't like the same things. Most students are more active in the evening and like to party. This is not how the participants like to spend their time.

Communicating

As mentioned in literature, autistic students have difficulties with Theory of Mind and thus with social communication, social norms and living up to society's expectations (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Pearlman-Avnion, Shlain, & Lowinger, 2019). Especially autistic women have difficulties with these social interactions because of the complexity in social female interaction (Cridland, Jones, Caputi, & Magee, 2013). This gives them a disadvantage compared to their male counterparts for developing and maintaining friendships. Men's interactions are not necessarily based on communication. The female participants, according to the findings, both experience **problems with social communication (in their student accommodations)**. They both have difficulties talking and bonding with their housemates, but when they were talking to me about their experience they were very open and I had the impression that they were comfortable. One of them would like a more open

and clear communication in her student accommodation. The male participant is very good friends with his housemates and they are **communicating openly with each other**. This communication is key to their living situation. His housemate mentioned that he had guided him with how he was approaching people's interests. According to his housemate when he shows interest in people, it seemed as if he has the same interests as them, however this was often not the case but he just wanted to make the other person feel good. To me, the male participant seemed a very social student and we got along well through talking about our mutual interest: architecture.

5.1.3. SHARED VERSUS INDIVIDUAL SPACE

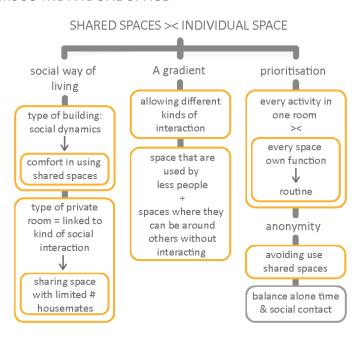


fig. 38 Aspects related to shared versus individual space

Social way of living

In Leuven there exist a diversity of options in type of student accommodation. Living in a student accommodation is a social way of living in which other people's activities are taken into account. The choice of a student accommodation may be affected by whom one will be sharing space with. The participants live in very different kinds of accommodation, because of different factors they could or could not take into account. The male participant had an opportunity to live with his best friend in a co-housing situation, which is not a typical form for a student accommodation, and accepted that offer. The three housemates do many activities together inside and outside the house. This dynamic is very different from how the female participants are experiencing their living situation and the male participant is much more comfortable in using the shared spaces compared to them. The female participants however did not take into consideration the people they would be living with, they both where not sure whether it would be helpful if they had known someone from the start. Both are living in a bigger student accommodation in which they share spaces with respectively nine and 14 other students. However, the social aspect of living together is only very limited because they spend most of the time on their own, although one of them explicitly searched for a student accommodation with social engagement. She chose a residence in the centre of Leuven that provided this and was close to the train station and her campus. The other lives in a KU Leuven residence, because of financial reasons. Although she doesn't like it here, she believes that this is probably the best option for her, however this is because of the peaceful environment and closeness to her brother and not because of sharing space and getting to know new people.

Different options for the **type of private room** exist as well, allowing a **choice in what kind of social interaction a student will have with their housemates**. All three participants share every space, except for their private room, within their accommodation with others. The male participant enjoys the different shared spaces that are present in the house. One female participant choose explicitly for a **private room with shared facilities**, and didn't want a studio, so she would cross her housemates more often. The other participant originally would have preferred a private room with private facilities where she would not come in contact with people, although she already feels lonely in her current student accommodation. Because of financial reasons and her mother saying that this would be a bad idea because she would be completely isolated, she doesn't live in a studio. After seeing how the male participant was living, she thinks that this would be a very good fit for her because she would **share spaces with less people, who are willing to get to know her**. In such a situation she wouldn't even need private facilities.

Student houses are shared domestic spaces where other peoples' attitudes towards hygiene, noise and thoughtfulness can influence how their housemates might feel (Card & Thomas, 2018; Holton, 2016). The female participants both mentioned several times that other people's lack of keeping the shared spaces clean bothered them. They like that the shared spaces are cleaned professionally. They also mentioned that their housemates are very loud and sometimes inconsiderate towards the fact that they are living with other students.

A gradient

Living in a student accommodation is typically about sharing space with other students. This implies that social relationships develop in the built environment. The different ways the students can interact with their housemates can make a difference in how comfortable they are in their student accommodation. When living together with others, there is a need for a social gradient (fig. 39), which allows different kind of interactions, especially for autistic people living on their own. One participant for example has different options for social interaction allowing him to choose the intensity thereof. They learned what each other's boundaries were in terms of privacy. It also helps that he is only living with two other people so places will never be too crowded. Another participant also has different options to come in contact with other students, however she rather avoids these. She does this because the space are too open and can be used by too many other students (nine or more) who she does not know. The last participant has two options in her student accommodation: being alone in her own room or use a space that can be used by 14 other students. The female participants might be missing a greater variety of shared spaces that allow different kind of interactions. Such spaces can be a) a shared space which is used by less people, around who they can be comfortable and/or b) a space where they can be around others without having to interact with them.

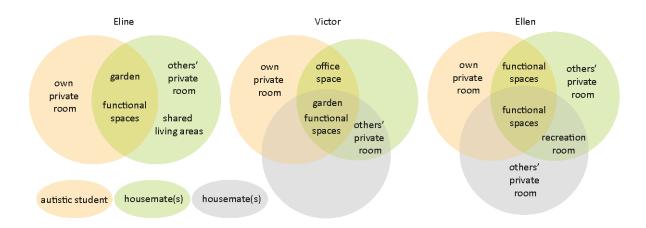


fig. 39 Gradient in social contact through use of space

Prioritisation of the bed-space?

Often seen with students is that they prioritise their own private space over the communal areas (Holton, 2016). Every simple activity is done in the private room, which makes that a less rigid structure exists for activities of the daily life (Card & Thomas, 2018; Holton, 2016). This phenomenon only occurs for one participant's situation, she does everything from her bed, which is just the way she likes it. She only leaves her room when it is absolutely necessary. The other female participant has a more structured life thanks to the communal meals in the dining room. The male participant also structured the spaces in the house. Every space has its own function. He will not study in his private room or eat in the office space. This has the advantage that he can focus better on what he is doing. However, he is also fond of flexibility within a space, in the office space they have multiple options to work. When autistic people are living alone it is best that functions are separated so they can live according to a routine (Mostafa, 2010). The male participant is very fond of the routines they have developed together in their household.

Anonymity

Autistic women will try to avoid social situations, close themselves off and often have difficulties with trusting people (Pearlman-Avnion, Shlain, & Lowinger, 2019). This is definitely the case for one of the participants. People don't know that she is autistic, because, according to her, it is not really visible, she just seems a really shy person who is not interested in connecting to others. She **avoids using the shared spaces because she feels that she couldn't be there unnoticed**. This is also why she wanted a room on the second floor, so people from outside couldn't see what she is doing in her room. She likes her privacy and will always close the door to the corridor so she doesn't have to interact with people. She doesn't like communicating over *Facebook* with her housemates and she preferred communicating through the physical chalkboard in the kitchen because in that way she can be **anonymous**. To some extent this holds for the other female participant as well, although she is trying to find a connection with her housemates. She prefers studying in the library over studying in the study room in her student accommodation because in the library she can ignore people. She experiences difficulties with **balancing**, on the one hand, her need for anonymity - and thus being alone – and, on the other hand, wanting social contact with her housemates. The male participant didn't mention anything about

wanting or needing this kind of anonymity although he doesn't want to take in much space in the shared spaces⁹⁵.

5.1.4. FINDING REST AND AVOIDING STRESS

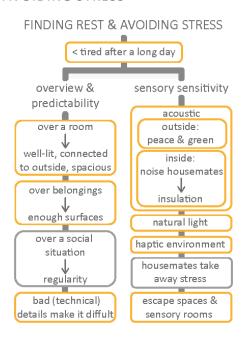


fig. 40 Aspects related to finding rest and avoiding stress

People experience the world around them through their body, their senses and their memories (Franck & Lepori, 2007). The body is continuously exchanging information with the environment. The built environment can offer people things (affordance), which may be enabling or disabling human capabilities (Baumers & Heylighen, 2015). Autistic people process what the environment offers them differently than neurotypicals. For one they may experience sensory input more of less intense or it gets mixed up in their head (Kinnaer, Baumers, & Heylighen, 2016). Literature also suggests that autistic women may have a higher sensory sensitivity (Pearlman-Avnion, Shlain, & Lowinger, 2019). Autistic people also have a more detailed way of processing the environment (Spek, 2014). These two traits can result in the autistic person feeling exhausted and stressed out after a long day of processing environmental information (Lowinger, 2019; Van Hees, Moyson, & Roeyers, 2015). The male participant is often tired after a long day, which shows him that he has been doing too much, when he comes home he can restore his energy. Also one female participant needs to find rest after a long day at her internship.

Overview and predictability

For autistic people the built environment needs the be predictable, consistent, compatible and controllable because other people might be confusing (Kinnaer, Baumers, & Heylighen, 2016). Their living environment needs to be familiar, stable and clear (Atsmon, Yaakobi (Gorga), & Lowinger, 2019; Steele & Ahrentzen, 2016). All three participants talk about situations in their accommodation where they need this. One participant doesn't use the study room in her student accommodation anymore because when studying there she couldn't get an **overview of the space** and she was getting distracted

⁹⁵ Victor, (not) feeling at home, p 62.

by her housemates who were moving around. Another participant has to know the room to be able to focus, because he otherwise gets distracted due to all the details he has to take in. His eye for detail also showed in his carefully and precise way of hanging up his mirrors. He finds rest in having an overview of the spaces he is in. Rooms that provide him this are spacious, well-lit and connected to outside. He is also looking for predictability in space, like the lamp in the hallway which makes clear when someone is using the toilet without having to interrupt them. He says that making things understandable without having to bother anyone is what architecture should do. The other female participant also feels more comfortable in spaces that are open, well-lit and modern. Modern spaces are for her cleaner and tighter and represent rest, by offering an overview. That is why she wanted to live in a new building. Two participants like to have an overview of their belongings. One has a big desk on which he can layout his schoolwork. Another has multiple shelves and closets to display her belongings. One participant wouldn't be so stressed to attend social events in her student accommodation, if they were more predictable and completely thought through. She would benefit from regularity in this kind of events, like eating together once a week in the kitchen instead of alone in the private room. However a situation where they have to eat together every weekday, would also be too much for her.

Sensory sensitivity

The environment is multi-sensory and thus is experienced through all our senses and not only the visual sense (Franck & Lepori, 2007; Pallasmaa, 2007; Steele & Ahrentzen, 2016). It seems that autistic people pay more attention to the different aspects of the built environment. The quality of spaces are measured through using all the senses (Pallasmaa, 2007). Student accommodation needs to be affordable, yet this shouldn't have a negative effect on the living quality (Steele & Ahrentzen, 2016). Lower quality can have a negative influence on autistic people's experience of their living situation.

The acoustic environment around and inside the building turned out to be an import factor for the three students. They are all looking for a peaceful environment, which is represented by greenery, to live in. Autistic people (and neurotypical people) benefit from a green, healthy environment when living independently (Steele & Ahrentzen, 2016). A peaceful and green environment can have a big influence on someone. For one participant's brother, for example, this was so important when he went searching for student accommodation, that all other criteria he had in mind for his student accommodation became suddenly less important. Another participant is living in a quiet suburb of Leuven, where he likes to take care of the plants in the house because they give him rest. Another participant asked for a room with garden view so she wouldn't hear the street noise and she enjoy the view from her window. Both female participants mention that they are very much bothered by the noise of their housemates and they can hear them very clearly when they are doing things in their own rooms. The male participant and his housemate also mentioned that the noise, coming from other rooms in the house is annoying and that better acoustic isolation would be good. A student accommodation should be properly insulated against noise to make living together more pleasant for all residents, especially for autistic students.

On participant pays much attention to **natural and artificial light**. For him spaces can reflect rest through **a connection to outside**, **a good view**, **being naturally well-lit and spaciousness**. Not only spaces can provide rest but also objects, like his nightlamp that totally changes the atmosphere in his bedroom. Also his **housemates can take away stress** he is experiencing. For another participant the

haptic environment plays a prominent role in her student life. The warmth and softness of her bed, make that she likes doing her daily activities from there.

To find rest in their student accommodation and to balance the input they perceived all day, autistic people might require access to **escape spaces and sensory rooms with elements for sensory stimulation** (like plants and pillows) to fulfil their needs. For example one participant could benefit from a space where she can listen to music while being surrounded by pillows. Another participant finds rest through the plants in his office space. Also the other participant could use such a space to find rest in her student accommodation, because she couldn't find this there now.

For autistic people, living in student accommodation every week is already difficult. When small (technical) details don't work, it can cause much stress which makes living in their student accommodation even more difficult and less comfortable. Both female participants' student accommodations have small (technical) details that don't work. Also the male participant notices small details that bother him, but this is minor compared to all the good things in his living situation.

However, I am aware that many aspects mentioned above fit under multiple concepts, because they are in some way all intertwined. The next scheme is a combination of all the schemes for the four concepts and gives an overview over the different aspects (fig. 41).

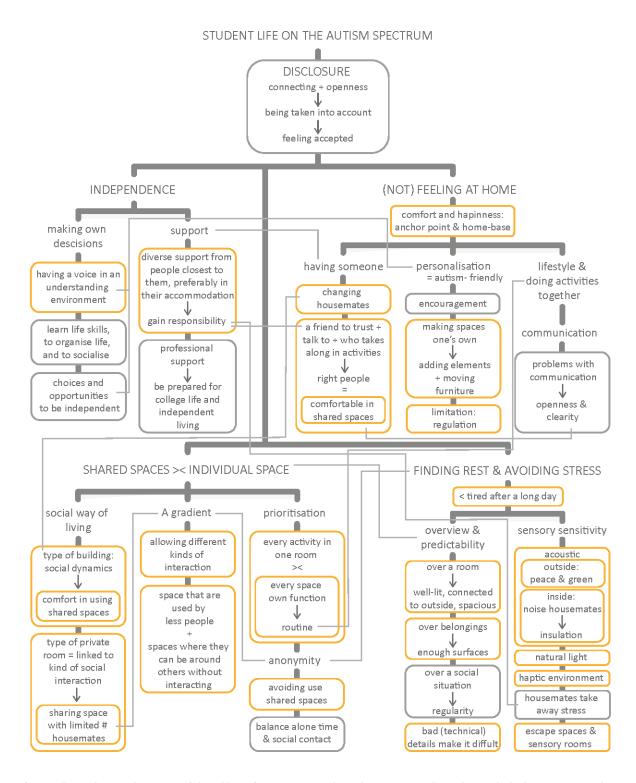


fig. 41 Scheme showing the aspects of shared living for an autistic student. The aspects in yellow relate to the built environment. The smaller grey lines are connections between different aspects and show that aspects fit under multiple concepts.

5.2. REFLECTION METHODOLOGY

Originally I had planned to use three different participatory methods: photovoice, walk-along interviews and co-analysis. I also used one classic method: the semi-structured interview. Due to COVID-19 people were not allowed to meet in person and the walk-along interviews were not conducted. However, this was not a big issue as the photovoice meeting turned out to deliver enough data to work with. While it would have been more beneficial if the data could have been verified and extended through walk-along interviews, I still verified the data by going back to the participants with the initial findings. It turned out I had interpreted their statements correctly. On some topics the participants gave additional information. This was not only fruitful for the reliability of my analysis but also for the participants themselves. By showing them how other autistic students are living I gave them the opportunity to reflect on their own living situation and, in the case of Ellen, even broaden her view about how she would like to live.

I used the methods in different ways in each case. Although I couldn't talk with other students who were living with the autistic students, because it is important to respect the participants' choice not to involve their housemates, I still obtained valuable information. Eline and Ellen haven't told their housemates about their autism, with the result that their housemates don't know that they are living with an autistic student, but they are in fact experiencing it. So in a sense they do know what it is like to live with an autistic student but interviewing them would risk disclosing that Eline and Ellen are on the autism spectrum.

I listen carefully to what the participants wanted and let them decided how things would go. They were allowed to suggest other ideas about the approach and they were in charge of choosing when (and where) every meeting would take place. This made that the participants became more involved in deciding about the set-up of the research. For example Eline only wanted to meet once so I adapted what I had planned to her preference.

For Eline I prepared an interview, which I had sent upfront because she asked for it. After having been interviewed, she also suggested to do a tour around the building. In this way I still had conducted one walk-along interview, be it that this was not as well thought through as I had intended. However this turned out to be informative, in terms of what she told and what I observed, and was a valuable addition to the story she had told during the interview. The pictures she sent afterwards, but which we didn't discuss, helped to structure the findings and offer the reader visual material to better understand her living situation.

I had met with Victor and Koen, and Ellen and her mother a first time to allow them to get to know me -also a student- and the research. I think this was helpful because it was an informal way of meeting and made the participants and myself feel more at ease for the next meetings. I think that this helped them to be more open towards me and the topic.

With Victor and Koen, I invited them both to make pictures of their living situation. Victor choose to pay more attention to the architectural aspects of living there and Koen showed the influence of Victor's presence. After discussing the pictures, the interview was conducted. These two methods provided each their own information but also allowed for triangulation. The pictures, they both took, are very similar, which shows that they have the same view on their living situation. Through using both their sides of what it is like to live together, the analysis becomes more reliable. When I went

back to them with the initial findings, they had no additional comments or remarks that I interpreted things wrongly. This shows the value of having multiple informants in this research. I asked them how they experienced the photovoice exercise. Victor said that the beginning was difficult because he wanted to help me by approaching it from an architectural point of view. When he knew what he wanted to show, it went smoothly because he had made up in his mind how he wanted the pictures to look. He said he enjoyed thinking about it. Koen thought it would be difficult, but it turned out to go smoother than expected. He had immediately the idea of making a picture of their calendar and then the others were easy to make. Putting the pictures into a word document and providing them of text went easy. He says the instructions were very clear and had fun doing it and found it fun to talk about the pictures with Victor as well.

With Ellen and her mother, I only let Ellen make pictures of her living situation. Because her mother doesn't live there, I didn't invite her to make pictures herself, but to comment on the pictures Ellen took. This gave me information about how Ellen and her mother thought about different elements of her living situation. After we discussed the pictures, the interviews were conducted. Here as well through linking everything together, the data became reliable. This shows again that having multiple informants in this research was indeed a good choice. Asked how they experienced the photovoice exercise, Ellen thought it would be difficult before she started and found it indeed very difficult to take pictures and write what she wanted to show with them. Taking pictures of the shared spaces was difficult because she was afraid of running into someone. She didn't think it was pleasant to do because she finds it difficult to express feelings and emotions. If it was something more objective, more black and white, more clear, she thinks it might have been easier. She says she asked help from her mother, but according to Tessa, Ellen thought of most pictures all by herself. Tessa thought it was a funny concept and liked that she could see what her daughter was photographing.

I found the photovoice method useful when talking about them with the participants. The pictures they took also helped me during the analysis to better structure findings and made the different aspects I was looking into more clear. I used the pictures in reporting on the findings so the reader could visualise better how the autistic students are living.

5.3. RESEARCH LIMITATION AND FUTURE RESEARCH

The findings of this research are reliable because of the previous mentioned way I dealt with the information⁹⁶. However what this research teaches us about how the built student accommodation plays out in autistic people's experience might be not that autism-specific. There are some limitations to the research.

Limitations in relation to the participants

The first one is that this research **only represents three cases**. The three students' living situations are all very different, which is in line with the divers options there are for living in a student accommodation. However there are many more options that may show interesting ways for living in a student accommodation for autistic students. More cases are useful because every (autistic) student is different and has another view on what a good way of living together with others entails. The data could be enriched by looking into additional cases of both male and female students in other kinds of

⁹⁶ See 5.2 Reflection methodology

student accommodation, for example living in a student accommodation where the landlord also lives, in a smaller student house with only six residences, or in a student accommodation 'met omkadering'⁹⁷.

The second possible limitation of this research is that **one of the participants is living in an extraordinary way**. He doesn't live in a typical student accommodation with other students, but in a co-housing situation with his best friend who adapted his life completely to support him. This participant is the only male representative in this research which makes it difficult to address specific aspects (such as disclosure) as something that only girls engage in. It may be that a male autistic student in their situation would also keep his autism to himself. However thanks to the mother of Ellen, aspects of her autistic son's life in student accommodation were also brought up. I would have liked another case with a male autistic student in a more typical student accommodation. However this case turned out to be very interesting and showed some strategies that could be applied to make other autistic students more comfortable in their living situation.

Limitation in relation to approach

A third limitation of this research, was beyond my control: because of the pandemic I couldn't conduct walk-along interviews in the student accommodations of the two participants who had done the photovoice exercise. It would have been interesting to see what method they preferred or were more comfortable with. I can only tentatively conclude that how comfortable the participants are with making pictures in their student accommodation depends on their attitude towards the exercise and how comfortable they are in their student accommodation. However not being able to conduct the walk-along interviews had little impact on the reliability of the existing data because of the use of multiple informants and taking initial findings back to the participants.

A note

I want to note that it was not possible to gain information about how neurotypical students experience living with an autistic student in their student accommodation. This out of respect for the participants' choice not to involve their housemates because they haven't told them about their autism. This could in fact be a fourth limitation of my research. However 1) the risk of disclosing the participants' autism would have been too high, and 2) not in every student accommodation the students are close or undertake activities together. More often students in one student accommodation have their own group of friends outside their student accommodation with whom they share college life.

Further research

A more elaborate study, which reaches more participants in different living situations would allow to confirm or challenge insights gained in this research. Originally I had planned to conduct with the participants and their housemates a co-design workshop about ways to improve living in their student accommodation, however this was not possible due to a) the choice of two participants to not disclose their autism to their housemates, and b) the pandemic. Although I could have tried to organise such a workshop online, I choose not to do so because this would ask a lot of time from the participants, which they seemed not to have anymore. It would be interesting to design a student accommodation

⁹⁷ See footnote 8, p 22.

together with these or other participants, where the aspects from this research (and further research) are taken into account.

CONCLUSION

This master's thesis looked into how autistic students, with attention to the difference between male and female students, experience living in a student accommodation and what role the built environment plays and can play in this. This was approached by gaining information about three different living situations. Each situation had its own way of approaching where different methods were used during multiple meetings. Through the discussion I tried to identify different aspects to keep in mind when looking into student accommodation for autistic students. Because living in a student accommodation is often about sharing spaces, it becomes difficult to separate the social environment from the built environment. This built environment affects how students' social interactions are shaped.

First of all, the **attitude** of the autistic student has a big influence on how they are experiencing living together with others. This research showed that the female participants, due to masking their differences very well, had difficulties opening up to their housemates about their autism. They were afraid that they would be treated differently or that they would be judged. Their insecurity can be explained by the fact that many people don't know what autism is exactly and that the term is often still used as an insult. By not telling their housemates about their autism, they **experience difficulties to connect** with them, with the result that their housemates are less able to take them into account. The prevailing attitude towards autism is that it is a spectrum disorder. However several (autistic) people advocate to approach autism, not as a disorder but as an aspect of **diversity**. A first step in making student life for an autistic student comfortable, is ensuring they feel accepted by encouraging them about **disclosure** and making their housemates aware, open to their differences and willing to take them into account.

Going to college is for both neurotypical students and autistic students a critical transition period for becoming an adult. However, for autistic students this might be more stressful. The (autistic) student should have the opportunity to decide how this transition process is going to go and how they are going to adapt to the chosen living situation. They should be able to make their own decisions about their living situation, possibly under the guidance of others. Through using the shared spaces students might learn important life skills as cooking, cleaning or proper social communication from each other. Every student is looking for a sense of belonging and autistic students might find this best in a supportive (social) environment where they are encouraged to grow and are able to escape from social isolation. For example one of the participants⁹⁸ is living together with adults who give him this opportunity to grow while another participant's ⁹⁹ opportunities to learn new life skills and communicate properly are taken away. College life can be hard and some people might need a bit of ((non)-academical) support to keep them on track. Autistic people are likely to need this minimum amount of support for aspects related to living independently. They will often reach out to their family for help, but one participant can count on his housemate for different kinds of help. This proves to be very successful and is also desired by another participant.

⁹⁸ Victor, independence, pp 59-60.

⁹⁹ Eline, independence, p 52.

Most students live in two different places, the parental home and the student accommodation. If they are feeling comfortable, they might refer to the latter as their second home. The student home is often the central place in the students' daily lives, which is not different for the autistic students. According to two participants they have a place in their accommodation which is their anchor point and through which they can control their lives. There are different aspects of someone's living situation that might affect them feeling at home. By analysing the stories of the three participants I found that having a friend, lifestyle, personalisation options, and communication where important factors that determined the feeling of home. In a student accommodation it is common that people you are living with change every year, which means that the dynamics in the accommodation constantly change. The participants note that their feeling comfortable in the shared spaces, depends on who were their housemates that year. Changing housemates make it difficult for the autistic students, who have difficulties with social communication and thus will not (easily) talk to people they don't know, to find a friend who guides them in the social aspects of living in a student accommodation. Judging from the living situation of the participant who is co-housing, it may be better for the autistic students to live with a smaller group (max 5 to 6 people) of people throughout their academic career. These would be people they trust and who have complementary lifestyles to their own, for example other autistic students and shy people who ensure a restful atmosphere, and with whom they could occasionally do planned activities in and outside the student accommodation. This would help the (female) autistic students to expand their social connections and help against loneliness they are experiencing in their student accommodation. So having a friend in their student accommodation would be valuable. The participants all need an open and clear communication which allows them to bond better with their housemates. One of the participants was actively looking for this kind of social contact in her student accommodations but it didn't turn out the way she had planned. A very important factor for feeling at home is the possibility to personalise the built environment in the student accommodation. It showed that the participant who was encouraged to show his identity through making adaptations in the whole accommodation, really felt at home and had a place where he could be himself without having to adapt to social norms. The regulations in the other student accommodations made it impossible to completely adapt the spaces to how they would have liked. However, one participant actively changed the layout of the furniture to her way of living which made her at least feel a bit more comfortable in her private room.

Students can choose from a variety in types of student accommodation and private room. Their choice has an influence on what kind of social relationships they are likely to have with their housemates. All the participants have a private room but share other facilities within their building with their housemates. Two participants¹⁰⁰ wanted to live in this way, but also two participants¹⁰¹ don't feel comfortable in using the shared spaces because they are sharing these spaces with too much people. In the end they all think a studio wouldn't be a good fit because of the higher risk for social isolation. The living situation of the participant who is co-housing with only two others is considered as more or less ideal. Another aspect often observed in student accommodations is the prioritisation of the bed-space over the shared spaces. This is only observed, for one participant, be it in an extreme form. For the other participants, life in their accommodation is more structured. One of these participants even implemented a separation of functions, while allowing flexibility in using the space for that specific activity. Autistic people's independent living improves when they can develop a routine. Especially in student accommodation, social relationships develop in the shared spaces. Autistic students might

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¹⁰⁰ Eline and Victor

¹⁰¹ Eline and Ellen

benefit from having a diverse range of options, a gradient, for social contact. They prefer spaces that are used by less people (who they preferably know) and where they don't have to socially interact, however they also don't want to be overlooked in a conversation. Especially the female participants don't feel comfortable in the shared spaces because they don't want to stick out and would like to keep their anonymity. More secluded spaces that offer them privacy and where other people don't see what they are doing can result in them using the shared space more often and in a more comfortable way. The possibility to find a balance between their need for social contact and need for being alone and coming to rest could make the autistic students feel more comfortable in their student accommodation.

Autistic students may be easily exhausted after a long day of processing (sensory) information, this is why they are looking for **rest** and the possibility to reload their energy in their student accommodation. I feel that this is not priority number one for neurotypical students, because for them their student accommodation is a place to first of all socialise intensely. To find this rest autistic students may need a predictable and familiar environment. This translates itself in needing a) an overview of the spaces they use, which can be achieved through aspects of the room as spaciousness, cleanness (modern looking), good lighting and/or a connection to the outdoors, b) needing space to display their belongings, and c) a predictable social environment where there is a regularity in doing a limited number of activities with their housemates. People experience the built environment through their senses, autistic people might pay more attention to this sensory input, which makes that they are more in need of a restful and stress free environment. In a student accommodation the acoustic environment (both in and outside) has the largest impact on all students, but autistic students may experience noise from others as more annoying. To allow them to find rest in their own private room better sound insulation should be a key concern. Also the haptic environment and (natural) light seemed to be important for the participants. (Technical) details that don't seem as concerning to most people can have a major impact on autistic students' comfort level, and make it more difficult to live in their student accommodation. To balance all these sensory inputs autistic students might benefit from sensory rooms and escape spaces within their student accommodation.

Judging from this research, the most important for autistic students in a student accommodation is that their social experiences are made more comfortable. Through applying the elements mentioned above to the built student accommodation and ensuring that they live with people who are invested in them, they might have a positive experience of living independently in a shared living situation.

Reflection

Looking back at this research, I feel that I can relate to different aspects the participants had brought up. Just like Victor I don't like to be interrupted when I am working on something and just like Ellen and Eline I don't like to stick out. However this never made me not use the shared spaces in my student accommodation. From the start I felt home in my student accommodation because of a) the green environment, b) the rest I can find there, c) the closeness to campus, d) the possibility to have friends over in my private room, and e) the option to make my room, my own place. I also think that it is indeed very helpful to have a friend in your student accommodation because you are able to support each other and you always have someone to hang out with.

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7.1. MEETINGS WITH PARTICIPANTS

Eline, interview, 13 February 2020.

Ellen, photovoice meeting, 12 March 2020.

Ellen and Tessa, introduction meeting, 19 February 2020.

Ellen and Tessa, analysing skype meeting, 10 May 2020.

Koen, photovoice meeting, 3 March 2020.

Tessa, photovoice meeting through skype, 23 March 2020.

Victor, photovoice meeting, 3 March 2020.

Victor and Koen, introduction meeting, 24 February 2020.

Victor and Koen, analysing skype meeting, 12 May 2020.

8. APPENDIX

8.1. PHOTOVOICE PHOTOGRAPHS

8.1.1. INSTRUCTIONS PHOTOVOICE

Dutch

- Toon aan de hand van 6-8 foto's hoe jij het leven op kot ervaart.
- Maak foto's van allerlei verschillende soorten ervaringen op kot: gevoel, relaties, gebeurtenissen
- De foto's mogen positieve, negatief of neutraal zijn
- Geef de foto's een titel en een korte beschrijving van 1-2 zinnen
- Stuur ze door via e-mail voor het begin van de volgende sessie

English

- Show with 6 8 photographs how it feels to live in student accommodation.
- Make photographs of different kind of experience at student accommodation: feelings, relationships with housemates, events
- Include neutral, positive and negative photographs.
- Add a title to the photographs and a brief description of 1 or 2 sentences
- Send the photographs through e-mail before the next meeting

8.1.2. PILOTSTUDY WITH HOUSEMATE

The photographs and Word document were made on Friday 15 November 2019.



MIJN KOT IS:

Plek vanwaar ik alles met de fiets doe. Vanwaar alles dichtbij is

My student accommodation is:

The place from where I do everything by



MIJN KOT IS:

Waar niemand zegt 'ruim u kamer eens op'

My student accommodation is:

Where nobody says: 'Clean your room'

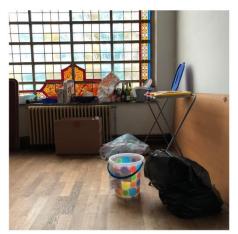


MIJN KOT IS:

Plek waar ik zelf kook. Niet altijd even goed als de mama

My student accommodation is:

The place where I cook for myself. Even if it is not as good as my mother does



MIJN KOT IS:

Waar het allemaal wat minder proper is.

My student accommodation is:

Where nothing is really clean



MIJN KOT IS:

lets te veel series kijken

My student accommodation is:

Where I watch a little too much series



MIJN KOT IS:

Samenleven met vrienden. Altijd gezelschap.

My student accommodation is:

Living together with friends. There is always company.

8.1.3. QUESTIONS AROUND THE PHOTOGRAPHS

Dutch

- Vertel wat je hebt willen tonen met de foto's
- Voor elke foto
 - O Wat heb je proberen weergeven op deze foto?
 - o Wat betekent dit voor jou?
- Wat heb je bewust niet op een foto gezet? En waarom?
- Welke foto geeft het best jouw ervaring weer? En waarom?
 - O Wat vind je leuk aan je woning? Komt hier een foto mee overeen?
 - Wat vind je niet leuk aan je woning? Komt hier een foto mee overeen?
 - O Wat is je favoriete plek in de woning?
- Wat vind je van deze opdracht?
 - Ging dit moeilijker of makkelijker dan gedacht?
 - O Hoe zou deze opdracht beter kunnen voor jou?
- Hoe heb je dit aangepakt?
 - o Heb je hulp gevraagd aan iemand? Of inspiratie gezocht?

English

- Tell me what you wanted to show with the photographs
- For each photograph
 - O What did you try to show with this photograph?
 - O What does this mean to you?
- What did you not photograph? Why?
- Which photograph shows best your experience. Why?
 - What do you like about your student accommodation? Is this visible on a photograph?
 - What don't you like about your student accommodation? Is this visible on a photograph?
 - o What is your favourite place in your student accommodation?
- What do you think about this exercise?
 - O Was it more difficult or easy than you thought?
 - O How could this be better for you?
- How did you approach this exercise?
 - O Did you ask help of someone? Did you look for inspiration?

8.2. SEMI-STRUCTURED INTERVIEW GUIDES

8.2.1. ELINE

- Studiekeuze en studentenleven
 - Wat studeer je? Waarom heb je voor deze studie gekozen? Wat beïnvloede je bij je studiekeuze?
 - Waar studeer en werk je voor je vakken? Waarom daar?
 - Wat doe je na de lessen en zelfstudie? Wat zijn **je interesses**?
 - o Hoe ziet een typische dag voor jou eruit?

- o Hoeveel tijd breng je door op de campus en op kot?
- Waar ben je goed in (sterke punten)? En waarin ben je minder goed (zwakkere punten)?
- Ervaar je voor- of nadelen in je dagelijkse leven omwille van enkele sociale factoren?
 Welke en hoe drukken deze zich uit? (vanuit gender, leefomstandigheden, invloed door ouders, vrienden, kotgenoten,...)
- Heb je ooit begeleiding of hulp gezocht (toen je jonger was of op de universiteit)? Op welke manier heeft dit je geholpen in je persoonlijke ontwikkeling en woonomstandigheden?

Leven op kot

- Wat was belangrijk bij het kiezen van je kot? Had je specifieke noden? Welke?
 Waarom?
- Waarom koos je voor dit type van studentenhuisvestiging? Wat was je redenering?
- Hoe beschrijf je je relatie met je kotgenoten? Reken je op je kotgenoten voor bepaalde zaken?
- Hoe is je relatie met je familie? Op welk familielid reken je voor het helpen bij bepaalde zaken?
- Kende je je kotgenoten op voorhand? Was dit een belangrijke factor in het kiezen van je kot?
- Hoe communiceren jullie op kot met elkaar?
- Voel je je thuis op kot? En in je eigen studentenkamer? Waarom wel/niet?
- o Wat vind je leuk aan je kot?
- O Wat vind je niet leuk aan je kot?
- o Ervaar je moeilijkheden van het leven op kot? Welke zijn dit?
- Ervaar je voordelen van het leven op kot? Welke zijn dit?

- Autisme

- Wanneer kwam je erachter dat je **autisme** had? (Hoe kijk jij naar jou autisme?)
- Waarom heb je je kot genoten niet vertelt dat je autisme had? Vertel je dit wel aan anderen?

- Na leven op kot

- Als je verhuist uit dit kot, wat zijn de 3 dingen die je bij wilt houden? Wat zijn de 3 dingen die je wilt veranderen? En waarom?
- o Wat betekent je kot voor jouw?

8.2.2. VICTOR

- Studiekeuze en studentenleven
 - Je studeert burgerlijk ingenieur architect,
 - waarom heb je voor deze studie gekozen? Wat beïnvloede je bij je studiekeuze?
 - Waar studeer en werk je voor je vakken? Waarom daar?
 - Wat doe je na de lessen en zelfstudie? Wat zijn **je interesses**?

- o Wat is een typische dag voor jou?
 - Hoeveel tijd breng je door op de campus en op kot? En de verplaatsing tussen beide?
- Heb je ooit begeleiding of hulp gezocht (toen je jonger was of op de universiteit)? Op welke manier heeft dit je geholpen in je persoonlijke ontwikkeling en woonomstandigheden?
- Leven in co-housing
 - Wat was belangrijk wanneer jullie gingen samenwonen? Had je specifieke noden?
 Welke? Waarom?
 - Heb je ooit overwogen om op kot te gaan met andere studenten? Waarom wel/niet?
 Wat zijn je noden dan?
 - Hoe beschrijf je je relatie met je huisgenoten? Reken je op je huisgenoten voor bepaalde zaken?
 - Je kende Koen op voorhand, was dit belangrijk wanneer jullie gingen samenwonen? Kende je de andere persoon ook al? Waar hebben jullie elkaar ontmoet?
 - Hoe communiceren jullie in dit huis met elkaar?
 - Kunnen je huisgenoten op jou rekenen voor bepaalde zaken?
 - o Hoe is je relatie met je familie?
 - Op welk familielid reken je voor het helpen bij bepaalde zaken?
 - Voel je je **thuis** in de woning? En in je eigen slaapkamer? Waarom wel/niet?
 - Hoe heb je je eigen kamer gepersonaliseerd? Het huis?
 - Hoe hebben jullie de kamers verdeeld?
 - Heb je je leefstijl van thuis aangepast toen je bij Koen ging wonen en op welke manier?
 - O Hoe is het om aan co-housing te doen?
 - Wat zijn de activiteiten die je in je woning doet? Alleen? Met andere huisgenoten? Met vrienden?
 - Wat vind je goed aan de co-housing, je woning? Aan je eigen kamer?
 - Wat vind je niet goed aan de co-housing, je woning? Aan je eigen kamer?
 - o Ervaar je moeilijkheden van het leven in deze co-housing? Welke zijn dit?
 - o Ervaar je **voordelen** van het leven in deze co-housing? Welke zijn dit?
- Autisme
 - o Wanneer kwam je erachter dat je autisme hebt? Hoe kijk jij naar jou autisme?
 - Wanneer heb je je huisgenoten vertelt dat je autisme hebt? Vertel je dit ook aan je vrienden?
 - Ervaar je hier voordelen uit?
- Na het leven op kot
 - o Wat betekent je woning voor jouw?
 - Als je verhuist uit dit co-housing project, wat zijn de 3 dingen die je bij wilt houden?
 Wat zijn de 3 dingen die je wilt veranderen? En waarom?

8.2.3. KOEN

- Job en leven met iemand met autisme
 - o Jij bent een leerkracht, hoe vormt dit hoe je naar mensen kijkt?
 - o Wat is een typische dag voor jou?
 - Voor Victor bij jullie kwam wonen en na? Is dit verschillend?
 - Hoeveel tijd spendeer je op het werk en thuis?
 - Op welke manieren hou je rekening met Victor?
- Leven in co-housing
 - o Dit is je huis, hoe lang leef je al hier?
 - Wat was belangrijk wanneer jullie begonnen samen te wonen? Had je specifieke noden of voorwaarden? Welke? Waarom?
 - o Hoe beschrijf je je relatie met je huisgenoten?
 - Reken je op je huisgenoten voor bepaalde zaken? Kunnen je huisgenoten op jou rekenen voor bepaalde zaken?
 - Je kende Victor op voorhand, kende je de andere persoon ook? Waar hebben jullie elkaar ontmoet?
 - Hoe heb je besloten dat Victor kon blijven?
 - Hoe communiceren jullie in dit huis met elkaar?
 - Voel je je **thuis** in de woning? En in je eigen slaapkamer? Waarom wel/niet?
 - Hoe heb je je eigen kamer gepersonaliseerd? Het huis?
 - Hoe hebben jullie de kamers verdeeld?
 - Heb je je leefstijl aangepast toen Victor bij jullie kwam wonen en op welke manier?
 - Hebben jullie bepaalde regels in verband met wie waar mag komen?
 - Op welke manier zorg je dat Victor zich hier thuis voelt?
 - Zijn er dongen die je niet meer doet omdat je met Victor woont?
 - O Hoe is het om aan co-housing te doen?
 - Wat zijn de activiteiten die je in je woning doet? Alleen? Met andere huisgenoten? Met vrienden?
 - Wat vind je goed aan de co-housing, je woning? Aan je eigen kamer?
 - Wat vind je niet goed aan de co-housing, je woning? Aan je eigen kamer?
 - Ervaar je moeilijkheden van het leven in deze co-housing? Welke zijn dit?
 - Ervaar je voordelen van het leven in deze co-housing? Welke zijn dit?

- Autisme

- Wanneer vertelde Victor je dat hij autisme hebt? Hoe ging je om met hem voor en nadat hij je dit vertelde?
- o Hoe kijk jij naar autisme?
- Na het leven in co-housing
 - o Wat betekent je woning voor jouw? Wat betekent co-housing voor jou?
 - Als Victor verhuist uit dit co-housing project, wat zijn de 3 dingen die je bij wilt houden? Wat zijn de 3 dingen die je wilt veranderen? En waarom?

8.2.4. ELLEN

- Studiekeuze en studentenleven
 - Je studeert bio-ingenieur,
 - waarom heb je voor deze studie gekozen? Wat beïnvloede je bij je studiekeuze?
 - Waar studeer en werk je voor je vakken? Waarom daar?
 - Wat doe je na de lessen en zelfstudie? Wat zijn **je interesses**?
 - o Wat is een typische dag voor jou?
 - Hoeveel tijd breng je door op de campus en op kot? En de verplaatsing tussen beide?
 - Je hebt begeleiding gekregen, kan je uitleggen waarvoor en op welke momenten in je leven?
 - Op welke manier heeft dit je geholpen in je persoonlijke ontwikkeling en woonomstandigheden?
- Leven op kot
 - o Wat was belangrijk bij het kiezen van je kot?
 - Had je specifieke noden? Welke? Waarom?
 - Waarom koos je voor dit type van studentenhuisvestiging? Wat was je redenering?
 - Op welke manier hebben jullie een kot gezocht?
 - o Hoe beschrijf je je relatie met je kotgenoten?
 - Kende je je kotgenoten op voorhand? Was dit een belangrijke factor in het kiezen van je kot?
 - Hoe communiceren jullie op kot met elkaar?
 - Reken je op je kotgenoten voor bepaalde zaken? Kunnen je kotgenoten op jou rekenen voor bepaalde zaken?
 - o Hoe is je relatie met je familie?
 - Op welk familielid reken je voor het helpen bij bepaalde zaken? En hoe?
 - Je broer zat tot vorig jaar ook op kot maar je haalde aan dat jullie niet in hetzelfde gebouw zaten omdat hij dat niet wou, waarom? En wat wou jij?
 - o Hoe zou je je kot beschrijven?
 - Hoe was het in het begin om op kot te zitten? En nu? Zie je een verschil tussen je 1^{ste} jaar op kot en je 4^{de} jaar? Welk(e)?
 - Heb je je leefstijl van thuis aangepast toen je op kot kwam en op welke manier?
 - Wat zijn de activiteiten die je op kot doet? Alleen? Met andere kotgenoten? Met vrienden?
 - Hoe heb je je kamer gepersonaliseerd?
 - o Voel je je thuis op kot? En in je eigen studentenkamer? Waarom wel/niet?
 - Wat vind je goed aan je kot? Aan je eigen kamer?
 - Wat vind je niet goed aan je kot? Aan je eigen kamer?

- Ervaar je moeilijkheden van het leven op kot? Welke zijn dit?
- o Ervaar je **voordelen** van het leven op kot? Welke zijn dit?

- Autisme

- O Wanneer kwam je erachter dat je autisme hebt?
- O Hoe kijk jij naar jou autisme?
 - Ervaar je voordelen? Ervaar je nadelen?
- Waarom heb je je kot genoten niet vertelt dat je autisme hebt? Vertel je dit wel aan anderen (je vrienden)?
- Na het leven op kot
 - o Wat betekent je kot voor jouw? Wat betekent individueel leven voor jou?
 - Als je verhuist uit dit kot, wat zijn de 3 dingen die je bij wilt houden? Wat zijn de 3 dingen die je wilt veranderen? En waarom?

8.2.5. TESSA

- Studiekeuze en studentenleven
 - Wat was u rol in de studiekeuze van u kinderen? Wat was verschillend?
 - Hoe hebt u hen geholpen?
 - Wat is u bijdrage aan het studentleven van Emma? Hoe is dit anders/ hetzelfde ten opzichte van u zoon?
 - Jullie hebben begeleiding gezocht voor Emma, hoe gaat dit in zijn werk? Op welke momenten bleek dit nuttig?
 - Hoe heeft dit bijgedragen tot de persoonlijke ontwikkeling en woonomstandigheden?
 - Heeft u zoon ook begeleiding gekregen? Op welke manier verschilt dit?
- Leven op kot
 - O Wat was belangrijk bij het kiezen van het kot?
 - Waren er specifieke noden? Welke? Waarom?
 - Waarom werd er gekozen voor dit type van studentenhuisvestiging? Wat was de reden hierachter?
 - Op welke manier hebben jullie een kot gezocht?
 - Hoe beschrijf je Emma's relatie met haar kotgenoten? Is dit verschillend dan hoe u zoon met zijn kotgenoten omging?
 - Op welke manier rekent Emma op je en hoe verschilt dit ten opzichte van u zoon?
 - Emma's broer zat tot vorig jaar ook op kot maar zij zaten niet in hetzelfde gebouw omdat hij dat niet wou, waarom? En wat vond u?
 - o Hoe beschrijf je Emma's kot?
 - Is er een verschil tussen toen ze voor het eerst op kot zat en nu 4 jaar later? Is er een verschil/gelijkenis met u zoon?
 - Heeft ze haar levensstijl van thuis aangepast en op welke manier?
 - Hoe vaak komt u langs?
 - Heb heeft ze haar kamer gepersonaliseerd en hebt u daarin geholpen?

- Voel Emma zich thuis op kot volgens u? En in haar eigen studentenkamer? Waarom wel/niet?
 - Wat vind u goed aan Emma's kot? Aan haar eigen kamer?
 - Wat vind u niet goed aan Emma's kot? Aan haar eigen kamer?
- O Zijn er moeilijkheden van het leven op kot voor Emma? Welke zijn dit? En hoe verschillen deze zich ten opzichte van die van haar broer?
- O Zijn er voordelen van het leven op kot? Welke zijn dit? En hoe verschillen deze zich ten opzichte van die van haar broer?

Autisme

- Wanneer merkten jullie dat Emma autisme heeft? En jullie zoon?
- o Hoe kijk jij naar autisme?
- Waarom heeft ze haar kot genoten niet vertelt dat ze autisme heeft? Vertel ze dit wel aan anderen (haar vrienden)? En hoe gaat u zoon hiermee om?
- O Wat is belangrijk om te weten over autisme?
- Laatste puntjes
 - Wat betekent Emma's kot voor haar? Hoe is dit verschilt van wat u zoons kot voor hem betekent?
 - o Wat vind u het belangrijkste om te onthouden?

8.3. TOPIC LISTS INTERVIEWS

INTERVIEW WITH ELINE

- individuality >< collectiveness / social interaction >< anonymity
 - communication and openness (social engagement)
 - missing a gradient
- balance
- change
- space
 - sensory elements
 - spatial organisation
 - interior design
- support

PHOTOVOICE MEETING WITH VICTOR

- Communication and openness
 - Gradient
 - Being together
- Routines and organisation
- Support and having a voice (inspraak)
 - Being yourself and being accepted
 - contribution
- Flexibility >< structure (spatial organisation)
- Sensory elements
- Finding rest

- Overview >< details
 - predictability

PHOTOVOICE MEETING WITH KOEN

- Communication and openness
 - Gradient
- Routine and organisation
- Adapting and support
 - Having a voice (inspraak)
- Space
 - Flexibility >< structure (spatial organisation)
 - Sensory elements
- Finding rest
 - Avoiding stress
 - Details
- Technology
- Home
 - Being together

PHOTOVOICE MEETING WITH ELLEN

- Individuality >< collectiveness / feeling alone >< wanting anonymity
 - Someone she can trust
 - Communication & predictability
- Change
- Sensory elements
- Spatial organisation
- Support and organisation
- Overview

PHOTOVOICE MEETING WITH TESSA

- Individuality >< collectiveness / feeling alone >< wanting anonymity
 - Someone she can trust
 - Social engagement
 - (Neglected) possibilities
- Support, organization (preparation) and counseling
 - Preparation
 - Counseling
 - Growth
 - Avoiding stress
 - Support & structure
- Finding rest/comfort (cleanness)
 - Sensory elements
- Overview/ predictability
- Spatial organisation

- (technical) details

8.4. STAGE EIGHT OF ANALYSIS

8.4.1. ORDERING AND COMPARING CONCEPTS WITHIN AND ACROSS CASES

ELINE

Individuality >< collectiveness/
social interaction >< anonymity
Communication and openness
Missing a gradient

Change Spatial organisation

Sensory elements

Interior design Support

VICTOR

Support and having a voice Being yourself and being accepted Contribution

Routine and organisation
Communication and openness
Gradient
Being together

Overview >< details
Predictability

Flexibility >< structure (spatial organisation)
Finding rest

Sensory elements

KOEN

Communication and openness
Gradient
Support and adapting
Having a voice

Routine and organisation

Finding rest Avoiding stress

details

Home

Being together

Space

Flexibility >< structure (spatial organisation

Sensory elements

Technology

ELLEN

Individuality >< collectiveness/ feeling alone >< wanting anonymity

Someone she can trust
Communication & predictability
Spatial organisation
Personalisation

hange

Overview Sensory elements

Support and organisation

TESSA

Support, organization (preparation) and counselling

Preparation, counselling, growth, avoiding stress, support & structure

Individuality >< collectiveness/ feeling alone >< wanting anonymity

Someone she can trust

Social engagement

(Neglected possibilities)

Spatial organisation

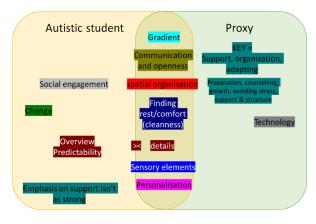
Finding rest/comfort (cleanness)

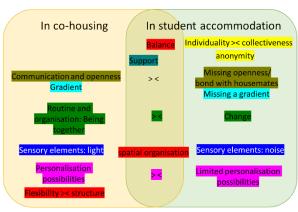
Sensory elements

Overview/ predictability

(Technical) details

8.4.2. DIFFERENCES AND SIMILARITIES





8.4.3. LINK CONCEPTS AND RESEARCH QUESTION

	Eline	Victor	Koen	Ellen	Tessa
Experience	Change Missing a gradient Spatial organisation Interior design	Being yourself and being accepted Contribution Gradient Flexibility >< structure (spatial organisation)	Gradient Routine and organisation Avoiding stress Home Flexibility >< structure (spatial organisation)	Spatial organisation Personalisation Change	(Neglected) possibilities Spatial organisation
Social interaction	 Balance Individuality >< collectiveness/ social interaction >< anonymity Communication and openness Support 	 Support and having a voice Communication and openness Being together 	Communication and openness Support and adapting Having a voice Being together Technology	Individuality >< collectiveness/ feeling alone >< wanting anonymity Someone she can trust Communication & predictability Support and organisation	Support, organization (preparation) and counselling: Preparation, counselling growth, avoiding stress, support & structure Individuality >< collectiveness/feeling alone >< wanting anonymity Someone she can trust Social engagement
Sensory challenge	Sensory elements	 Overview >< details Predictability Finding rest Sensory elements 	Finding rest Details Sensory elements	Overview Sensory elements	Finding rest/comfort (cleanness) Sensory elements Overview/ predictability (Technical) details

8.5. STAGE NINE OF THE ANALYSIS: CONCEPTUAL FRAMEWORK

- Autism
 - o Disclosure
 - Personal view
- Independence
 - Relying on, getting support from (someone in >< out the accommodation)
- (Not) feeling at home
 - People (change >< consistent/ routine & organisation)
 - Personalization (allowed >< not allowed)
 - o Communication: clear and open?
 - o A friend?!
- Shared versus individual space: spatial organisation
 - o Gradient of use of space
 - o Activities, being together
 - o Individuality >< collectively
- Finding rest & avoiding stress
 - Overview & details
 - predictability
 - Sensory elements: noise from housemates, connection to outdoors & greens, light, comfort (haptic sense)
- Fixed conditions for living in student accommodations
 - o Financially (Ellen)
 - o Troubles at home (Victor)