R

Research Booklet

vol. 1

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Dedicated to my loving parents, my father and my mother, who are my biggest supporters and source of inspiration in life.

And my partner Aksel, who believed in me and walked with me through every step along the process.

Without your support, none of this would be possible. Thank you.

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PREFACE

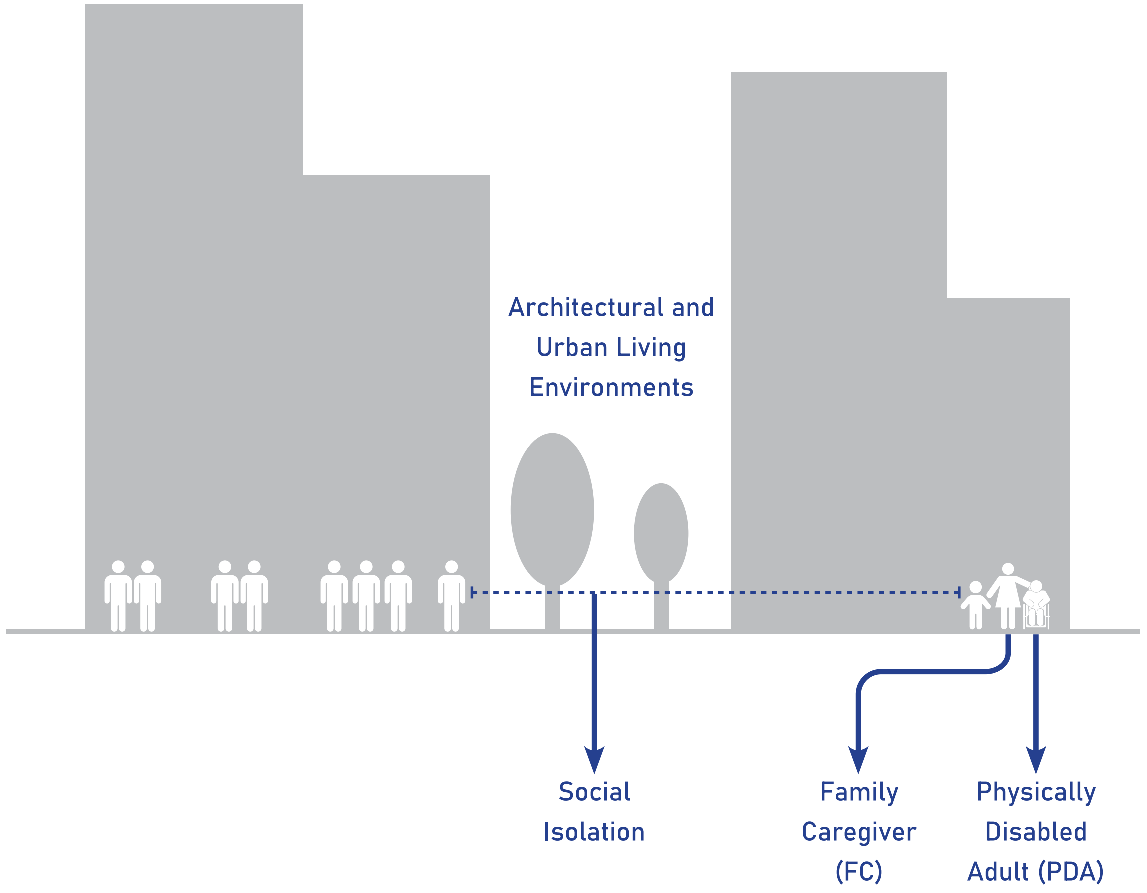
Since the day I was born, I have been exposed to the life of a disabled person. My father has MS since 1994 and I didn't get to know my father without MS – for me, it has always been something attached to him and is very normal to have. My parents always showed me that having MS and living our life with it was "not wrong" and our way of living was "the normal". As a kid, I thought every family went looking for a 'disabled parking spot' around the parking garage for half an hour or took days to prepare for a small trip to the nearest shopping mall for a Sunday afternoon. As a small child, I was oblivious to the not-normal parts of our lives but as I got older, I realized these are not part of a "normal" family's routine.

As years passed by, I started to think more and more about how we live our lives and why my parents cannot live a life similar to their peers. I started questioning why I cannot do "normal" family activities with both of my parents and why this is accepted as normal for everyone around me. As my parents got older, I witnessed how my dad's most comfortable place, his home, started to become unsuitable and how small changes that we could afford and our limited power to help him keep his daily routine turned out to be insufficient. I realized how my dad started to slowly isolate himself from the outside world and how this was mainly the society's fault. I saw the great love my mum has for my dad and how she doesn't want to do much because she cannot do them with my dad anymore.

I decided to study architecture when I was only 12 because I really believe I can change my parents' lives, and also the lives of people who are going through similar experiences and I can achieve this by changing their living environments. I learned over the years that being "inclusive" is not only adding a disabled parking spot at a garage or putting ramps and elevators in the buildings – but unfortunately, this is what the society thinks as 'good enough'. In the end, there are and always will be disabled people around us, why not accept their existence and see them as our equals in our daily lives and try to include them in our daily routines as much as possible? I believe that there is more we can do as members of the society. But speaking as a future architect, I know there is a huge responsibility on the members of this field: in the end, making inclusivity and accessibility key features in our living environments is something (only) architects can achieve.

This research booklet provides the initial step of a 10 month architecture project in which I tried to find an answer to the questions that I had in my mind since I was a small girl. I am really excited and hopeful that my project will be starting point for me in my career ahead of me to make a change. But I also hope for all the readers, this research booklet can create new thoughts, questions and ways to move forward as a society in which each and every member of the society can feel welcomed and understood.

I hope you, the readers, will enjoy the booklet as much as I enjoyed writing it!



KEY TERMS AND DEFINITIONS

ARCHITECTURAL AND URBAN LIVING ENVIRONMENTS:

Collins Dictionary defines the word ‘living‘ when it is an adjective as “sustaining of life“, and when it is a noun as “involving or characteristic of everyday life“. The definition of the word ‘environment‘ is given as “someone’s environment is all the circumstances, people, things and events around them that influence their life“ (Collins, n.d.). For this research, the term ‘living environment‘ includes both of these definitions and mainly refers to all the circumstances, people, things and events around someone that influences what is characteristic of their everyday life. The words architectural and urban in this expression refers to the designed spaces individuals make use of in their daily lives which are directly accessible by them, such as their homes, the buildings they reside in, their direct neighborhoods and places they spend time in in their daily life.

PHYSICALLY DISABLED ADULTS:

Mushtaq & Akhouri (2016) defines physical disability as “a state with remarkable defect, limitation or inability of certain organs or processes of the body, which create hurdle in carrying out normal physical movements and thus affect normal functioning in different areas of life“. Physically disabled adults are the group of people who are 18 years old or older who fit this description. For this research, the focus is on people who acquired the disability through a diagnosis with an (neurological or neurodegenerative) illness, condition or due to an injury (usually to brain or the spinal cord).

FAMILY CAREGIVERS:

Plank et al. (2011) defines a primary caregiver as “a person providing informal (unpaid) support for an individual unable to complete all of the tasks of daily living after discharge into home environment”. If this primary care is provided by one or more of the family members (spouses, siblings, parents, kids or other relatives) of the physically disabled adult, then they are accepted as the family caregivers of that individual.

SOCIAL ISOLATION:

Freeman et al. (2020) relates social isolation to the lack of social participation. They define that “the impact of reduced social participation is social isolation: objective lack of interactions with others of the wider community“. Macdonald et al. (2018) relate social isolation to social loneliness. They define social loneliness as “the absence of an acceptable social network: a wider circle of friends and acquaintances that can provide a sense of belonging“. Social isolation, on the other hand, is “concerned more with environmental impoverishment or restrictions that with individual’s ability to create and maintain social relationships. It is underpinned by environmental factors that relate to the breaking down of social networks“. For this research, a combination of these will be taken as the focus.

01

INTRODUCTION TO THE RESEARCH

IDENTIFYING THE PROBLEM AND THE RESEARCH

12%
of the people
in the Netherlands

↓

People with motor disabilities and
impairments is the largest group

↓

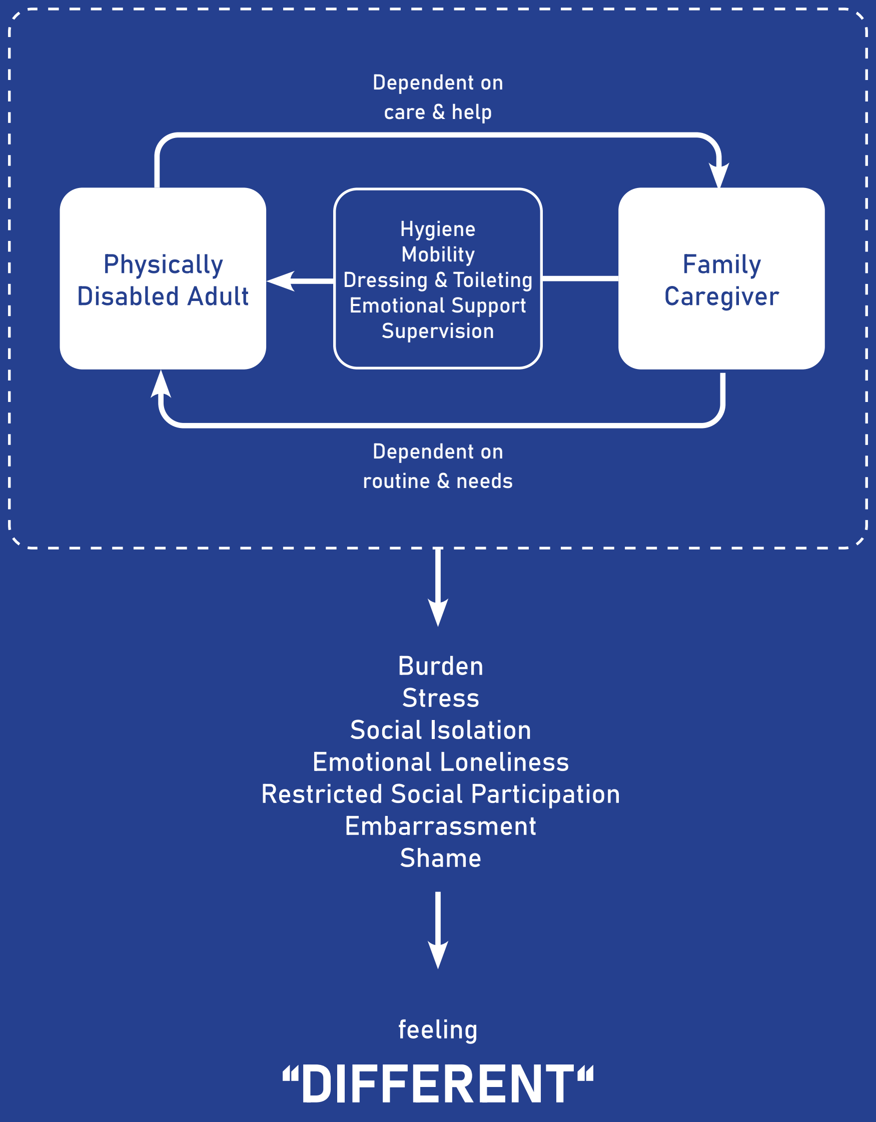
Family life and
continuing to live at home

01 INTRODUCTION

There are currently approximately 2 million individuals in the Netherlands who have a physical disability, this makes up 12% of the population. This data includes people who live in the Netherlands, who are 12 years old or older and who have motor disabilities or impairments, or physical impairments (including hearing and seeing). Motor disabilities and impairments make up the most in this 12% compared to physical impairments. No more than half of this group with motor impairments can visit their friends and acquaintances as they wish and only less than a third can leave their houses and make trips/journeys as they please. It is also reported that the motor disabilities and impairments increase and tend to worsen with age and when present at the same time as a chronic condition (that can also develop with age). It is shown that the proportion of individuals with a physical disability who stated that they can live their lives independently dropped over the course of years as well (Vermeij & Hamelink, 2021; CBS, n.d.).

Such physical disabilities appear through conditions that are inherited or present at birth, serious injuries or illnesses that affect the brain or the spinal cord or through accidents. Over the last years, number of physically disabled people and subsequently the number of informal caregivers have risen due to social and demographic factors. Projections of increasing chronic and invalidating illnesses (including neurological illnesses/conditions) act as reminders and as a challenge for the healthcare system as well as the family life for people with disabilities (Plank et al., 2011).

With the high pressure on the traditional healthcare system and the nature of the conditions of the physically disabled individuals (that their condition is permanent and they continue living at home - if possible), the responsibility on and expectations from families and family caregivers increase. This makes family caregivers responsible for a wide range of services that were normally provided by traditional healthcare providers (Elliot & Shewchuk, 1998).



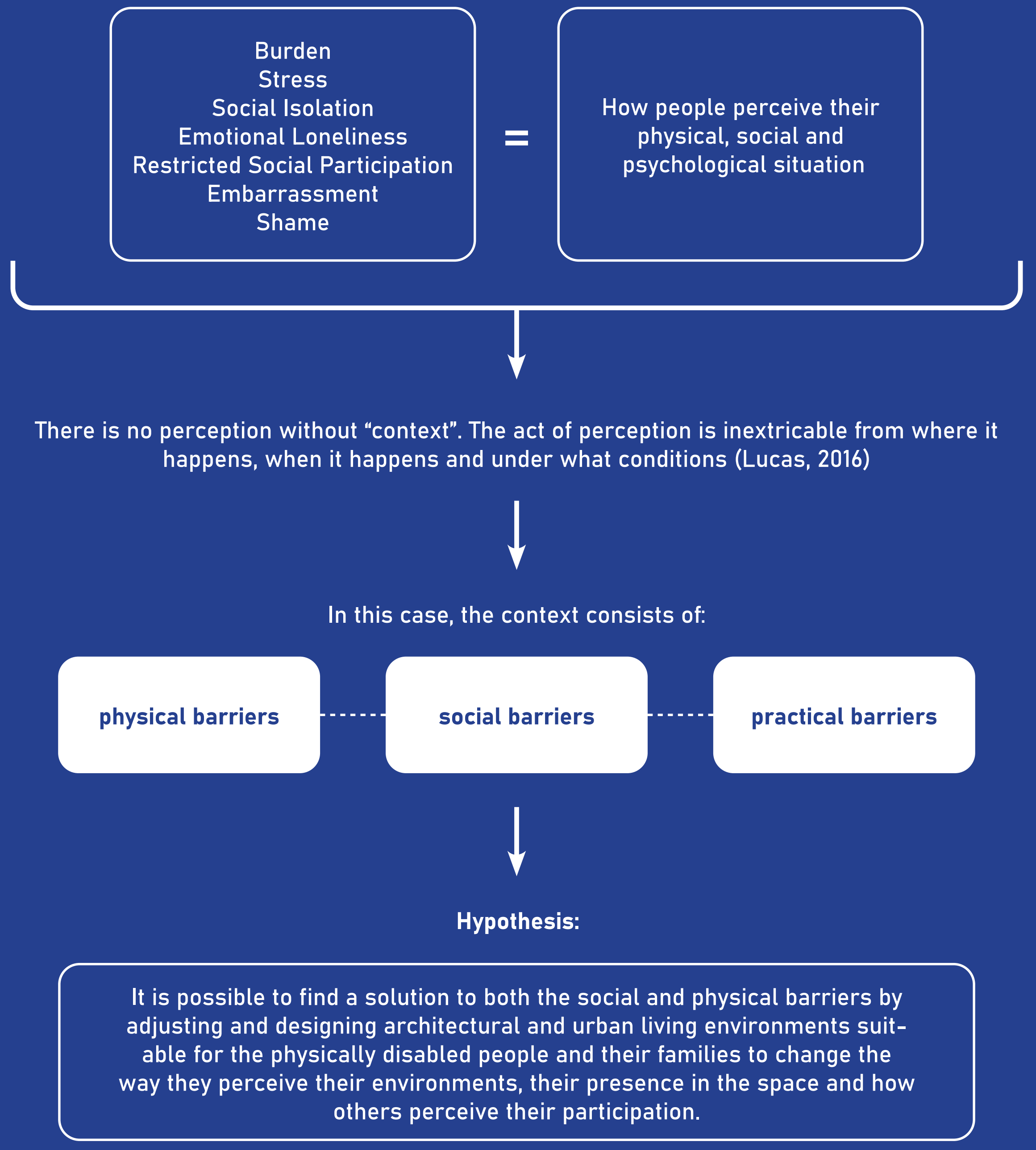
02 PROBLEM STATEMENT

A person with a physical disability often has no choice but to rely on their family (Kim, 2017). In such situations, the spouses, parents, kids, or close relatives of the physically disabled individual act as the family caregivers and they become responsible for a wide range of services that the disabled individual cannot perform themselves anymore (Elliot & Shewchuk, 1998). In contrary to other health conditions, people with physical disabilities (usually) do not require constant care. Instead, what they require is the occasional extra hand and a certain level of care at certain times of the day (namely for hygiene, mobility, dressing or toileting) (Fernandes & Angelo, 2016).

Between the two groups, the physically disabled and the family caregiver, there is a co-dependence which affects both sides and how they live their individual daily lives: the disabled person is naturally dependent on the care and eventual help of the caregiver and the caregiver is dependent on the routine, needs and current health status of the physically disabled family member (Mushtaq & Akouri, 2016; Freeman et al., 2020). The pressure increases when on top of their normal responsibilities (such as household chores, their jobs or other obligations), the family caregivers also assist with tasks that the physically disabled adult is unable to do themselves. These tasks not only include personal hygiene and mobility, but also providing an appropriate environment for their physical and mental health, supervising them during their daily activities, providing emotional support and taking over their duties in the household when they are not able to do them anymore (Plank et al., 2011).

It turns out that such chronic illnesses or physical conditions do not only affect the lives of those who suffer from a physical disability but also those of the family members who care for them (Lim & Zebrack, 2004). Preceding studies show that such a co-dependence as described earlier creates a burden and stress for both the disabled and the family caregiver: the disabled does not want to negatively affect their loved one’s life while the family caregiver does not want to make the physically disabled family member’s life harder. Issues around the presence of a physical disability within a family are not just limited to the individual with the disability but they also concern the whole family: the mental, physical, and financial burdens are shared, and care is usually provided as a result of collective effort (Kim, 2017).

Similar to the feelings of burden and stress, it has also been reported that people with physical disabilities are more likely to experience social isolation and emotional loneliness (Macdonald et al,. 2018). The functional and physical limitations restrict disabled people’s participation in social activities and gatherings and limit their social interaction. Feeling of loneliness and isolation can range from feeling like “being cut off from people“ to “being cut off from the society/world“. Not being able to reach family, friends or loved ones physically quickly escalates to become the sensation of being isolated from the world, feeling “different” and feelings of embarrassment and shame due to their condition. On this note, family carers play an essential role and they are equally affected by these emotions (Freeman et al,. 2020).



Burden
Stress
Social Isolation
Emotional Loneliness
Restricted Social Participation
Embarrassment
Shame

=

How people perceive their physical, social and psychological situation

There is no perception without “context”. The act of perception is inextricable from where it happens, when it happens and under what conditions (Lucas, 2016)

In this case, the context consists of:

physical barriers - **social barriers** - **practical barriers**

Hypothesis:

It is possible to find a solution to both the social and physical barriers by adjusting and designing architectural and urban living environments suitable for the physically disabled people and their families to change the way they perceive their environments, their presence in the space and how others perceive their participation.

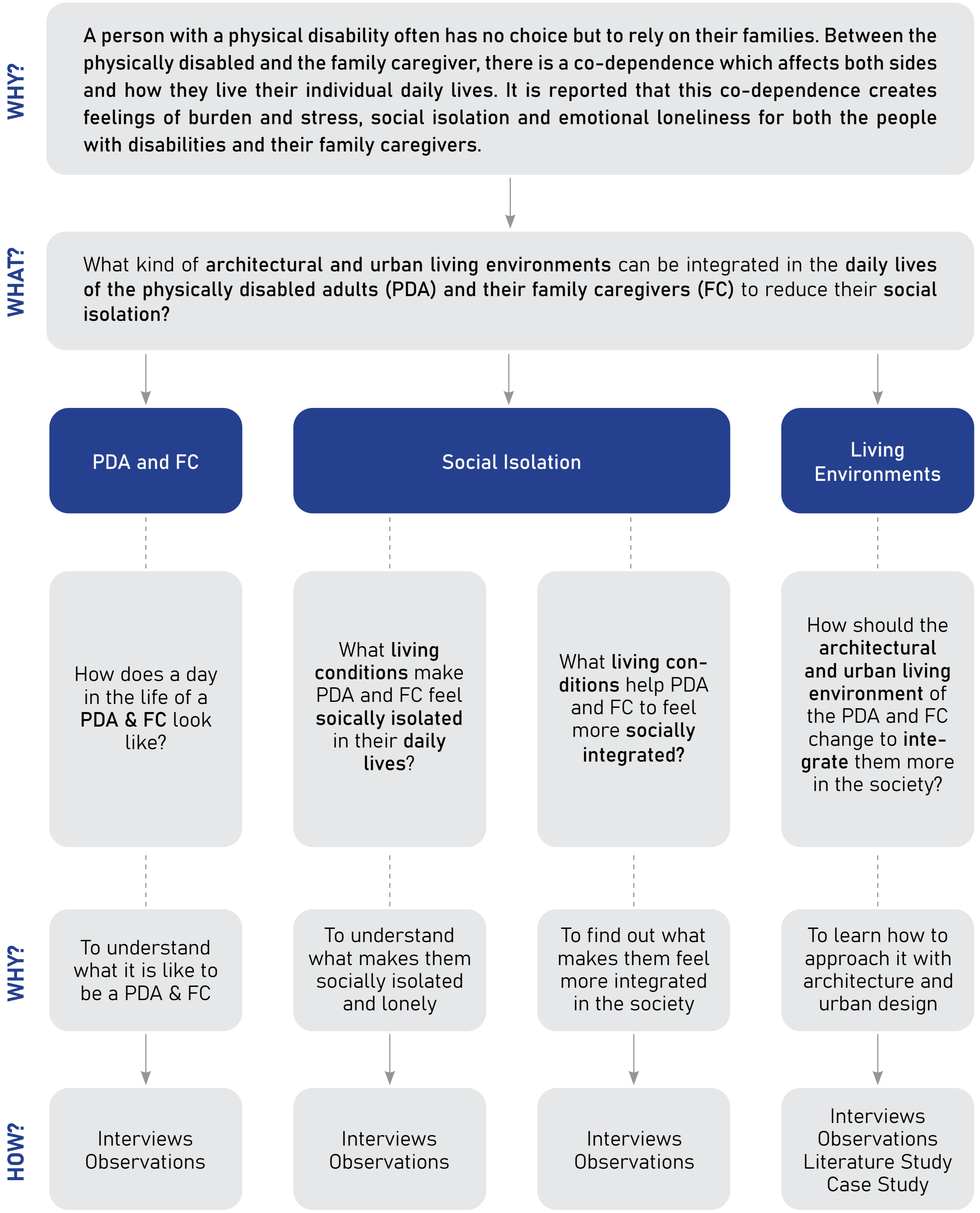
It has been studied that due to the challenges and responsibilities of caring for a family member, caregivers often feel tired, isolated, and overwhelmed. This is also enhanced with other problems such as lack of support, training, information, or someone to talk to (Li, & Zebrack, 2004). The feeling of “being responsible for everything“ weighs heavy on the family caregivers and creates the need to try and juggle various tasks simultaneously. In this challenging situation, research found that family caregivers also require emotional and social support, and in the absence of such support, they feel like they are left alone and like they are abandoned (Plank et al., 2011). It is noted that care-giving shows symptoms of chronic stress for both the caregiver and the physically disabled person, which comprises the physical and psychological health of both (Schulz, 2008).

It is especially significant for the family caregiver to be in good mental and physical health because failure to promote the emotional and physical well-being of the caregiver can have negative implications for both sides (Elliot & Shewchuk, 1998). What the caregiver is experiencing, and their health conditions have the potential to influence the health, welfare, and successful rehabilitation of individuals with a physical disability (Lim & Zebrack, 2004).

The architectural environments and the conditions of the spaces both the physically disabled individual and their family caregivers spend their times at during their daily lives can have an impact on their perception and how they handle their health and care situation and their outlook on their position in the society. It can be said that the origins of the feelings of stress, burden and social isolation goes back to the way people perceive their situation - either physical, social or psychological. As Tim Ingold states: “There is no perception without context. The act of perception is inextricable from where it happens, when it happens and under what conditions“ (Lucas, 2016).

There has been a good number of policies issued in the Netherlands with the aim of allowing as many people as possible to participate fully in society. The main aim is to help people with disabilities to live as they wish through changes in the social domain that will lead to noticeably fewer barriers. However, when it comes to participation and “barriers“, the first thing that comes to mind is the physical barriers that make access challenging. But accessibility and participation are also about the experiences people have once they access a particular environment. In other words, accessible and inclusive spaces are spaces that not only people can get into, but that they also feel welcomed to be into. In the end, when we talk about an accessible society, we are talking about more than just the physical or practical barriers - the social barriers that are part of the social structure and the way the society and living environments are organized (Vermeij & Hamelink, 2021). It is possible to find a solution to both the social and physical barriers by adjusting and designing architectural and urban living environments suitable for the physically disabled people and their families to change the way they perceive their environments, their presence in the space and how others perceive their participation.

03 RESEARCH



WHY?

A person with a physical disability often has no choice but to rely on their families. Between the physically disabled and the family caregiver, there is a co-dependence which affects both sides and how they live their individual daily lives. It is reported that this co-dependence creates feelings of burden and stress, social isolation and emotional loneliness for both the people with disabilities and their family caregivers.

WHAT?

What kind of **architectural and urban living environments** can be integrated in the **daily lives of the physically disabled adults (PDA) and their family caregivers (FC)** to reduce their **social isolation?**

How does a day in the life of a **PDA & FC** look like?

What **living conditions** make PDA and FC feel **soically isolated** in their **daily lives**?

What **living conditions** help PDA and FC to feel more **socially integrated?**

How should the **architectural and urban living environment** of the PDA and FC change to **integrate** them more in the society?

WHY?

To understand what it is like to be a PDA & FC

To understand what makes them socially isolated and lonely

To find out what makes them feel more integrated in the society

To learn how to approach it with architecture and urban design

HOW?

Interviews
Observations

Interviews
Observations

Interviews
Observations

Interviews
Observations
Literature Study
Case Study

MAIN RESEARCH QUESTION

What kind of architectural and urban living environments can be integrated in the daily lives of the physically disabled adults (PDA) and their family caregivers (FC) to reduce their social isolation?

RESEARCH AIMS

To answer the main research question, it is important to understand four key aspects:

- The daily lives of Physically Disabled Adults (PDA) and their Family Caregivers (FC)
- Living conditions that make PDA and FC feel socially isolated and lonely
- Living conditions that make PDA and FC feel (more) integrated in the society and daily life
- Changes in the architectural and urban living environments that would facilitate the change from social isolation to social integration

SUB-QUESTIONS

Each sub-question targets one of the research aims to facilitate a complete research.

- How does a day in the life of a Physically Disabled Adult (PDA) and their Family Caregivers (FC) look like?
- What living conditions make PDA and FC feel socially isolated in their daily lives?
- What living conditions help PDA and FC feel more socially integrated?
- How should the architectural and urban living environment of the PDA and FC change to integrate them more in the society?

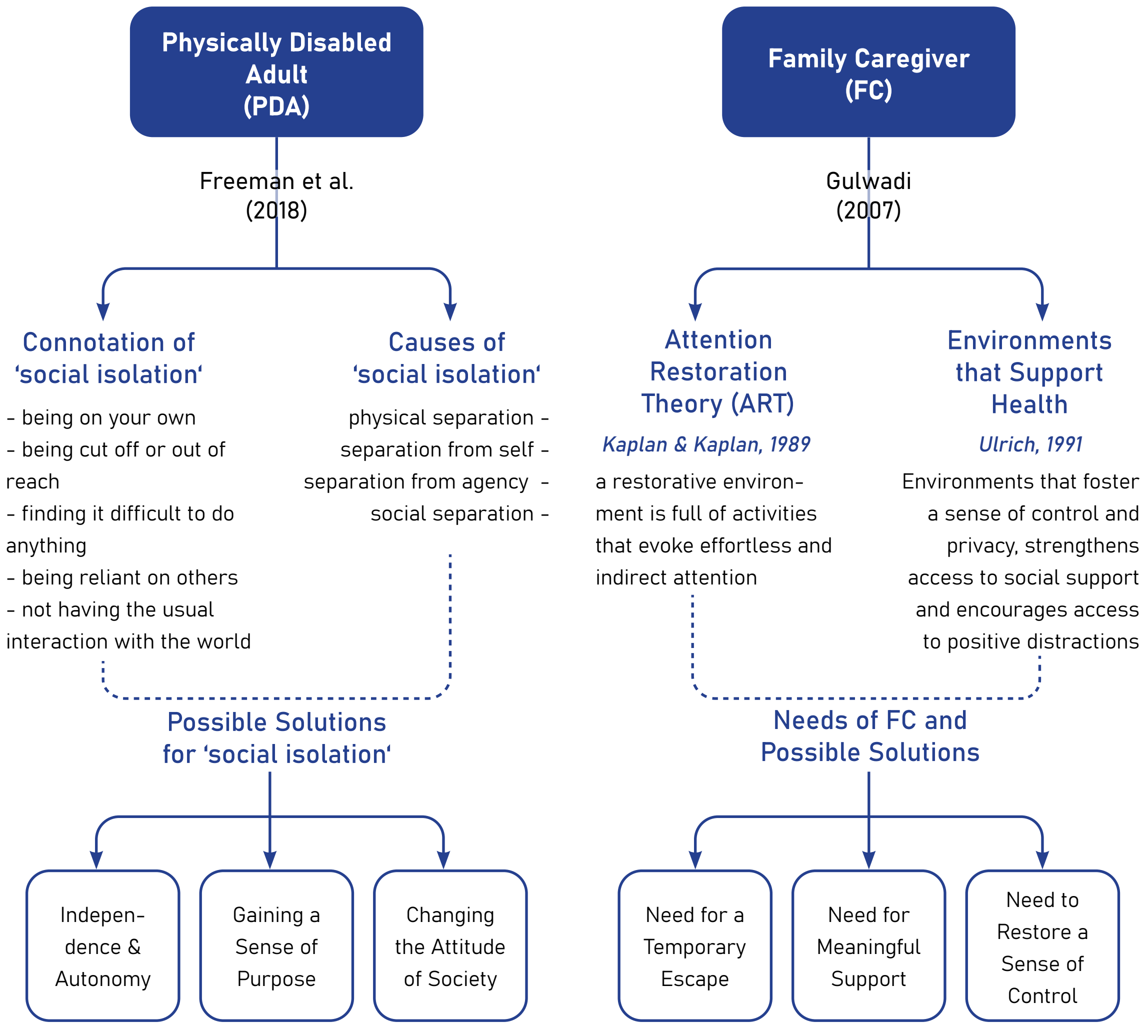
What kind of **architectural and urban living environments** can be integrated in the **daily lives of the physically disabled adults (PDA) and their family caregivers (FC)** to reduce their **social isolation?**

1 How does a day in the life of a physically disabled adult (PDA) and their family caregiver (FC) look like?

2 What living conditions make PDA and their FC feel socially isolated in their daily lives?

What living conditions help PDA and FC to feel more socially integrated in the society?

3 How should the architectural and urban living environments of PDA and FC change to integrate them more in the society?



04 THEORETICAL FRAMEWORK

There are two target groups identified in this research which are equally important: Physically Disabled Adults and their Family Caregivers. Both experience social isolation differently and subsequently, their needs to be more integrated in the society and how to achieve this are also different and have to be approached target-specifically.

Theoretical framework is established on academic literature done on these two target groups which identifies the meaning and causes of social isolation for each and what they need to do individually or what the society can provide for them in order to make them more integrated in the society in their daily lives.

A. PHYSICALLY DISABLED ADULTS (PDA) & SOCIAL ISOLATION

Interpretation of the term “social isolation“ differ depending on people’s experiences. Freeman et al. (2018) discovered a range of meanings attached to the phrase “social isolation” for PDA (specifically people who are impaired due to MS - Multiple Sclerosis). Connotations like ‘being on your own‘ to ‘being cut off or out of reach’ describe the implications of the physical limitations PDA faces on a daily basis and how it affects their participation in social life. Other definitions such as ‘finding it difficult to do anything’ and ‘being reliant on others’ show the interpretation of the PDA towards their struggles with mobility, ability and movement and the powerlessness that emerges from these struggles. The one definition that sums it up is ‘not having the usual interaction with the world’ which shows what social isolation feels like for PDA in terms of their participation in the world - they are left out because they cannot live their life like able-bodied people.

Freeman et al. (2018) share that the main cause identified by the PDA for their social isolation is ‘separation’. It all starts from ‘physical separation‘ as a natural consequence of their disability - inability to go out freely and access public spaces but also other considerations that come with their condition such as fatigue or incontinence. As their condition worsens over time due to age or the condition, ‘separation from self‘ comes in the play - the individual becomes unable to engage in the activities which gave them purpose and were part of creating their self-identity. By being reliant and dependent on others, PDA become powerless and lose their independence, choice and control over daily activities which is referred as ‘separation from agency‘. Finally, with PDA feeling that they cannot act according to the norms of social interaction leading to them feeling ‘different‘, they start to experience ‘social separation‘ - being separated from society and societal roles.

The research from Freeman et al. (2018) shows that even if social isolation starts with physical limitations and restrictions, it develops through social encounters and emotional reactions to daily experiences. As a response to how PDA define social isolation and what they identify as possible causes of it, Freeman et al. (2018) comes up with three key aspects to target for their social integration.

I. INDEPENDENCE & AUTONOMY

Being physically separated from social life and public spaces due to their physical health condition and also being separated from agency by not being able to decide for themselves anymore result in PDA to feel reliant on others and disempowered due to the lack of independence, choice and control. To combat the feeling of frustration and uselessness that emerge as a result of this sense of dependence on others and conditions of physical environments, it is important that the PDA gains self-confidence by being independent and autonomous in their daily lives. Improving the physical abilities of PDA through the design of their living environments that provide them with the ability to choose for themselves and be independent in terms of access and movement would lead to increased social participation and reduce their feelings of social isolation by making them feel capable, worthy and allow them to interact on their own terms (Freeman et al., 2018; Mushtaq & Akhouri, 2016).

II. SENSE OF PURPOSE & MEANING

Being separated from self and also from agency for PDA results feelings like having no longer a purpose in life, losing motivation and feeling unmotivated. It is key for PDA to feel that they are not a burden, they are capable of making their own decisions and that their actions have a meaning. By reassuring that they have a place in the world and a reason for interaction, experiences of social isolation can be reduced. Increasing social contact is not enough to integrate PDA back to society. Instead, it is essential for PDA to be helped by their surroundings - and their living environments or the people/programs involved in their living environments - to identify their role in the society and to find a sense purpose (Freeman et al., 2018).

III. ATTITUDE OF THE SOCIETY

Being separated from agency - lack of independence, choice and control over daily decisions - affects their interaction with others. Unless there is someone there to guide or support them, they tend to feel powerless and lose their ability to decide for themselves. This changes their perception of how the society views them, subsequently making them feel like a burden. This also creates feelings such as shame and embarrassment which leads PDA to limit their social interactions (Freeman et al., 2018).

Mushtaq & Akhouri (2016) adds to the topic by mentioning that PDA have problems with adjusting in the society since the society tends to label anyone who doesn't fit the description of "normal". It is clear that society's negative reaction to the PDA is responsible for their social and emotional problems. This points to the need of a change in attitude of the society towards PDA and a change in the attitude for the PDA towards themselves to gain confidence and to feel like a part of the society (Mushtaq & Akhouri, 2016).

B. FAMILY CAREGIVERS (FC) & SOCIAL ISOLATION

Responsibilities of FC frequently restrict their spatial and temporal range of activities within their living environments. In situations of familial caregiving, most daily activities take place within a house and the larger system that it is a part of, which become the main living environment for FC and PDA (Gulwadi, 2007). According to Gulwadi (2007), when caregiving restricts FC in their range of activities within this larger system, restorative attributes of the house as a living environment gain importance and should be addressed. These attributes are retrieved from two conceptualizations: environmental psychology (Kaplan & Kaplan, 1989) and from healthcare design (Ulrich, 1991).

According to the Attention Restoration Theory (ART), from Kaplan & Kaplan (1989), a restorative environment is full of activities that evoke effortless and indirect attention. Four components of restorative experiences are: Being away, physical and psychological distance; Extent, coherence and connectedness of living components; Fascination, engagement of the space; Compatibility, connection with what the person intends to do in the space. According to Ulrich (1991), 'Environments that support Health' fosters a sense of control and privacy, strengthens access to social support and encourages access to positive distractions.

Bringing the two conceptualizations together, Gulwadi (2007) comes up with three most important needs of the FC and how to possibly apply that to their living environments.

I. NEED FOR A TEMPORARY ESCAPE

One of the major negative consequences for caregiving is identified as the loss of leisure and consequent feelings of resentment. Caregiving responsibilities and time constraints affect leisure patterns, therefore making the house and its close surroundings the main restorative environment. Positive distractions in the proximal environment which can cater a sense of being away as well as the availability of sunny spaces can help FC with their need for a temporary escape.

II. NEED FOR MEANINGFUL SUPPORT

Overload of responsibilities experienced by FC often leads to social isolation. However, FC usually do not realize this and therefore do not know how to access help. Social support has at least three components: Instrumental (someone to assist with daily needs), Emotional (someone to confide in) and Informational (someone to ask for advice). Living environments with proper configurations can be contributive to socializing while maintaining comfort for the FC by providing dedicated multifunctional and flexible spaces away from their responsibilities.

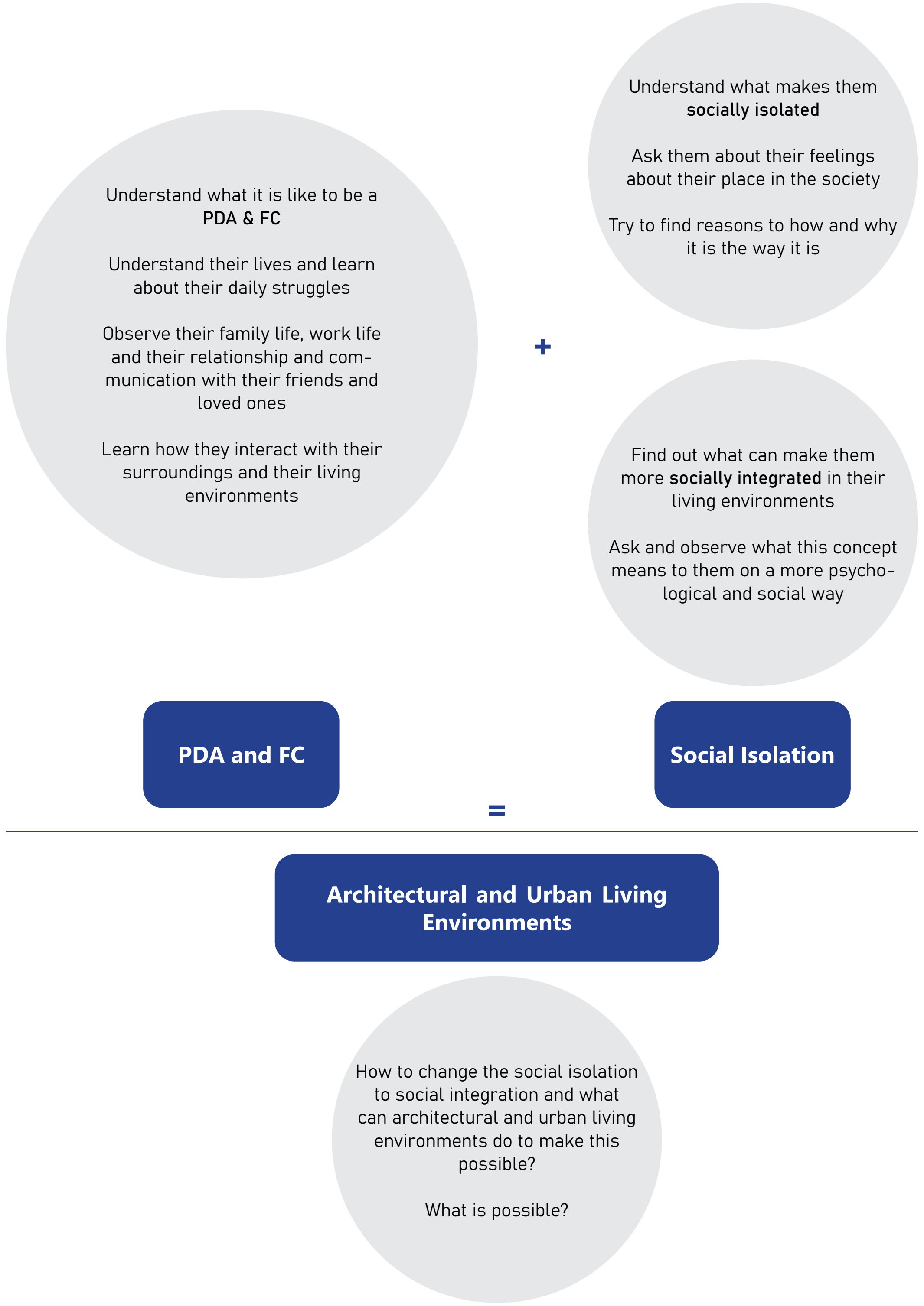
III. NEED TO RESTORE A SENSE OF CONTROL

When social interactions are strained and caregiving responsibilities become too much for FC to handle, their feeling of control over their surroundings and activities is undermined. In this context, it is key to regulate levels of privacy and social contact to restore the sense of control.

Gulwadi (2007) concludes that all of the needs mentioned above can possibly be answered through the configuration of the living environments, availability of spaces that FC can call their own and flexibility and adaptability of the house to meet the emotional needs of the FC.

C. INDIVIDUAL POSITION & HYPOTHESIS

PDA and FC appear to be co-dependent and highly influential for each other: supporting one directly positively affects the other. It is important to adapt their residential environments (where they spend most of their times) to have restorative features but it is also important to consider the larger scale. For both PDA and FC, it is key to be surrounded with supportive living environments in which the individuals of the community are open, understanding and willing to help if needed. The attitude of the people in the direct surroundings of PDA and FC have a significant influence on their integration back to the society. Facilitating PDA and FC to be in a more active, accepting and diverse living environment both in and outside of their homes can be influential to give them a sense of hope which in turn becomes a sense of meaning and purpose in life, subsequently improving their social integration.



Understand what it is like to be a **PDA & FC**

Understand their lives and learn about their daily struggles

Observe their family life, work life and their relationship and communication with their friends and loved ones

Learn how they interact with their surroundings and their living environments

Understand what makes them **socially isolated**

Ask them about their feelings about their place in the society

Try to find reasons to how and why it is the way it is

Find out what can make them more **socially integrated** in their living environments

Ask and observe what this concept means to them on a more psychological and social way

How to change the social isolation to social integration and what can architectural and urban living environments do to make this possible?

What is possible?

05 RESEARCH METHODS

This research will adapt qualitative research methods to answer the main research question and the related sub-questions. The methods include: literature study, observations, interviews and case studies. For the sake of the research, it is essential to gather information at the right time and to process the knowledge gained in the correct way. For this reason, the research will be conducted in 5 phases:

PHASE I: DESKTOP RESEARCH

Desktop research is the initial step of this research and already starts off during the formulation of the problem statement and theoretical framework. It mainly consists of literature study to gather preliminary information and helps to form a foundation before going in the field and interacting with the target groups (Phases II and III).

Literature study is particularly significant to form a basic understanding of the living environments and needs of PDA and FC and to understand the concept of social isolation in relation to caregiving and living with physical disabilities. The literature which are specifically identified to be significant for this research are the works of Freeman et al. (2018), Plank et al. (2012) and Gulwadi (2007) which together form the theoretical framework. The reasons and possible solutions for the social isolation of FC and PDA that they suggest help to formulate the next phase of this research.

PHASE II: FIELDWORK & ANTHROPOLOGICAL STUDIES

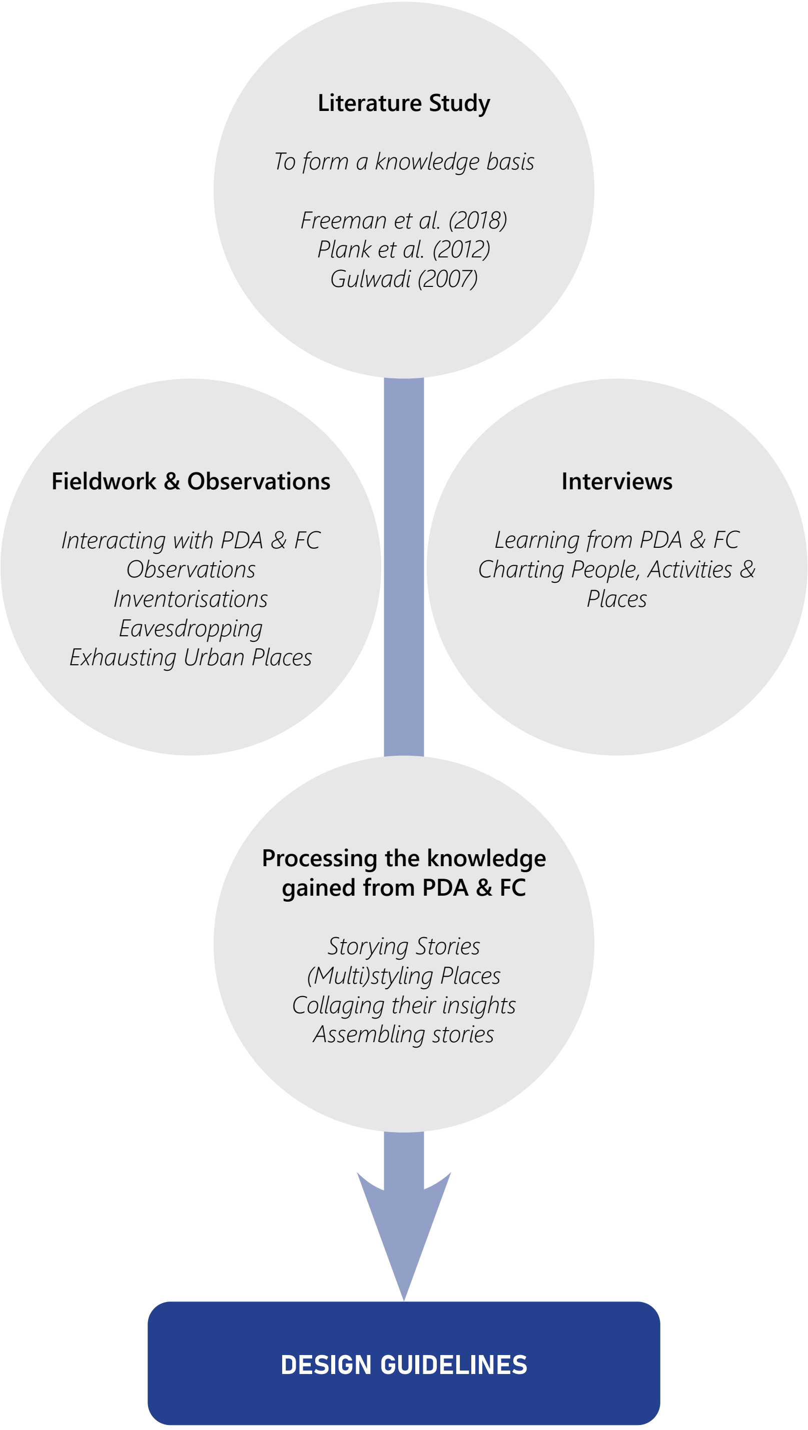
It is an essential part of this research to come in contact with the target group, PDA and FC, during the fieldwork*, which forms the basis of Phase II. Observations and inventorisations are the primary data to be obtained during the fieldwork, which will facilitate the understanding of daily life and the living conditions and environments of PDA and FC.

Main techniques/methods to be used for the observations and inventorisations are "Eavesdropping" and "Exhausting Urban Places" as described by Havik and Moura (2023). Eavesdropping consists of writing down what the observer hears and sees and how the focus on conversations and surroundings affects the experience of the area. Exhausting Urban Places is mainly creating inventories of what is visible (i.e. visible language, movements, sounds, items, observer's feelings, etc).

These will lead the way of the production of basic sketches/drawings of PDA and FC's living environments and keeping diaries of the movements, behaviors, reactions and interactions of PDA and FC with each other and with their surroundings. The locations for these observations are chosen to be from a variety of different settings which are from a part of their daily lives and routines, such as their own homes, their day-care facilities or when they come together for a support-group meeting.

PHASE III: INTERVIEWS

To understand the target group (PDA & FC) thoroughly and to relate to their experiences in their daily lives, it is essential to get in direct contact with them to discuss and talk openly



about their experiences, needs, opinions, and feelings. Interviews will be organized during the fieldwork week with PDA and FC who wish to participate in the research and who are open to share their experiences and daily lives. By recruiting interviewees through carefully chosen associations and institutions**, a wide range of information on PDA and FC will be gathered which corresponds to different social and cultural backgrounds.

One of the techniques/methods to be used during the interviews are “Charting People, Activities & Places“ as described by Havik and Moura (2023). This method includes asking the interviewees about their local environments that they visit in their daily lives through their memories and stories. This will help gather narrative interviews in which memories, experiences and feelings will be discussed. Interviews will be recorded (if the participant is comfortable with it) to enable possibilities of re-listening while processing the data in Phase IV.

PHASE IV: PROCESSING THE DATA

After the fieldwork, information gathered will be organized based on the topics/titles identified in the theoretical framework and also on the topics the participants mentioned & the content of the observations and inventorisations. Some of the techniques/methods to be used at this phase are “Storying Stories“ and “(Multi)styling Places“ as mentioned by Havik and Moura (2023). (Multi)styling Places is a response to the observations: by using the diaries from the fieldwork, the text will be re-written thinking of a specific recipient or thinking how someone else would tell this story. In this research, the personas to be played with will be the PDA and the FC. Storying Stories includes re-listening the interviews and re-writing the interview as a story (with a beginning, climax and resolution). All these methods will help to identify main topics and patterns obtained during fieldwork.

PHASE V: CASE STUDIES

Case studies will act as a supporting method for the research to analyze and understand what has been done in architectural and urban projects before, what approaches have been applied to living environments of PDA and FC and to what extent these approaches and interventions help or not. By evaluating the case studies on their “success“ in integrating the PDA and FC back to the society, lessons will be taken to finally formulate design guidelines. Case studies for this research will be chosen based on whether or not they fulfill the criteria (all cases need to include at least two of the following criteria):
- specifically designed to accomodate and address PDA and/or FC
- social benefits are considered and worked out (social integration, stimulating independence for PDA and/or FC, etc)
- effective on multiple scales (housing unit, community living, neighbourhood, etc.)

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*More information about the fieldwork week can be found in the Appendix (A1).

**To protect the privacy of the interviewees, the names and details of the associations and institutions will not be shared in this research booklet.

MAIN OBJECTIVE

Exploring the architectural and urban living environments significant for the daily lives of PDA and FC to identify elements/conditions that enhance their feelings of social isolation and determining goals and design methods the facilitate the social integration of the PDA and FC through their living environments

RESEARCH AIMS	METHOD(S)	EXPECTED OUTPUT
Learning about the daily lives of Physically Disabled Adults (PDA) and Family Caregivers (FC) and what it is like to be a PDA & FC	Interviews Observations	List of needs and wishes from the PDA and FC on their daily living environments, collected through literature study, interviews and observations
Exploring the environment conditions that make PDA and FC feel socially isolated and lonely and defining the strengths and opportunities of such environments	Interviews Observations	List of architectural and urban environment conditions and elements that point to (strong) experiences/ feelings of isolation and what to pay attention to while designing
Understanding the conditions that make PDA and FC feel (more) integrated in the society and daily life and determining environment conditions that facilitate integration	Interviews Observations	List of elements and conditions in the architectural and urban environments that enhance feelings/experiences of social integration acquired through interviews and literature study
Exploring the possible approaches in the architectural and urban living environments that would facilitate the change from social isolation to social integration	Interviews Observations Literature Study Case Study	Design requirements and toolkit based on the interview results and findings from the case studies which point to effective solutions in the living environments for PDA and FC for social integration

LIMITATIONS

With the main objective given on the left, this research has 4 specific research aims that will be answered through the 4 sub-questions, presented in chapter 3. To answer these question through the methods mentioned earlier and to reach the expected outputs, there are some choices made. The choices limit the research outputs to an extent and is significant to acknowledge.

- PDA for this research is limited to individuals who are 18 years old or older who have physical disability or motor impairments. People with (only) hearing or visual impairments are excluded from this research as their experiences of the living environments require separate attention.

- For the interviews and methods, only individuals who acquired the disability later on in their lives are included. People born with physical disabilities are excluded from this research due to practical limitations but also because of their difference in experience of their conditions and their perception of their living environments.

- PDA and FC of different social and cultural backgrounds will be observed and interviewed, which might have an impact on their outlook in life, their needs and requirements from their living environments. It is not the objective of this research to focus on the origins of their answers, thus the impact of cultural and social backgrounds will be disregarded.

02

LEARNING FROM THE ‘OTHER‘

DAILY LIFE OF PHYSICALLY DISABLED ADULTS & FAMILY CAREGIVERS

This chapter includes the main findings from the fieldwork corresponding to the daily lives of PDA and FC. Observations done at activity/training centres and during the house-visits as well as the interviews conducted with the target group inform the findings of this chapter. The 4 sub-chapters are organized in a way that corresponds to aspects of the daily lives of the PDA and FC that were encountered during the fieldwork. Complete material from the fieldwork can be found in the “Fieldwork Booklet”.

HOW DOES A DAY IN THE LIFE OF A PHYSICALLY DISABLED ADULT AND FAMILY CAREGIVER LOOK LIKE?

“You can always ask for help through the intercom system. You call, the little lightbulb turns on and they ask you what you need. Most of the time if you say something that you really need help with, they come over. But it does take them 5-10 minutes to come over. We try to call them and ask for multiple things at once, to not keep them busy throughout the day and call for small things.”

Mrs. M (60+) lives with her husband in a care home since 2011. They had to move to the care home because they started to require 24h care and it was really difficult to arrange through private care organizations and with nurses on their own. Here at the care home, they see the problem of crowdedness and lack of caregivers: there are simply too many clients and not too many caregivers.

“People sometimes have to get divorced so that they can find a housing faster or sometimes, just to get on the waiting list!”

“Living with other PDA in the flat is good for me because I spend time with them when I feel lonely”

Mr. P (37) also lives in a care home on his own. He had to wait in the waiting list before getting this apartment, and the list can go up to 6 years. It is only possible to live there if you have an indication and it also depends on the urgency of your condition (severity of the disability and the condition of family caregivers). In the flat that he lives in, there are 42 apartments in total and 15 of them are part of the care organization while the rest is occupied by healthy individuals. He thinks this kind of mix is good, but he doesn't have much contact with most of his 'healthy' neighbors.

01 HOUSING AND CARE

For the PDA to receive care and to reside at the same location, there are only a handful of options in the Netherlands. During the fieldwork, three of such residence alternatives have been identified and at least one example of each has been visited to observe differences and main properties. Main findings are presented in this chapter, together with some quotes and stories from the fieldwork interviews.

CARE HOMES VIA A CARE ORGANISATION

At care homes, PDA lives under 24h care. Once the PDA receives an indication from the government that states 24h care is necessary (or if the PDA lives alone in their current home with no one to care for them) they get the right to be put on a waiting list (approx. 2 years) for such a home. Since it is a form of 'co-housing', there are several group activities and social events organized by the care organization throughout the day. This way, residents have the opportunity to socialize with each other and can make use of social amenities within the building if desired. In most of them, there are common dinners and lunches organized daily. Residents can choose to join the group at the common room to eat together or they can also decide to cook for themselves in their own homes if they can. At such homes, however, it is not possible to live with a partner or with other family members (unless they also have an indication). This means that they either need to separate or get a divorce if one needs 24h care and the other cannot provide it – otherwise (if the PDA already has a registered partner) it is very difficult to get housing through such organizations.

FOKUS HOMES THROUGH HOUSING ORGANISATIONS

Fokus homes are carefully adapted independent homes in which there is care available on demand. They usually exist in between regular homes in a flat or on a street and appear to be regular homes at first instance. What makes them stand out is the care centers nearby that are in service 24/7 if the PDA demands it. All houses with PDA are connected to the care center through an intercom system from which they can request someone to come help with health or care related issues anytime during the day. The people at the care points do not help with daily activities or other needs in contrary to the care homes. Here, it is possible to live with a partner or with other family members and the houses are well equipped to host 'normal' life with (usually) more than one bedroom and occasionally with a guest bathroom. The downside of this type of housing is that it can get lonely if the individual lives there alone, without their families or partners. Since this is in essence not a co-housing initiative, there are no social gatherings organized by the housing cooperation or the care center which creates little to no opportunities to socialize or go somewhere else other than their homes in their daily lives.

“I feel like for the past 4 years that I have moved here that I am on a luxurious vacation. Whatever I need, I ask the care center and they come to help me. Most importantly, my sons don’t have to worry about me anymore. Beforehand, my sons took more care of me than I could care for them. Now, I am good taken care of so I can actually spend quality time with my boys.”

Mr. R (55) lives in a Fokus home with his two sons. The nurses of the care center help him with getting out of bed, going into bed, going to the toilet and everything else he needs throughout the day. He had to wait 1.5 years on the waiting list before getting the opportunity to move here. Before moving here, he lived independently with ‘thuiszorg’ but he thinks it was not enough for him and his condition because he needs help throughout the day at different times and not at one specific moment.

“In my own house, I have my freedom. I am not dependent on someone to come to help me to go to bed. If I am tired, I go to bed early. I don’t need to wait for a nurse or caregiver to come and put me in bed. I decided how I will live, and it is not the same as living in a care home. Sometimes, for example, putting something on my bread is difficult and my wife says, ‘Let me do it for you!’. But no, I will try and do it myself. I am stubborn about my independence and freedom.”

Mr. W (54) lives in a house with his wife and youngest kid that they bought before he got sick. Luckily, the house is on the ground floor, and everything is on one floor, so they didn’t have to move after he got sick. He thinks he is very lucky that he could continue living at his own house with his wife and kids. He can still physically do a lot of things himself, but he sometimes requires his wife’s help.

INDEPENDENT HOMES

In independent homes, the individual chooses to stay in their own homes, usually with their families or partners. In such housing, the individual can choose to get help through private nurses and they also mostly adapt their own homes according to their own needs with the financial aid through the government to live as independently as possible. Within this type of living, other than some fixed times during the day in which the nurses arrive to help, daily care and answering the needs of the PDA becomes the obligation of the family caregiver, which creates a sense of responsibility on them and on other family members with whom the PDA lives together with. The upside of this type of housing is that PDA can continue their life as normally as possible with little to no change in their daily routines and with maximum independence if the house is adapted accordingly. However, in this case, PDA is mostly surrounded by regular homes with healthy individuals in their neighborhood or flat, which can mean that the living environment is not fully adapted for the PDA to move around easily and can create little to no opportunities to socialize or go somewhere else other than their own homes in their daily lives.

“I am too young to not go to an AC or TC. I should try keep my days as full and as busy as possible at this age.”

Mr. P (37) goes to an AC and a TC once a week each. The AC and TC that he goes to are two different locations, and he does different activities at each. He thinks this separation of AC and TC for different activities is good for him because he gets to meet different people and doesn't interact with the same people throughout the week. It also distinguishes his work and social life for him.

Ms. N (40) comes to an activity and training center 4 times a week to do ceramics for two days and work at the production for two days. She loves coming to the AC/TC because there she keeps busy and because she can still walk better than some other people who come to the AC/TC, she loves helping them when they cannot do certain things.

“I always look forward to the days that I am going to the elderly home because it gives me a reason to be out of my bed that day. It is always nice to spend time with them.”

Mr R (55) volunteers at an elderly home 2 afternoons a week to spend time with the elderly, help them with things they cannot do themselves and play games with them.

Ms. M (56) goes to help her friend at her store at least once a week and sits by the cashier's desk. She thinks this is a good occupation that keeps her busy and she doesn't need to do so much physically while spending good time with her friend. She also volunteers at a hotline 3 afternoons a week and sometimes even more if they need more people to help. She loves going there and she can always cancel if she is not feeling in good shape that day. She likes not being responsible or being on a contract and obliged to work.

02 WORK AND DAILY OCCUPATION

Most PDA have an indication for “arbeidsongeschiktheid”. This means that due to their (physical) health condition, they cannot do regular jobs to their full extent so they either get paid partially while they work less hours, or they receive full financial support from the government if they can physically not participate in paid jobs anymore. Similarly for the FC, when caring becomes their full-time duty, they might be forced to quit their regular jobs to look after their loved ones and stay mostly at home during the day. This creates a need for both of them to find other ways to keep themselves busy or opportunities to create their own occupations from their homes.

ACTIVITY CENTRES

Activity centers (AC) are places for physically disabled people to go to during the day to spend their times at. There are specific AC for specific health conditions or diseases but there are also more general AC for people with all sorts of physical disabilities (of different causes). For the PDA, activity centers are places where they can do various activities ranging from arts and crafts to singing, cooking and even wood workshops. At the AC, there is always a caregiver/supervisor (begeleider) present (at least one caregiver present per activity or room, and usually 1 caregiver per 7-8 clients) and the space is fully adapted for physical disabilities. These adaptations include wide spaces, suitable bathrooms, handles on the corridors, automatic sliding doors and easy-to-move surfaces. There, they get to socialize with others while doing such activities and they can also explore new activities and find out new hobbies. PDA gets to choose how many days a week they want to go to the AC, and they can also choose which AC they'd like to go to – depending on the range of activities that they provide but also it is up to their personal preference.

TRAINING CENTRES

Training centers (TC) are similar to AC, but they are resembling more of proper workplaces where the PDA can get to work for clients and companies. Each TC has a focus and range of products that they offer, and they offer their services for little to no cost – the main aim is to get PDA to have a job opportunity and to provide instances where their skills are useful for the general public. According to PDA, TC is generally seen as a regular job, and they take what they do there very seriously even though they usually don't get paid for it. Depending on the task they are assigned, they get to cooperate and improve their skills or explore new skills with the guidance of a supervisor (begeleider) or their colleagues. They can also come up with their own projects and tasks and work on them together with their colleagues and supervisors. Similar to AC, PDA gets to choose how many days a week they want to go to TC and more or less what kind of job they want to work on. The jobs/tasks at the TC are currently mostly limited to graphic design assignments or basic labor including boxing materials produced by companies (or by themselves) or preparing holiday cards for organizations, etc.

"You have a choice, you either mourn what you were able to do and get depressed or you choose to reinvent yourself based on what you can do now. I found new things to do and carved a new path for myself."

Mrs. M (42) had to quit her job when she got diagnosed because her work required her to be active physically. After her diagnosis when she was just above 30, she started her MSc degree and now has her own practice. She goes to her office approximately 4 days a week and mostly works from home in the mornings.

Mr. J (60) stays at home most of the time because he got retire 2 years ago from his full-time job. He is now mostly spending time on his computer trying to find all his ancestors. He also works on Wikipedia to edit information there that he thinks is missing.

VOLUNTEER WORK

Some PDA decide to spend their days doing meaningful work for themselves or for others which is also comfortable for them in the sense that they don't require physical skills. This can range from answering phones for hotlines, being a salesperson at a store and even going to a nursing home to play cards with the elderly. This provides PDA with an occupation on a regular basis that does not create any harsh responsibility or stress on them – in most cases, stress for PDA is not good.

HOBBIES AND OTHER ACTIVITIES

Due to all sorts of reasons ranging from physical barriers to social barriers (as mentioned in the introduction), some PDA choose to stay in their homes during the day and do what they enjoy from there. These activities can range from creative work and pursuing what they enjoy as a hobby (such as painting, graphic design, music etc.) to doing activities for self-development purposes (puzzles, research, reading, work on computer, etc). These are all ways PDA find to spend their time and keep busy in their own physical boundaries.

REGULAR JOBS & WORKING FROM HOME

Not all PDA are severely disabled, and they can and want to still continue to work in their regular jobs, (usually less hours & in different conditions). This can mean that their workplaces have to be adapted for them to go to work or they do their work partially or fully from home. This way, PDA gets to continue living their life with almost no change.

“I like to to go to a regular fitness centre for healthy people in my neighbourhood so that I can meet people and talk about things with them, from the “real life”. ”

Mr. W (54) does physiotherapy once or twice a week at the AC that he goes to. He says that he tried to go to another AC where the fitness room is bigger, but he realized the instructor is more important than how big the room is. Now, Mr. R (who is the instructor) is an awesome and very positive person who gets Mr. W try harder and makes him smile. He also mentioned that he continues to go to a regular gym once a week.

“Because I go to the gym, I am strong! Sports is very important because whatever you can do, you can still keep on doing.”

Mrs. M (42) says that she used to not do so much sports but after her diagnosis, she saw how important it is for her to maintain her health. Now, she goes to a gym with a personal trainer at least twice a week and goes to yoga class once a week.

Mr. J (40) goes swimming once a week because there is a group class with PDA organized a little bit further than his house. He enjoys going to these swimming classes and he thinks it is very important that what they do in the pool is specifically for people with disabilities.

Mr. R (55) goes to the local swimming pool once a week or every two weeks to swim and exercise. He goes there together with a volunteer who helps him in the pool and exercises with him. He really likes that the pool is near is house and that he gets to enjoy exercising with a volunteer.

03 SPORTS AND HEALTH

It is important for PDA to stay active and to maintain their current health status as much as possible. Especially for people who are disabled due to a neurological condition, it is crucial to work necessary muscles under the guidance of an expert to keep the muscles active and to reduce the decline of the disease. During the interviews that took place in the fieldwork, interviewees mentioned three types of physical activity to maintain their health status and independence to become stronger.

PHYSIOTHERAPY

For those with neurological conditions or illnesses, it is important to do sports under the supervision of a physiotherapist who knows which muscles to target. For this reason, most PDA with neurological conditions go to physiotherapy centres specialized in their condition at least once or twice a week. This differs per severity of the illness and condition.

FITNESS AND OTHER SPORTS

Fitness is important for PDA of all conditions and severity to work and strengthen their muscles that they cannot use so much in their daily lives to stay as healthy as possible. Since they require advice and help, they tend to work out with someone who knows their condition and can help them if required. This can be a friend or in most cases, can also be a personal trainer or a specialist. Most of them do fitness at least once a week at locations that support their condition and that are accessible – it doesn’t necessarily have to be a fitness centre specifically for PDA, but it is mentioned that they should be accessible with suitable toilets and elevators, etc.

SWIMMING

Swimming is an important part of their sports routine and most PDA name swimming as an activity that makes them feel good and also works their muscles. It is easier to move in water because of water’s physical properties so it is recommended for people who have difficulty moving certain parts of their body to train in water. Some swimming pools offer group classes for PDA several times a week and some offer private lessons with an instructor or a volunteer. PDA values this opportunity and mostly makes use of the swimming pool once a week or once every two weeks to maintain their physical health and to strengthen the muscles that they cannot use to the full extent in their daily lives.

“Because it is a familiar place, most of my friends go there. Every time I bump into someone that I know. I can do everything I need at one location, so it is easy and compact for me so that I can be back home quickly and spend time with my husband.”

Mrs. A (66) is a FC for her husband, and her favourite place to visit in her free time is a shopping mall nearby her house.

“When I am at the park on a sunny day, I have peace.”

Mr. J (40) likes to take his scootmobile to go outside when weather is good. He thinks it is very nice that he has a park nearby his home so it is easy to get fresh air and have a good time when he needs.

04 LEISURE & OTHER ASPECTS

Other than housing, occupation and sports, leisure is also a big part of their weekly schedules. Shopping in various forms, visiting museums, going to restaurants or cafes, taking a stroll with their electrical wheelchair to a park, spending time with their friends and participating in cultural activities (such as going to cinema, theatre, etc.) are only a handful of aspects that were mentioned by the interviewees during the fieldwork. The key point here is that PDA prefer to go to places that they find accessible for themselves and that they can move around easily and preferably without any help. This includes wide-enough spaces where the wheelchair can easily fit, smooth surfaces on which the wheelchair/rollator/ scootmobile can move easily, roads or entrances without any ‘drempels’ which are mentioned to be important things that both PDA and FC keep in mind when they go out for leisure.

Two recurring activities that PDA and FC mentioned during the fieldwork as they enjoy doing in their spare time are going to shopping malls – or going shopping in general – and spending time outdoors (i.e. at a park or walking under the sun). The smooth surface, availability of (multiple) elevators and having no-drempels make shopping malls desirable places for PDA to visit with their friends and family for a day out. It is also convenient for them since at a shopping mall, almost everything they might need can be found at one location which helps them greatly. Outdoors is also valued by the PDA especially when the weather is good. They have mentioned that spending time outside brings them peace and makes them feel relaxed.

03

SOCIAL ISOLATION AND INTEGRATION

LIVING CONDITIONS THAT LEAD TO ISOLATION AND INTEGRATION

This chapter extracts architectural and urban living environment conditions that lead PDA and FC to experience social isolation and integration in their daily lives using the fieldwork findings as the main source of information. This chapter consists of 2 sub-chapters dedicated to each target group and each are organized following the key aspects for social integration of PDA and FC defined in chapter 1, under theoretical framework.

WHAT LIVING CONDITIONS MAKE PDA AND FC FEEL SOICALLY ISOLATED IN THEIR DAILY LIVES?

WHAT LIVING CONDITIONS HELP PDA AND FC TO FEEL MORE SOCIALLY INTEGRATED?

01 FOR PHYSICALLY DISABLED ADULT

INDEPENDENCE AND AUTONOMY

Due to their physical condition and their disability, PDA has to rely on help and care to go by their daily lives. The level of help and care varies per individual, but all the interviewees mentioned that they require some sort of help with daily activities. Depending on where they live and with whom they reside, the source of this help and care differs.

Majority of the PDA who live in independent houses have to rely on their family members (FC) for the care that they require or on the private nurses that come and help during the day. Mr. R (55) who used to live independently (which later decided to move to a Fokus home) mentioned that waiting for help to come at certain hours made him feel more socially isolated because he started to plan his day according to the times that he can get care which restricted him physically and socially: **“WHATEVER I NEED, I ASK THE CARE CENTER AND THEY COME TO HELP ME. MOST IMPORTANTLY, MY SONS DON’T HAVE TO WORRY ABOUT ME ANYMORE.”**

Almost all of the PDA that live in care homes and Fokus homes mentioned their appreciation towards the presence of having care nearby and on demand. Especially residents of Fokus Homes that were interviewed talked highly about the benefits of having care whenever they need and how it makes them feel ‘independent’ and ‘comfortable’ in their daily lives – since they don’t spend time during the day worrying about their care anymore and instead, spend more time on other things that they love and enjoy.

All of the PDA interviewed mentioned the importance of ‘true’ accessibility inside and outside of their homes and how homes that are adapted specifically for the PDA contribute to them living as autonomously as possible in their daily lives. Mrs. J (60) says **“A WELL-ADAPTED HOUSE IS A MUST! WE HAVE ADAPTED EVERYTHING FOR HIM (MR. J (60) SO HE CAN DO EVERYTHING INSIDE THE HOUSE AND CAN JOIN EVERYTHING.”**

All the PDA that live in care homes and Fokus homes mentioned that their homes have been adapted specifically to their bodily functions, abilities and to their size when they first moved into their homes. This helps them to make use of all the rooms in their house, move freely and as they wish through their living environment and be able to do as much as possible without the need of asking for help. For PDA that live in independent homes, such adaptations are done to their homes after their diagnosis/disability and aim to provide an autonomous living for the PDA as much as possible.

Independence outside of their homes is mostly dependent on how the spaces are designed in terms of accessibility and inclusivity, and what the space offers for PDA to visit there without someone to rely on. PDA that go to AC/TC, for example, think these locations are very suitable for them since they are adapted for the needs of people with disabilities. A plus point for AC/TC is also the presence of caregivers that are ready to help in case of need. PDA that work (voluntarily or in their regular jobs) only choose to work if their workplaces are physically accessible for them – otherwise they prefer either not working there anymore or finding a more suitable alternative. Ms. M (56) volunteers at her friend’s store for a few days a week and one of the reasons that she goes there is because the store is easily accessible for her. Mr. J (60) who continued to work at his regular job mentioned that the workplace was adapted slightly so that he can easily access the rooms he needs as part of his job and can be independent at the workspace, which made him feel like a regular employee – thus, more integrated at his workplace.

One common aspect for all PDA was the fact that their occupations are activities or work that they can pursue on their own – without anyone’s help. Mr. W (54) said that he likes what he is doing because he can do it independently for the most part and does not require help – this way he feels that his disability does not hold him back. It has also been mentioned that PDA tend to be open to exploring and/or improving their skills if they can no longer pursue their occupation independently. Mrs. M (42) said that she decided to go back to her studies after her diagnosis because she could no longer work at her job independently since she needed help from her colleagues to continue working. After her second study, she now has her own practice where she offers her services to others – which makes her feel less isolated since she feels more capable: **“YOU HAVE A CHOICE, YOU EITHER MOURN WHAT YOU WERE ABLE TO DO OR YOU CHOOSE TO REINVENT YOURSELF BASED ON WHAT YOU CAN DO NOW. I FOUND NEW THINGS TO DO AND CARVED A NEW PATH FOR MYSELF.”**

All of the PDA mentioned that they do sports on a regular basis, and they all mentioned the importance of being active for their physical health and their overall experience of daily life. Mrs. M (42) talked highly about the benefits of doing sports for herself, but also for her family – as she trains at the gym and goes to physiotherapy, she feels stronger and gains the courage to participate more in the ‘normal world’. She told the story of how she fell from her scootmobile one day: **“PEOPLE ON THE STREET CAME TO HELP WITH MY SCOOTMOBILE, BUT I STOOD UP BY MYSELF. IT IS SO EMPOWERING WHEN I CAN MANAGE TO DO IT - GET UP MYSELF WHEN I FALL. AND IT IS ONLY BECAUSE I AM STRONG AND I WORK OUT”**

PDA also talked about how the features of their neighbourhoods and the general public space affect their experience in their daily lives by allowing them to be more independent. An example often talked about by the PDA was the bike paths – majority of PDA interviewed make use of electrical wheelchairs or scootmobiles to move around and they (mostly) don’t have a problem with reaching where they need to thanks to bike paths. Bike paths are mostly without level differences, smooth to ride on, wide enough for wheelchairs and scoot-mobiles to fit and are well-connected throughout the city which allows them to travel independently without help. Mrs. M (42) mentioned that once she is on a bike path, she can practically reach anywhere she needs: **“THANKS TO THE BIKE LANES, I CAN GO EVERYWHERE ON MY OWN”.**

SENSE OF PURPOSE

The transition from being a healthy individual to having a physical disability is a big step and it takes some time for the PDA to get used to their new roles as it creates frustration towards themselves for not being able to do what they could do before. During the interviews, it emerged that PDA has to learn to accept their condition and newly acquired roles first, which then allows them to start exploring ways to live with their new identity as a disabled individual. This exploration makes them more open to opportunities which allow them to contribute to the society with what they are able to do. It has been mentioned by Mrs. M (42) that it is really important for PDA to have opportunities so that they can explore and see how they can be a part of the society with their new identity: **"I BELIEVE THAT WE NEED EVERYONE AS A SOCIETY. EVERYBODY HAS SOMETHING UNIQUE TO CONTRIBUTE TO THE SOCIETY AND WE NEED TO FIND A WAY TO FACILITATE THAT SO THAT PEOPLE CAN FIND OUT THEIR SKILLS AND WORK ON THEM."**

During the fieldwork, it has been mentioned by the PDA that it is not so easy to find jobs due to their physical disabilities, which makes them feel excluded from the society. For this reason, even if they cannot get a regular job, they try to find other occupations to keep themselves busy throughout the day that replaces 'work' aspect in their daily lives and gives them a purpose. Mrs. A (66) mentioned that her PDA husband – who is trained as an engineer – couldn't find a proper job after his diagnosis. She emphasizes the need for job opportunities for PDA as she believes most PDA who receive their disability later in life are capable to continue working: **"I THINK IT IS A GOOD IDEA FOR PDA TO KEEP WORKING – SO THAT THEY GET TO GO OUT OF THEIR HOUSES. BOTH ME AND MY HUSBAND USED TO WORK AND IT WAS REALLY NICE FOR BOTH OF US. UNTIL HE COULDN'T GO TO WORK ANYMORE AND STARTED TO WORK FROM HOME PART-TIME."**

Mrs. M (42) touched upon the same subject, saying that PDA who have regular jobs tend to work from their home remotely for the most time – mostly due to inaccessible workspaces. She shared her observation that having a designated workspace, if they cannot travel to the office, is important for PDA to be productive and motivated to keep working: **"BECAUSE OF MY JOB, I GET TO SEE A LOT OF PDA AND I KNOW THAT MAJORITY OF THEM CONTINUE TO WORK REMOTELY. IT WOULD BE NICE FOR THEM (AND ALSO ME BECAUSE I AM IN A SIMILAR SITUATION MYSELF) TO BE IN A SOCIAL AND PROFESSIONAL SETTING WHILE WORKING."**

AC and TC locations are important for PDA in their daily lives – it has been mentioned by majority of the PDA that they see AC and TC locations as their 'workplaces' and take what they do there very seriously. For most PDA, an important criterion while choosing their AC and TC is the range of activities they offer. Ms. V (30) mentioned that she prefers the AC she is going nowadays because it has a good range of activities that she can participate that she enjoys.

As people who are in need of help from others, almost all of the interviewees mentioned their awareness about the importance of being there for others and how much they all enjoy helping others to whom they think they can be of help – in a way that they can do with their condition. Mr. W (54), who used to be a teacher before his illness, still tries to be an example to younger people (especially to younger PDA) with his stories, knowledge, and positivity. He goes to AC everyday to maintain his positive mindset and meet other PDA to whom he believes he can help: **"I ALWAYS TRY TO BE POSITIVE AND I ALWAYS GET VERY HAPPY WHEN I SEE THAT I CAN HELP OTHERS WITH MY EXPERIENCES. I TELL A LOT OF STORIES, I LAUGH A LOT, TRY TO BE POSITIVE AND BE AN EXAMPLE. 'HELPING OTHERS' IS WHAT I LOVE TO DO – WHAT I DID BEFORE I GOT SICK, AND I WILL DO AFTER MY SICKNESS AS WELL."**

For PDA that cannot or does not want to work, spending time with other people is an important aspect which keeps them busy throughout the day and provides them with a reason to go out of their homes that day. In all care homes and majority of fokus homes, for example, it has been observed that the presence of common rooms, social activities during the day and the possibility of having lunches and dinners together with the other PDA in the building/ neighbourhood gives them a sense of purpose. These amenities are appreciated by the PDA as well, as they mentioned that they make use of the common spaces almost every day, and it creates structure in their daily lives. Mr. P (37) says the common room in his building is used actively by the PDA: **"OUT OF THE 12 PDA, THERE IS ALWAYS AT LEAST 7 OF THEM JOINING FOR THE DAILY DINNERS. WE ALSO COME TOGETHER TO WATCH TV OR PLAY GAMES IN THE EVENINGS. IT MAKES ME FEEL BETTER AS I HAVE SOMEWHERE TO GO IF I FEEL BORED OR ALONE."**

ATTITUDE OF THE SOCIETY

Fieldwork showed that PDA tend to feel “different” since they believe that the society does not understand the concept of ‘physical disabilities’. When asked about social isolation, more than half of the interviewees responded that the way they are behaved when they are in public and how certain people address them in the society makes them feel misunderstood and excluded. This also makes them refrain from trying to participate in social activities since they don’t feel welcome to join under such circumstances – thus socially isolating themselves. Mr. J (60) recognizes the first time he had to sit in a wheelchair after his diagnosis while he was out with a group of colleagues: **“I REMEMBER WE WENT TO GET ICE-CREAM WITH THE WHOLE GROUP. LADY THERE ASKED MY FRIEND ‘DOES HE ALSO WANT AN ICE-CREAM?’ THIS WAS THE FIRST TIME I NOTICED THIS – NOT BEING SEEN AS A PERSON. SINCE THEN, IT NEVER CHANGED, THE WAY THEY TREAT ME IS ALWAYS THE SAME.”**

Mr. W (54) told a similar story: **“I WAS (SOMEWHERE) FOR A GATHERING. AND THERE, SOMEONE ASKED MY WIFE ‘DOES HE ALSO WANT A COOKIE?’ WHEN I WAS JUST NEXT TO THEM. WELL, I SAID ‘SIR, YOU CAN ALSO ASK ME, YOU KNOW THAT RIGHT?’. I CAN TELL WHAT I WANT FOR MYSELF - THEY DON’T UNDERSTAND THAT!”**

All types of homes that were visited during the fieldwork were examples of ‘mixed living’ – they were not buildings or streets where only PDA reside, but they were mixed in terms of their residents’ ages and conditions. All interviewees that reside at care homes and fokus homes mentioned their satisfaction on this type of living as it makes them feel like a part of the ‘normal’ world. Additionally, they touched upon the benefits of living closeby to other PDA as it reduces their feeling of loneliness – since there is always another PDA nearby that they can talk to who, they think, usually understand them better than healthy people. Mr. J (40) that lives in a fokus home mentioned how living in a flat with other PDA makes him feel understood as he believes other PDA understand him better compared to most healthy individuals.

During the talks with PDA, it has been discovered that changing the attitude of the society starts from getting to know each other better. Majority of PDA mentioned that they feel more comfortable when they spend time with other PDA, with their families or with people that they know. However, when asked about what they need or miss in their daily life, almost all of the PDA (especially the ones that reside in independent homes and the ones that live alone) answered that they would want more places to socialize in their residential area, more contact with their neighbours, more community feeling in their residential context and having people (regardless of their health situation – PDA or healthy) around them in the neighbourhood that they can become friends with. They stated that by interacting with people around them, they can influence the way they are getting treated. Mrs. A (66) says: **“PHYSICAL DISABILITY IS ABOUT BEING PHYSICALLY DISABLED – PEOPLE NEED TO UNDERSTAND THAT! THEY CAN SEE IT THE BEST IF THEY ACTUALLY MEET AND INTERACT WITH PDA”**.

Almost all of the interviewees touched upon the topic of showing respect to one another as a society and how when they have considerate individuals around them who are willing to help and make each other’s lives easier, they feel very much like a part of the society and consider themselves integrated in their social environment. The effort of strangers to include them in the society helps them to feel respected and as a result, integrated in their social environment. As they mostly spend their times at their homes or in the close surroundings of their homes, it is important for PDA to be surrounded by people – their neighbours – that they like to spend time with. Mr. R (55) says **“IT IS GOOD TO HAVE PEOPLE LIVING CLOSE TO ME WHO ARE ON THE SAME PAGE AS ME. THEN IT FEELS LIKE I HAVE FRIENDS NEARBY – LIKE-MINDED PEOPLE.”**

Majority of PDA that were interviewed talked about their disappointment about how people who live on the same street or in the same flat do not know anything about each other anymore. This situation makes PDA and FC feel socially isolated as they do not feel like a part of the community in their own neighbourhood. Ms. M (56) says **“THERE ARE A LOT OF PEOPLE LIVING ON THIS STREET THAT I DON’T KNOW – EVEN THOUGH IT IS A VERY SMALL STREET. PEOPLE ARE SO DISTANT, AND THEY DON’T KNOW EACH OTHER ANYMORE. I DON’T LIKE THIS AT ALL!”**

Mrs. A (66), Mrs. M (42), Mr. W (54) and Mr. & Mrs. J (60) all agreed on how important it is to learn to be respectful towards differences people might have from a young age. Mrs. A (66) says **“PEOPLE LEARN TO RESPECT FROM THEIR FAMILY, SO IT STARTS FROM A VERY YOUNG AGE. THERE WAS A KID IN MY DAUGHTER’S KINDERGARTEN GROUP WHO HAD DOWN SYNDROME. I REMEMBER THAT MY DAUGHTER WAS THE ONLY ONE PLAYING WITH HER, AND I WAS THE ONLY PARENT WHO DIDN’T COMPLAIN. I THINK IF KIDS ARE EXPOSED TO ALL SORTS OF PEOPLE IN THEIR CLOSE SURROUNDINGS GROWING UP – LIKE MY DAUGHTER – THEN THEY LEARN TO SHOW RESPECT TO EVERYONE.”** Mr. W (54) mentioned that one of his kids is working in healthcare right now, even though she did not study anything related to it in university. He thinks this is because she is sensitive towards such people since she grew up watching her father and tries to help as much as she can: **“I GOT SICK WHEN MY DAUGHTER WAS ONLY 6. SHE SEES THAT HER FATHER FIGHTS TO DO WHAT HE WANTS TO DO, AND THAT HE HAS TO FIGHT TO DO CERTAIN THINGS. AND SHE WANTS TO HELP OTHERS LIKE ME.”**

The topics/aspects that were mentioned under each title of this chapter are shown on the right. Each title covers one of the three main aspects mentioned by Freeman et al. (2018) to combat social isolation of PDA that also promote social integration. As part of the interview, each of these three topics are discussed with PDA to learn about their experience and how it is influenced by their living environment. The points under the titles on the right present the living (environment) conditions that were mentioned by the PDA (and also FC) during the fieldwork to be related to their feeling of social isolation and integration of PDA.

INDEPENDENCE

AVAILABILITY OF CARE

EASE OF ACCESS AND MOVEMENT

CAPABILITY IN DAILY SKILLS

CONNECTIVITY OF SPACES

SENSE OF PURPOSE

POSSIBILITIES FOR ACTIVITIES

POSSIBILITY TO HELP OTHERS

POSSIBILITIES FOR WORK

EXPLORING & IMPROVING SKILLS

ATTITUDE OF THE SOCIETY

NON-INSTITUTIONAL LIVING

LIKE-MINDED NEIGHBOURS

NETWORK IN NEIGHBOURHOOD

INFORMAL SOCIAL CONTACT

02 FOR FAMILY CAREGIVER

SENSE OF BEING AWAY

Due to their responsibilities, FC tend to feel under pressure. During the interviews, it has been mentioned by the FC that they tend to lose majority of their leisure time in favour of the PDA they are caring for – and this is one of the main reasons why they feel isolated in their daily lives. In the leftover leisure time that they have, all interviewees talked about different things they enjoy doing. Mrs. A (66) mentioned that she likes to go to shopping malls in her free time where she can visit various shops and can find everything she needs. It creates an opportunity for her to go out and at the same time, run errands for the household. She also mentioned that she can go there easily with her PDA husband since most malls are very easily accessible with wheelchairs. This way, she gets to spend time with her husband somewhere outside of their home which makes both of them step away from their routines. Similarly, Mrs. J (60) mentioned how much she enjoys going to concerts and other cultural events with her PDA husband – since such locations tend to be accessible with the wheelchair and easy to go to.

Mrs. A (66) and Mrs. J (60) also talked about the importance of their independence in their own homes in addition to their disabled family member's independence. They both mentioned that they sometimes seek a room or a place within their immediate living environments where they can be away from their responsibilities and just focus on themselves. This helps them to turn to themselves and spend their time independent from others and get some rest. Mrs. J says: **"I THINK WE BOTH NEED SOMETIMES TO BE ALONE. FOR ME IT'S EASY – I HAVE UPSTAIRS ALL FOR MYSELF, HE CANNOT COME UPSTAIRS AT ALL SO IT IS MY TERRITORY."**

Mrs. A (66) and Mrs. J (60) also talked about how they try to make the most of their homes since they sometimes feel "trapped in their own homes". Mrs. A (66), for instance, mentioned that whatever she does at home to spend her time, she prefers to do sitting by the window so that she can look at the people passing by and try to see what people outside are doing. Mrs. J (60) also mentioned how much she enjoys spending time in their backyard and how much joy it brings her to have the opportunity to be outside without leaving her home. These are all aspects that help them feel away from their responsibilities and less isolated as they get to form a connection with outside.

SENSE OF CONTROL

Even though caring for their disabled family members sometimes feels like a big responsibility, FC that were interviewed mentioned that they still choose to provide majority of the required care themselves as it gives them more control over their environment, daily life and routines. Mr. J (60) says: **"IN THE MORNING, NURSES COME AT A CERTAIN TIME. IN THE EVENING, HOWEVER, MY WIFE PUTS ME TO BED BECAUSE SOMETIMES WE WANT TO SLEEP LATER OR EARLIER AND WE WANT TO HAVE CONTROL OVER OUR LIVES."** Similarly, Mr. W (54) mentioned that his wife is the only person that cares for him and this is what they decided as a couple since they didn't want the nurses to come at certain hours and affect their schedules: **"IF I AM TIRED, I GO TO BED EARLY. I DON'T NEED TO WAIT FOR SOMEONE TO COME AND PUT ME IN BED. MY WIFE HELPS ME WITH THAT AND SHE SAYS SHE DOESN'T NEED HELP FROM SOMEONE TO DO THIS EITHER."** Mrs. A (66) mentioned how she realized her PDA husband's well-being is really important for her own well-being and how providing care for him on her own terms helps her to have control over herself, her time, routine and living environment: **"DURING COVID WHEN I WAS WORKING FROM HOME, I REALIZED HE NEEDS BETTER CARE, AND IT WOULD BE BETTER IF I DID IT MYSELF SO I TOOK OVER A LOT OF RESPONSIBILITY. I CARE FOR HIM WITH LOVE AND I THINK IT HELPS HIS WELL-BEING GREATLY. IT ALSO MAKES ME FEEL LIKE EVERYTHING IS UNDER CONTROL SINCE I AM IN CHARGE"**

All the FC that were interviewed talked about how they control their time and routine while caring for their disabled family member. Mrs. A (66) mentioned that her husband has a very fixed routine every day and she plans her day according to his routine – when he is busy with other things, she finds some time for herself. This helps her to have more control on her life since she knows he is doing well for the time being and she can focus on herself a little more. Similarly, Mrs. J (60) mentioned that she plans meetings with her friends according to the moments her PDA husband is busy or with someone else – so that she can gain control over her life while being at peace that he is not alone or in need.

MEANINGFUL SUPPORT

As mentioned earlier, all PDA require some assistance and care to go by their daily lives and the level of this help and care varies per individual. For PDA and FC that live together in independent houses, this care is mainly handled by the FC. It has also been mentioned that in some cases, private nurses come to assist as well. Both PDA and FC appreciate this opportunity – to have some professional that they can reach out to when they need. Mr. R (55), for example, who lives in a fokus home with his sons, talked about how much he enjoys living 'normally' with his family while getting care and help. This way, his sons don't need to worry about his care as much since there is always medical support around the corner for them.

However, meaningful support is not only about medical support – it also includes the informal support both PDA and FC receive, which helps to reduce the pressure on FC. Mr. and Mrs. J (60) talked about how his personal connection with one of his neighbours at their previous apartment brought joy and comfort to him – to know that he has a friend around the corner. They mentioned that such friendships make it easier for FC and PDA to ask for help and support in times of need, instead of isolating themselves further as a result of helplessness. Mrs. J (60) talked about how not being able to ask for help from their neighbours and how their ignorance make both of them not want to try anymore, thus making them feel (more) isolated.

A different example for support is the case of Mr. H and Mrs. M (60+) who live together in a care home (as they both have indications). During the interview, they talked highly about the benefits of having each other and living together as they have different levels of abilities: **"ONE THING HE CANNOT DO, I CAN DO BETTER OR VICE VERSA – SO WE HELP EACH OTHER OUT. IT IS GREAT TO HAVE EACH OTHER".**

For the PDA and FC that continue to live together, the deep connection between PDA and their partners and families is mentioned by all of the interviewees during the fieldwork. Both parties tend to feel more socially integrated as they continue to live their 'normal' lives with their families. The fact that they are surrounded by people who love and care for them also makes them feel less lonely and isolated. Mrs. A, for instance, mentioned that even though she feels tired and under pressure most of the time, she still feels support from her PDA husband – she has someone she can talk to and her 'best friend' always with her which is a great support system for her: **"EVEN THOUGH I WISH I WAS MORE FREE SOMETIMES, I KNOW THAT WE BOTH FEEL THE MOST COMFORTABLE WITH EACH OTHER – HE IS MY BEST FRIEND AND MY BIGGEST SUPPORTER."**

Meaningful support also comes in the form of friendships and social relationships – not only for FC but also for PDA – which affects the experience of both parties positively. Mrs. J and Mr. J (60), for instance, talked about the benefits of support group meetings where Mr. J gets to meet like-minded people who suffer from the same disease where he gets to open up, make friends and learn from other people's experiences. This also helps Mrs. J greatly since she finds support from other patients' experiences. Mr. and Mrs. J also talked about a moment when they met someone via a close friend of theirs who was sharing the same interest as Mr. J and offered to take him on a day trip to pursue this interest together – this was appreciated by both of them since Mr. J got to spend a day out with a 'friend' and Mrs. J got to rest and spend time on herself for a day when he was away. They both said that it wouldn't be possible if they didn't go out on that day and didn't get to meet this 'new' friend – so it is important for them to be socially active and meet & interact with new people with whom they can form friendships and get meaningful support from.

The topics/aspects that were mentioned under each title of this chapter are shown on the right. Each title covers one of the three main aspects mentioned by Gulwadi et al. (2007) to form a resorative living environment for FC that help to combat their experience of social isolation and promote social integration. As part of the interview, each of these three topics are discussed with FC to learn about their experience and how it is influenced by their living environment. The points under the titles on the right present the living (environment) conditions that were mentioned by the FC (and also PDA) during the fieldwork to be related to their feeling of social isolation and integration of FC.

SENSE OF BEING AWAY

PRIVATE TIME AND SPACE

CONNECTION TO OUTSIDE

EASE OF ACCESS AND MOVEMENT

SENSE OF CONTROL

CARE ON OWN TERMS

HAVING ALONE TIME

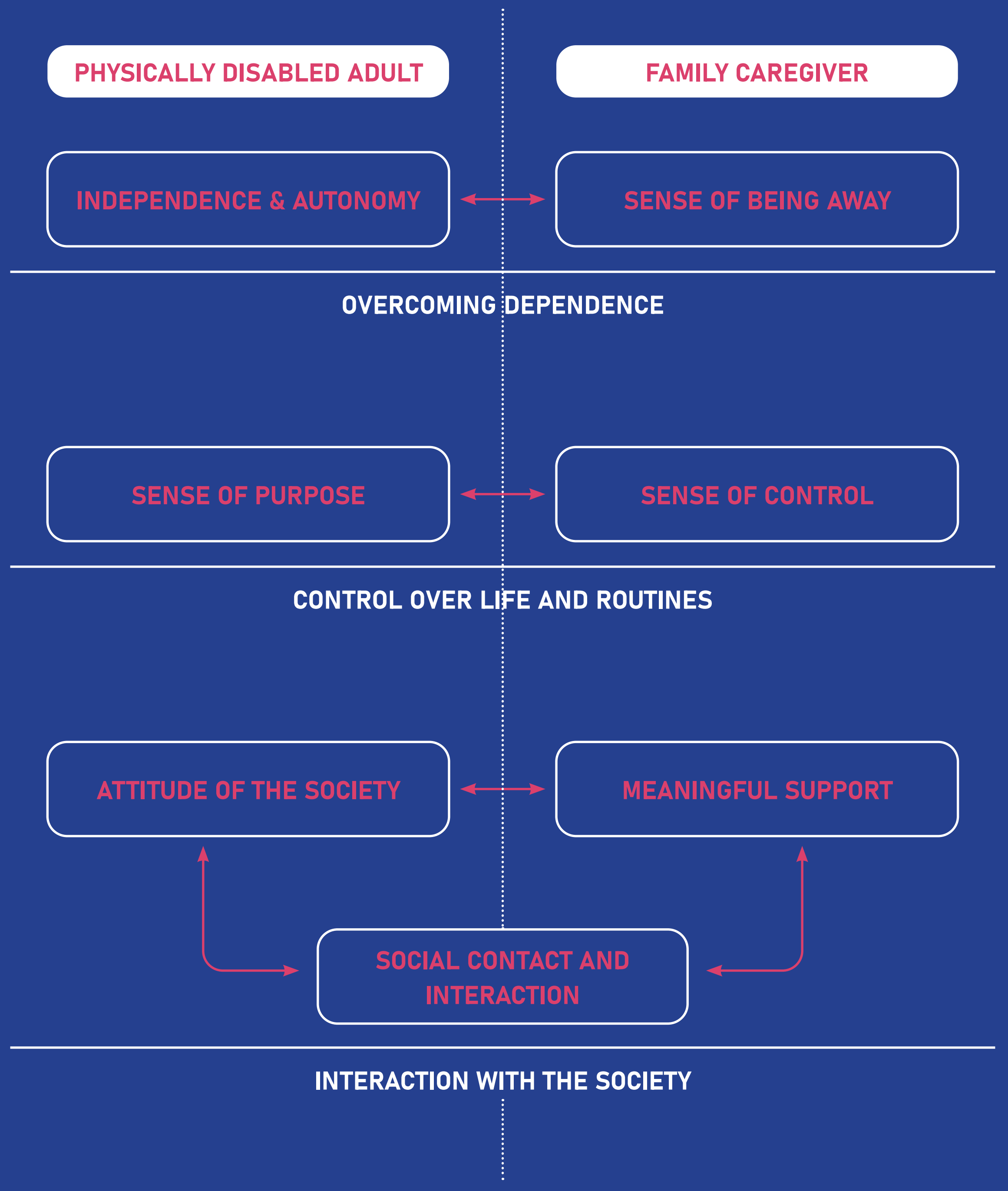
MEANINGFUL SUPPORT

FAMILIAL SUPPORT

SOCIAL SUPPORT

MEDICAL SUPPORT

NETWORK IN NEIGHBOURHOOD



03 CONCLUSION

This chapter described living conditions from the daily lives of PDA and FC that lead to social isolation and integration – using the points from the theoretical framework to present the findings from the fieldwork. Looking at the chapter as a whole, there 3 main findings that are essential to note before moving on to the next chapter:

1. SOCIAL ISOLATION AND INTEGRATION ARE INSEPARABLE FROM EACH OTHER.

From the answers of PDA and FC when they were asked about their opinions and feelings of social isolation and integration, it has been discovered that isolation and integration go hand-in-hand: sometimes absence of certain experiences which makes PDA or FC isolated can lead to feeling integrated and similarly, lack of experiences that would have made PDA and FC them more integrated can cause them to feel isolated in their daily lives. This is why, in this chapter, findings for isolation and integration are bundled to present the full picture.

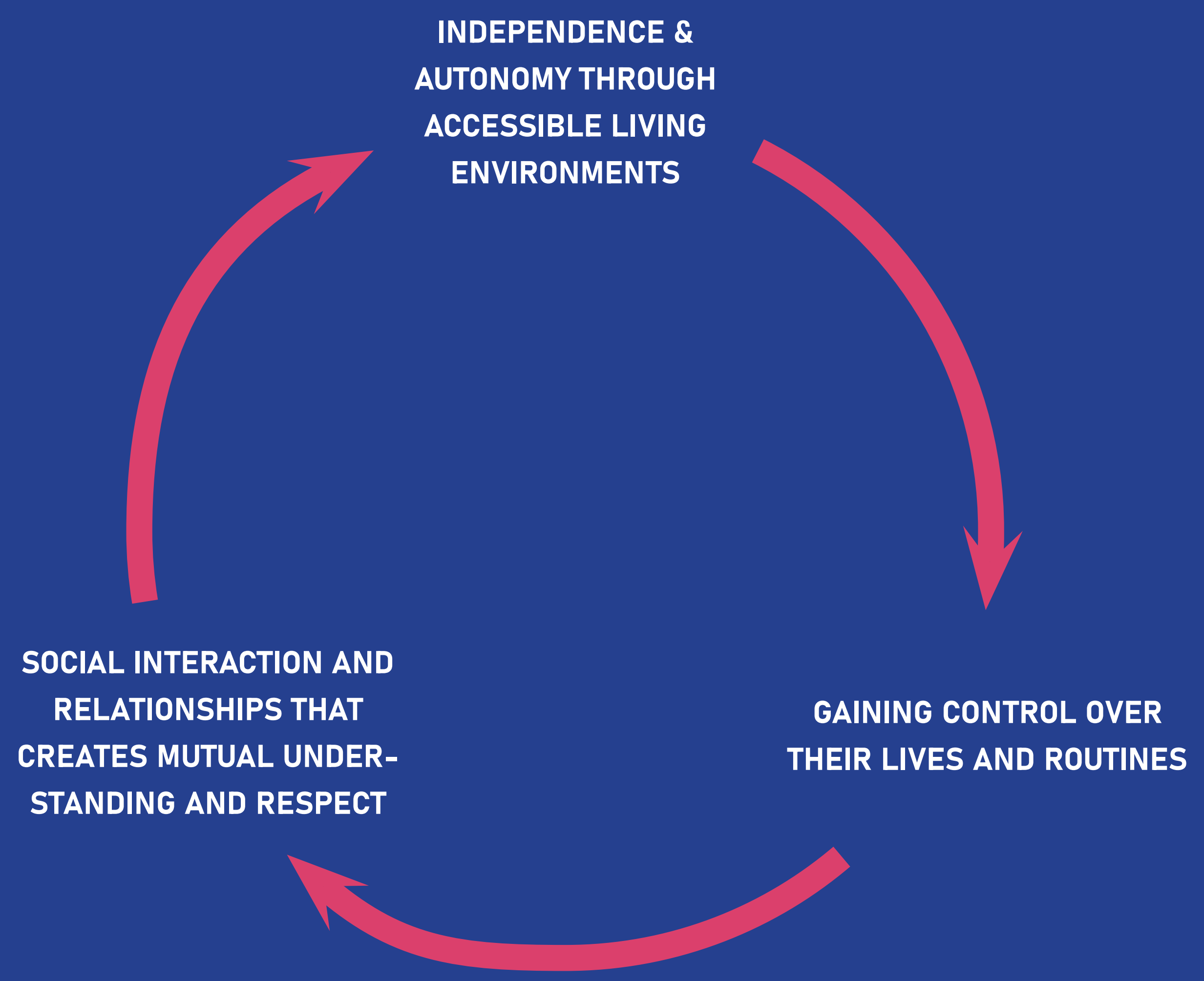
2. SOCIAL INTEGRATION OF FC IS HIGHLY DEPENDENT ON THE PDA.

During the interviews of FC, it has been discovered that their answers on social isolation and integration are highly dependent on the condition and abilities of their disabled family member. It can be said that an FC is only an FC if there is a PDA around them and once the PDA's well-being is established, it influences the daily life of FC positively as a result. It is best to see the findings for FC and PDA as a whole that complement each other.

On this note, it has also been discovered that the 3 points from the theoretical framework for the PDA and the 3 points for the FC are parallel to each other: 'Independence & Autonomy' and 'Sense of Being Away' are parallel to each other since both are about overcoming the dependence of the target group to others and to each other; 'Sense of Purpose' and 'Sense of Control' go hand-in-hand since they are both about ways the target group aims to tackle their changing roles and finding a new normal; and finally 'Attitude of the Society' and 'Meaningful Support' are both about the interaction of PDA and FC with the outside world and other people around them so they can be seen as a whole as well.

3. SOCIAL CONTACT IS AN IMPORTANT FACTOR FOR SOCIAL INTEGRATION OF BOTH PDA AND FC.

It has been repeated by many PDA and FC that social contact and interaction with others are something that they miss in their currently daily lives. Throughout the chapter, social contact has been mentioned repeatedly under almost all of the sub-chapters and is important to facilitate the social integration of PDA and FC. Especially for 'Attitude of the Society' and 'Meaningful Support', which are both about the interaction of the target group with others.



Overall, looking at the chapter as a whole and bringing together all discussions with PDA and FC as part of the fieldwork, the following conclusion can be made to summarize the social isolation and integration of the target groups and how it can be tackled:

“PDA AND FC HAS THE OPPORTUNITY TO BE INDEPENDENT IN- AND OUTSIDE OF THEIR HOMES WHEN THEIR LIVING ENVIRONMENTS ARE DESIGNED TO BE ACCESSIBLE AND PDA CAN BECOME MORE AUTONOMOUS. THIS OPENS UP OPPORTUNITIES FOR THEM TO EXPLORE THEIR NEW IDENTITIES AND GAIN CONTROL OVER THEIR CONDITION. ONLY AFTER ACCEPTING THEMSELVES, THEY CAN START TO FORM SOCIAL RELATIONSHIPS AND INTERACT WITH OTHERS – WHICH INCREASES MUTUAL UNDERSTANDING AND RESPECT BETWEEN THE TARGET GROUP AND THE SOCIETY. ONCE THEY UNDERSTAND EACH OTHER MORE, THEN IT IS POSSIBLE TO MOVE FORWARD WITH MORE ACCESSIBILITY AND INTEGRATION.”

The table on the next page combines all of the key points from this chapter, providing an overview of design guidelines to be applied in the living environments of PDA and FC that lead to less social isolation and more social integration.

04 SUMMARY OF FINDINGS

Bringing the points for PDA and FC together by combining the titles that are along the same lines (shown on previous page) for the two target groups and combining the points that repeat more than once, the following scheme can be obtained. Here, some of the guidelines are bordered with double lines because they repeat multiple times for PDA and/or FC, thus is more important for the social integration for the target group - this creates the need for more attention on these titles compared to the rest.

INTERACTION WITH THE SOCIETY

OVERCOMING DEPENDENCE

LIKE-MINDED NEIGHBOURS

SOCIAL CONTACT & SUPPORT

AVAILABILITY OF CARE

EASE OF ACCESS AND MOVEMENT

CAPABILITY IN DAILY SKILLS

CONNECTED SPACES

NON-INSTITUTIONAL LIVING

NETWORK IN NEIGHBOURHOOD

POSSIBILITIES FOR ACTIVITIES

PRIVATE TIME & SPACE

CONNECTION TO OUTSIDE

POSSIBILITIES FOR WORK

CARE ON OWN TERMS

POSSIBILITY TO HELP OTHERS

EXPLORING & IMPROVING SKILLS

CONTROL OVER LIFE AND ROUTINES

04

TRANSLATION TO DESIGNED SPACES

IMPLEMENTING LIVING CONDITIONS FOR SOCIAL INTEGRATION THROUGH DESIGNED SPACES

This chapter explains how the living conditions that lead to social integration of PDA and FC, that were unraveled in the previous chapter, can be implemented in their living environments, using the information gathered from the fieldwork and literature study as the main sources. The 3 main points that were discovered as conclusion to the previous chapter form the 3 lenses for this chapter and aim to find design implementations of the living conditions for social integration of PDA and FC.

HOW SHOULD THE ARCHITECTURAL AND URBAN LIVING ENVIRONMENT OF THE PDA AND FC CHANGE TO INTEGRATE THEM MORE IN THE SOCIETY?

01 OVERCOMING DEPENDENCE

In the book called "Independent Living for Physically Disabled People", Crewe and Zola (2001) mention that the needs and wishes of PDA from their living environments vary due to their disabilities: the self-supported PDA has the ability to care for themselves once they are in a barrier-free environment and might not need additional services; and the system-supported PDA needs support services on a daily basis. During the fieldwork, PDA who fit both of these categories have been interviewed and it has been identified that even if the PDA is self-supported, availability of caregivers in the vicinity brings a sense of comfort and safety in their daily lives. On this note, it is important to mention the concern Mrs. M (60+) talked about: when she asks for help from the caregivers, she noticed that they usually come in 10-15 minutes (due to shortage of staff) and this causes her to refrain from asking for help until it becomes urgent or serious. Using this information, it can be said having **A CAREGIVER (MEDICAL) CENTRE IN THE NEIGHBOURHOOD (WITHIN 5 MINUTE WALKING DISTANCE FROM THE HOUSES OF PDA)** can be of help to overcome their dependence on their family members and it can reduce the time they spend waiting for help to arrive.

It is important to look closely at these so-called "barrier-free environments": Rostron (1995) mentions that even though the problems of PDA can be solved partially by assistance from others, a preferable course of action is to prevent difficulties that are caused by the conditions of the living environments. Some key findings (from the answers of the PDA to the interviews conducted as part of the fieldwork) for such barrier-free environments that facilitate ease of access and movement can be listed as following: **LARGE FLOOR SPACE** (with wide corridors and larger-than-conventional rooms) that provides enough space for the wheelchair or other supportive tools of PDA to fit and move easily; **OPEN FLOOR PLAN** (with sliding and/or automatic doors) to enable PDA to enter rooms freely; **VERTICAL TRANSPORT OPTIONS** (with ramps and lifts) so that PDA can move between floors and spaces independently; and **COMPACT FLOOR PLAN** to reduce the effort spent by PDA to move around.

To further facilitate barrier-free environments and enable PDA to become more independent, improving their capabilities in daily skills is essential. Each PDA has different levels of abilities which point to different requirements from their living environments to give them independence. Universal Design principles cover some points that can be applied in all spaces to provide equality and independence to the users by enabling them to make use of the space. It mentions the importance of **FLEXIBILITY IN USE** so that the design is easily adaptable by the user to their abilities, ease, and comfort. It also talks about the importance of **SIZE AND SPACE** regardless of user's ability, posture, size or skills by providing **CLEAR SIGHT** and **EASY REACH** to all components comfortably (Null, 2014; Stafford & Baldwin, 2015). Raschko (1982) also mentions that designing with the disabled in mind, rather than for them, creates environmental standards that will assist everyone, reducing the need for adaptation and specialized design.

Imrie and Kumar (1998) talk about the lack of transportation options for PDA. As mentioned during the fieldwork, bike paths are important in this sense since they allow PDA to go from place to place with ease and independently. One aspect that was mentioned by Mrs. M (42) that should be considered is the **CONNECTIVITY** of the bike paths to allow for worry-free transport for PDA. Rostron (1995) provides further requirements for PDA's easy transportation such as **WIDE PATHS** (to allow for wheelchair to pass with ease) and **NO ABRUPT CHANGES IN LEVEL**. Stoneham & Thoday (1994) also touch upon the importance of the distance, stating that **NECESSARY FUNCTIONS FOR THE PDA SHOULD BE WITHIN REACH** (ideally within 10 minutes wheelchair/scootmobile ride – as mentioned by interviewees) and the journey should include **PLACES TO REST AND SIT** (especially for PDA that make use of walkers).

As described in chapter 3.1, confidence in capabilities is important for PDA to become independent and autonomous on a daily basis. Majority of the PDA train regularly to maintain and improve their capabilities and Mrs. M (42) specifically talked about how working out makes her feel stronger and gives her confidence. Following this information, it is safe to say that **AVAILABILITY OF SPORTS FACILITIES WITHIN REACH** for PDA is important to encourage them with their training. which is also mentioned by Stoneham & Thoday (1994) as a design consideration.

Independence for FC emerges from being away from responsibilities. Allowing PDA to be autonomous creates independence for the FC since many of the tasks that are now expected from the FC can then be done by the PDA themselves. Additionally, it has been mentioned by the FC that they sometimes need places where they can be on their own, to take some rest and step away from responsibilities. Mrs. A (66) and Mrs. J (60) both talked about **HAVING A SPACE THAT THEY CALL AS 'THEIRS'** in their homes where they get to retreat and rest. Raschko (1982) describes such private spaces as "a space under direct control of an individual where they may choose to seclude themselves from outside observation, stimuli and participation". In addition to having their private areas, both Mrs. A and Mrs. J talked about having **CONNECTION WITH OUTSIDE** as a positive aspect of their homes. Mrs. A mentioned that she enjoys sitting at the balcony or by the window to see other people walking by, and Mrs. J mentioned how much she spends time in their backyard where she gets to get fresh air and sit under the sun to rest. The importance of **LIGHT AND SIGHT** has also been mentioned by Platform 31 as an advantage for people who spend a lot of time at home to have contact with the outside world. In the same document, it has also been mentioned that this visual contact with the street is possible only **UNTIL 5TH FLOOR** – then the human scale is lost (Mantingh & Duivenvoorden, 2021).

Bringing all these points together, it is possible to obtain design guidelines for the living conditions that were mentioned in the previous chapter. Next page shows how the 'what's obtained in chapter 3 can be turned into 'how's using the information provided.

AVAILABILITY OF CARE	EASE OF ACCESS AND MOVEMENT	PRIVATE TIME AND SPACE	CAPABILITY IN DAILY SKILLS	CONNECTIVITY OF SPACES	CONNECTION TO OUTSIDE
CAREGIVER CENTER IN THE NEIGHBOURHOOD	LARGE FLOOR SPACE	HAVING OWN ROOM/SPACE IN THE DWELLING	FLEXIBILITY OF SPACES	CONNECTED PATHS	LIGHT
	OPEN FLOOR PLAN	AVAILABILITY OF POCKETS THAT CREATE PRIVACY	ADAPTATIONS SPECIFIC TO PDA TO MEET THEIR SIZE	WIDE PATHS	SIGHT
	VERTICAL TRANSPORT		CLEAR SIGHT	NO ABRUPT LEVEL CHANGES	MAX 5 FLOORS
	COMPACT FLOOR PLAN		EASY REACH	FACILITIES WITHIN REACH (5-10 MINUTES RIDE)	BALCONY
	FLEXIBILITY IN USE		SPORTS FACILITIES WITHIN REACH (10 MINUTES RIDE)	PLACES TO SIT AND REST ALONG THE WAY	GARDEN/OUTDOOR SPACE

02 GAINING CONTROL OVER LIFE AND ROUTINES

PDA finding their sense of purpose helps them greatly to gain control over lives and routines, also mentioned by Freeman et al. (2018). The topic of sense of purpose can be examined through the Japanese term "Ikigai", related to the things that make an individual's life worthwhile while providing a sense of satisfaction, purpose and joy (Garcia & Miralles, 2017). Ikigai consists of 4 main aspects: what you love, what you're good at, what the world needs and what you can be paid for. During the fieldwork, it has been discovered that majority of the PDA spend a big part of their daily lives with 'what they love' and to do this, they have their **DESIGNATED SPOT IN THEIR HOMES WHERE THEY PURSUE THEIR HOBBIES OR DAILY OCCUPATIONS**: sometimes it is only a desk in the corner of the living room or sometimes a whole room dedicated for them. It has also been mentioned that PDA enjoy participating in communal activities. As mentioned earlier, PDA who live in care homes or who visit AC locations regularly get to do various activities that they like in **COMMUNAL SPACES** and with others. Platform 31 mentions the importance of communal spaces within residential buildings so that residents can have a safe collective space where they can do activities that they cannot or do not want to in their own homes. It also includes that such collective spaces are manageable in the residential context for a group of **MAXIMUM 30 PEOPLE** and for more intimate activities like cooking and eating together, **UP TO 10 PEOPLE** is the most suitable (Mantingh & Duivenvoorden, 2021).

In order to help PDA explore and possibly improve their skills and find "what they are good at", it is important to have **ACTIVITY SPACES WHERE A RANGE OF ACTIVITIES CAN BE DONE.** AC locations from the fieldwork are good examples of such activity spaces – and an important criterion that was mentioned by PDA was the range of activities AC's offer. To allow various activities to take place within the collective spaces of residential areas, aspect of **FLEXIBILITY** can be introduced – as suggested within Universal Design principles. This way, instead of providing monofunctional spaces that serve for one activity, flexible spaces can be introduced that can be used for any activity by anyone.

It is mentioned in chapter 3 that PDA tend to be sensitive towards other people in need and try to help as much as possible with their condition. It has also been mentioned that support group meetings are appreciated by PDA to get to know other PDA with similar conditions since they can learn from each other and help each other with their problems and question. To facilitate this interaction further, **MEETING ROOMS** or **SPACES OF SUPPORT** can be introduced within the communal space that will allow for PDA who is in need to receive the support that they require from other PDA or FC that share similar experiences.

Finally, as part of "what you can be paid for", lack of job opportunities and workspaces have already been mentioned in the previous chapter. Following what Mrs. M (42) touched upon – about PDA usually working remotely from home due to inaccessible workspaces – availability of **COLLECTIVE WORKSPACE** in the close surroundings of their houses can encourage PDA to work more efficiently and help with their productivity.

Getting used to the role of being an FC is best tackled when FC gains a sense of control over their daily lives, routines, and their living environments - since change of roles can make FC feel like they are losing control. This also includes having control over the care of their disabled family member. Both Mrs. A and Mrs. J talked about their preference of taking over the responsibility so that they can have more control in their lives and less dependence on the help to arrive. For them provide help and care with ease, it is important that there is **ENOUGH SPACE IN THE ROOMS USED BY THE PDA FOR ASSISTANCE** and **NECESSARY DEVICES** are installed that make it easier for FC to care for their PDA family members. As final point, Mrs. A and Mrs. J both mentioned that they feel the most in control when their disabled family member is not at home or when they are busy with something else because then, they can have better control over their own needs. For this, it is important for PDA to be busy with other things so that FC can restore control in their living environments – which is thoroughly mentioned in the previous paragraphs on sense of purpose for PDA.

Bringing all these points together, it is possible to obtain design guidelines for the living conditions that were mentioned in the previous chapter. Next page shows how the 'what's obtained in chapter 3 can be turned into how's using the information provided.

POSSIBILITIES FOR ACTIVITIES	POSSIBILITY TO HELP OTHERS	POSSIBILITIES FOR WORK	EXPLORING & IMPROVING SKILLS	CARE ON OWN TERMS
COMMUNAL SPACES FOR 10 PEOPLE FOR MORE INTIMATE ACTIVITIES	AVAILABILITY OF MEETING ROOMS TO MEET OTHERS	DESIGNATED WORK/ACTIVITY SPACE	FLEXIBILITY OF COMMUNAL SPACES FOR VARIOUS ACTIVITIES	LARGE SPACE FOR ASSISSTANCE
COMMUNAL SPACES FOR 30 PEOPLE FOR MORE COMMUNAL ACTIVITIES		CO-WORKING SPACE	IN AND OUTDOOR ACTIVITY SPACES	AVAILABILITY OF DEVICES SUCH AS THE TILLIFT

03 INTERACTING WITH THE SOCIETY

Social inclusion is an important term which is investigated and explored by many architects and urban designers that focus on diversity of living environments. Even though many of the research on social inclusion does not focus specifically on disabilities or impairments, it provides an overview on how diversity in cities and districts can be used for the advantage of its users – focusing more on the bigger scale by looking at cities and districts. Jane Jacobs is seen by many as the pioneer of social inclusion in urban design. In her book "The Death and Life of Great American Cities" from 1961, she talks about how the diversity within cities and districts – through a **MIX OF RESIDENTS AND VISITORS** with different backgrounds, income levels and lifestyles – can lead to lively cities. Considering mix of residents was also mentioned repeatedly during the fieldwork as an appreciated aspect of the living environments of PDA, it is worth noting as a design consideration. Another point for lively cities according to Jacobs is the **DENSITY OF CITIES AND NEIGHBOURHOODS**. According to her, density means liveliness - if there is enough people living at a certain area, businesses will thrive to bring livelihood in the district. She also talks about, the importance of diverse functions within cities/districts and how the **VARIETY OF ACTIVITIES AT ALL TIMES** makes the city/district connected (Jacobs, 1961).

Another one of such names that works on social inclusion in cities and districts is Richard Sennett. He is a sociologist, who is influenced by Jane Jacobs's work, and similar to Jacobs, he also talks about the importance of tolerant and open cities where difference (of people) is celebrated. In his book "Building and Dwelling: Ethics for the City", he describes open forms for an inclusive city, one of which is the importance of **VARIOUS ACTIVITIES TAKING PLACE SIMULTANEOUSLY** within a district to ensure there is something for everyone at all times – similar to Jacobs. He also talks about the importance of **POROUS SPACES THAT ALLOW FOR FLOW BETWEEN INSIDE AND OUTSIDE – CREATING PLACES FOR INTERACTION AND EXCHANGE** (Sennett, 2018).

The idea of Sennett to allow interaction and exchange between spaces and people has also been mentioned by the PDA and FC as points that make them feel more integrated in the society. When asked about what they would change in their living environments, almost all of the PDA talked about their wish for more interaction with others, especially with non-PDA – so that they can develop a better understanding of each other and exchange experiences. In the report called "Design for Meeting", Platform 31 talks about how important it is for people to be in contact with the others that live in the same neighbourhood so that they start understanding each other – and this requires spaces for people to meet (Mantingh & Duivenvoorden, 2021).

Such 'spaces to meet' has been named by Ray Oldenburg as 'Third Places' in his book called "The Great Good Place" (1989). He states that people tend to stay in their homes while Third Places lead public to balance their private home life with their social life by providing gathering places in addition to their homes and workplaces (Oldenburg, 1997). With third places, community life is introduced to the daily lives of people which is important for social-wellbeing and social equality among people (Oldenburg, 1989).

While Oldenburg touches upon the so-called Third Places, Platform 31 talk about how and where to place such third places or other locations where casual encounters take place which lead people to interact with one another. Platform 31 state in "Design for Meeting" that if spatial design connects scale levels of neighbourhood – residential block – house and pay attention to the zones of transition in between the levels, chances of casual encounter increase and pleasant environments with room for contact are created. This points to such in-between spaces to be sufficient in size & quality and also for them to be actually used by residents to be beneficial for the community. The report includes a set of guidelines for such encounters to take place (Mantingh & Duivenvoorden, 2021):

- Narrow streets – for safe encounter
- Pedestrian focused design & lively plinth
- Mix – common interests & shared lifestyle
- Facilities – connected
- Density – liveliness means safety
- Familiarity as people approach home
- Route through public and collective spaces
- Ownership, Possibility to appropriate spaces
- Choice – to reach home (elephant paths)
- Availability of common rooms
- Small sized community
- Transition – public to private
- Life long homes
- Flexible floor plan
- Light & sight – contact with outside

While Platform 31 focuses majorly on neighbourhood level for encounters how to design spaces for people to meet and socialize, Jo Williams (2005) focuses mostly on the building level to increase contact between residents in her research called "Designing Neighbourhoods for Social Interaction". She states that social interactions between residents of the community provide them knowledge about each other which helps to build trust among residents, exchanges to take place and social networks to be formed. It is worth noting that Platform 31 considers residential buildings as a type of neighbourhood on its own - this points to similar points to pay attention for both. Williams (2005) brings together the research by Franck & Ahrentzen (1989) and Fromm (2000) and adds her own findings to come up with some design principles which develop social interactions among residents of the same building or neighbourhood:

- Indoor and outdoor communal facilities
- Good visibility into all communal spaces
- Car-free communities - parking on the edges
- Gradual transition between public and private
- Semi-private outdoor space close to private units for socializing (buffer zones)
- Positioning of facilities on shared walkways
- Tendency of private dwelling to be of smaller than average size
- Loss of space in the private unit supported by communal spaces
- Greater diversity of residents and individual/private units
- Involvement in decision making processes

NON-INSTITUTIONAL LIVING	NETWORK IN NEIGHBOURHOOD	SOCIAL CONTACT AND SUPPORT	LIKE-MINDED NEIGHBOURS
LARGE ENOUGH HOUSE FOR FAMILIES TO LIVE TOGETHER	ACTIVITIES AT ALL TIMES	AVAILABILITY OF COMMON ROOMS	SHARED LIFESTYLE
AVAILABILITY OF GUEST BATHROOM	PEDESTRIAN FOCUS (CAR-FREE)	BUFFER ZONES BETWEEN PRIVATE AND PUBLIC SPACES	PDA CLOSEBY
MIX OF RESIDENTS	CHOICE TO REACH HOME	FAMILIARITY OF THE LIVING ENVIRONMENT	
OWNERSHIP - DECISION MAKING	DENSE NEIGHBOURHOODS	SHARED FACILITIES	
	NARROW STREETS		

05

CATALOGUE OF EXAMPLE PROJECTS

CASE STUDIES ON DESIGNED SPACES FOR PDA AND FC

This chapter presents 3 examplary projects that show real life applications of the design guidelines and implementations presented at the end of chapter 3 and 4. The projects are chosen to be addressing different aspects as their guiding theme - which are in line with the themes identified in this research booklet - and they are all different in their context and setting. First case is a single-family house for a paraplegic individual who lives with his family. Second case is an co-housing initiative that aims to provide a sense of purpose for its residents and third case is a communal housing project where community living and shared amenities are central.

CASE 01: RAMPENHAUS

Name: Single Family Residence in Gstadt
Architect: Florian Höfer
Location: Gstadt am Chiemsee, Germany
Date: 2004
Category: Residential (Single family house)
Program: 6 - room wheelchair friendly dwelling
Scale: Site of 650 m^2 on which 280 m^2 is built area

After living in various houses and adapting the houses for his needs, the client - who is paraplegic - decided with his family to build his own house. It is the main objective of the client and the architect to ‘not just tailor the building for wheelchair, but also make a feature of this‘.

During a published interview with the client, he mentioned that he wanted to be more in control of his living environment and asked the architect to make sure every room (especially the bathroom) is easily accessible for him, so he can use all spaces without needing any help. For this, they decided to include as much space as possible in the living environment and tried to create an open floor plan with flush-thresholds in between spaces so that he can move easily with his wheelchair without depending on help. It was important for the client to have all features of the house wheelchair-friendly - which the architect thinks is unusual-looking, but it does not immediately make an outsider think that a PDA resides in this home (Fischer & Meuser, 2009).

“A HOUSE THAT LOOKS AS NORMAL AS POSSIBLE WITHOUT HINDERING THEIR ABILITIES. INSTEAD, IT HELPS THEM.“

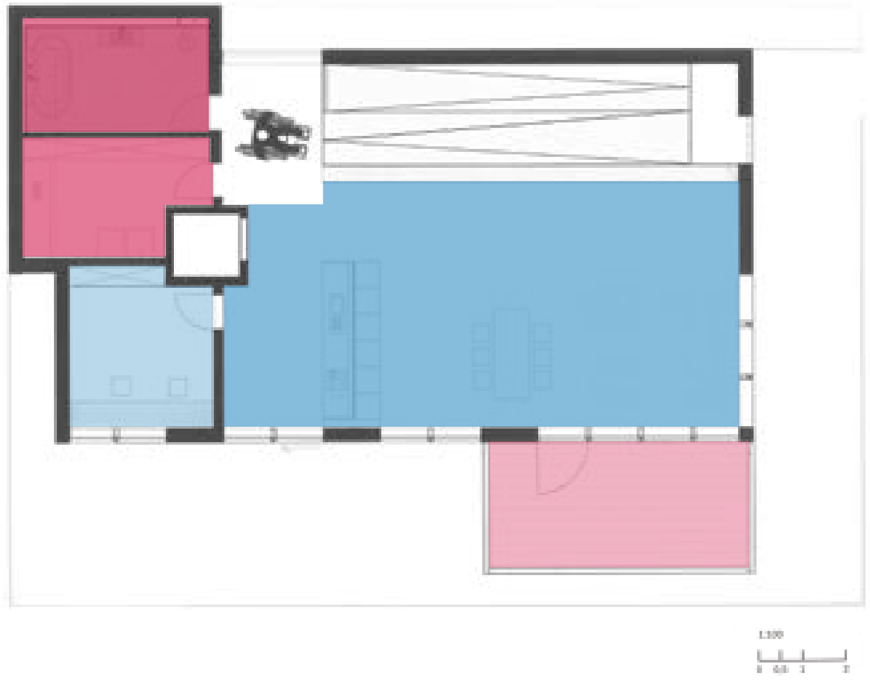
(HÖFER, 2009)

EASE OF ACCESS & MOVEMENT

CAPABILITY IN DAILY SKILLS

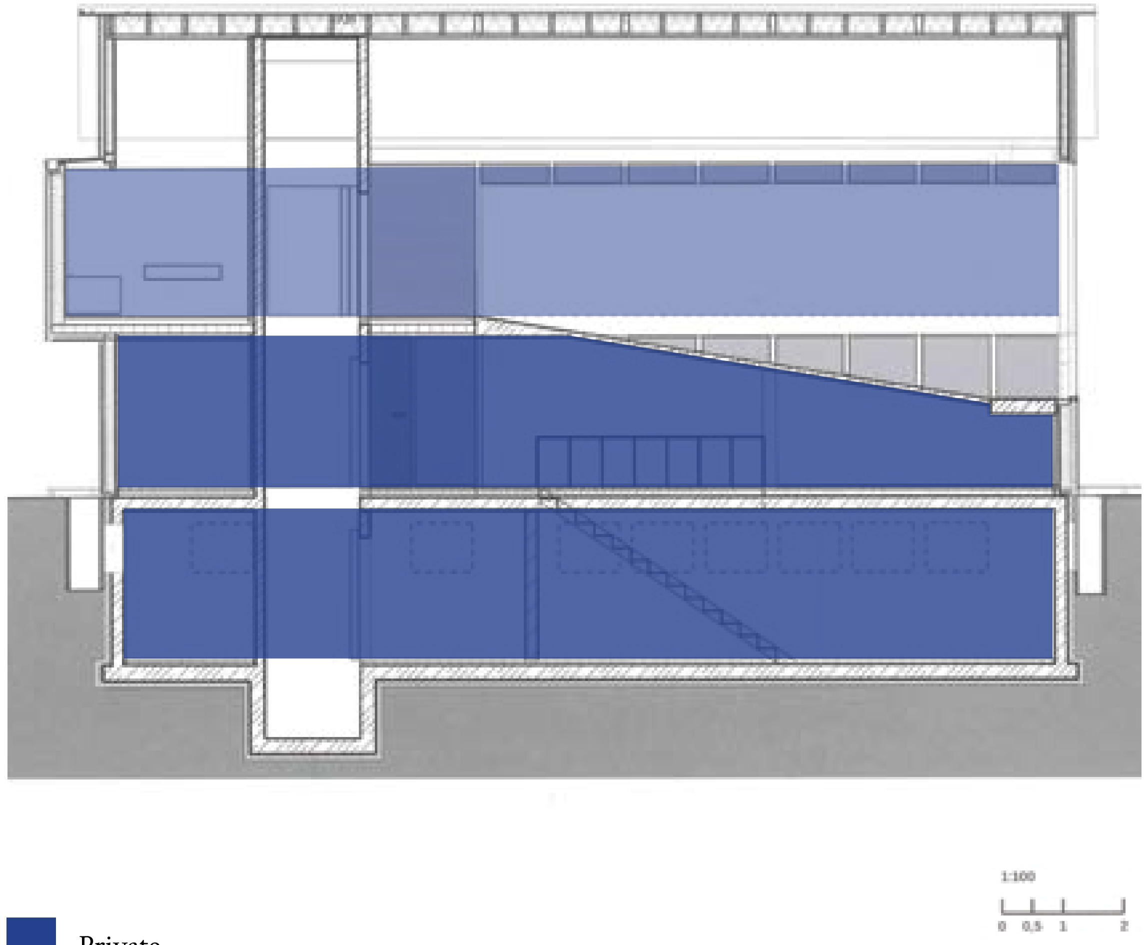
CONNECTION TO OUTSIDE

FUNCTIONS
Ground Floor Plan



FUNCTIONS
First Floor Plan

- ■ Bedrooms
- ■ Living Room
- ■ Bathroom/WC
- ■ Outdoor Space/Balcony
- ■ Office Space
- ■ Garage



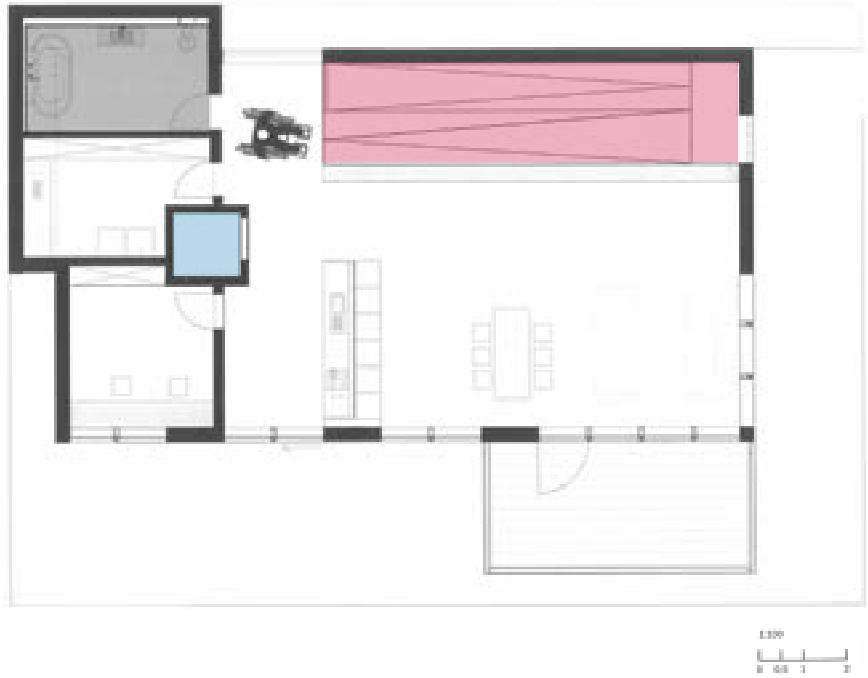
- ■ Private
- ■ Semi-Private (guests are welcome)

PRIVATE-PUBLIC
Section

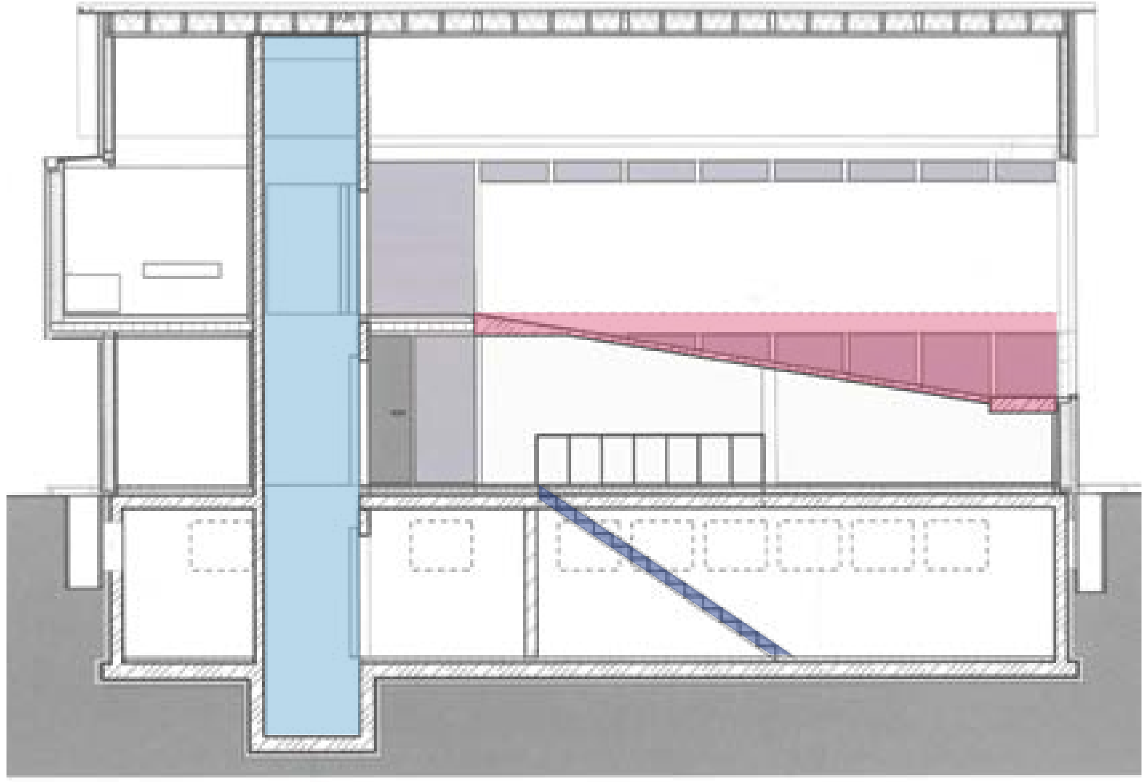
From the floor plans on the left, it is clear to see that there is a clear distinction between the two floors in terms of functions. In his published interview, it can be seen that the client himself requested this specifically - since he spends majority of his time at home, he wants to have a nice view and wants to be able to see outside clearly from the living room and his office, where spends most of his time. This is the main reason why the spacious living room & kitchen and also the office is location on the 1st floor. He also mentiones during the interview that office being on the upper floor makes him feel more included since he is closeby the living room and can hear and see everything that his family is doing from where he is.

More private functions, like the bedroom, office space and also the private balcony are all located on the back-side of the house. This not only protects their privacy so that people passing from the street cannot look inside, but also provides the opportunity for the ramp to be placed on the front facade, emphasizing it from the street-side rather than hiding it away from view (Fischer & Meuser, 2009).

CIRCULATION
Ground Floor Plan



CIRCULATION
First Floor Plan



🟪 Stairs (inaccessible)

🟥 Ramp (inclusive & accessible)

🟦 Elevator (accessible)

1:100
0 0,5 1 2

CIRCULATION
Section

The ramp on the front side is a key feature of the house. It's been mentioned that there are no stairs in the house, except to go to the basement. This means that everyone - including the visitors - have to use either the elevator or the ramp. This way, a sense of equality is created between the PDA and others who reside in or visit the house. This also helps the PDA to have more control in his house, where he spends majority of his time at.

The large windows by the ramp makes the ramp and the users clearly visible from outside which is mentioned in the published interview with the client: **"I CAN LOOK OUT, BUT IT MEANS PEOPLE CAN ALSO LOOK IN"**. He says on this topic that he decided not to hide this part of their life as a family but in the end, this is a personal choice and does not apply to every PDA and every society.

A published interview with the architect of this house includes his finding that PDA want their living environment to feel and look as normal as possible, so that they can feel like a part of the society (Fischer & Meuser, 2009).

CASE 02: HASBAHÇE

Name:	Hasbahçe Sustainable Healthy Living Foundation
Architect:	A. and E. Eyüboglu (also the founders of the initiative)
Location:	Mugla, Turkey
Date:	2018
Category:	Residential & Collective Housing
Program:	4 rooms equipped with private bathroom, common rooms, collective workspaces, flexible living room, basement/cellar, shared kitchen and collective storage & laundry
Scale:	Site of 1000 m^2 on which 75 m^2 is built area (total floor space is approx. 200 m^2)

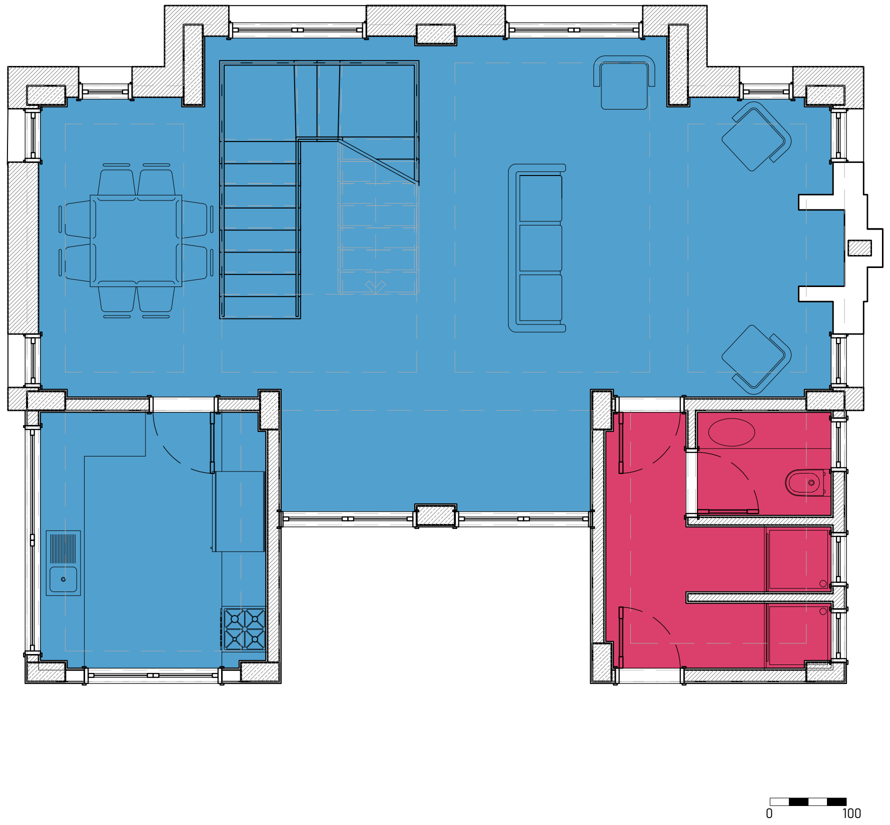
Living in the big city their whole life, Mrs. A and Mr. E decide to grow older in nature in a house that they have designed and built to their liking. Mrs. A realized that due to her obligation of looking after her elderly mother - who refuses to go to a care home - she is very limited in her daily life and it causes her to reflect on her own age and what is about to come. As a person who ideally doesn't want to live in a care home and wishing to be independent and capable for as long as possible, she sat down with her partner Mr. E and they asked themselves "what do we want from our living environment".

Finding (and maintaining) their feeling of sense of purpose and doing this with other people around them are the key points that they aimed to achieve with this project. After purchasing land in western Turkey, close to the coast, they initiated a foundation that aims to bring together like-minded people of all ages who share the same ideas as them so that they can live together or cooperate to help each other further. Currently, with 2 permanent residents and a lot of volunteers that come and go temporarily, they have built a strong network and a successful initiative. *Information about this project is gathered thanks to an interview with Mrs. A on 15.01.2024.*

POSSIBILITIES FOR ACTIVITIES

POSSIBILITIES FOR WORK

EXPLORING & IMPROVING SKILLS



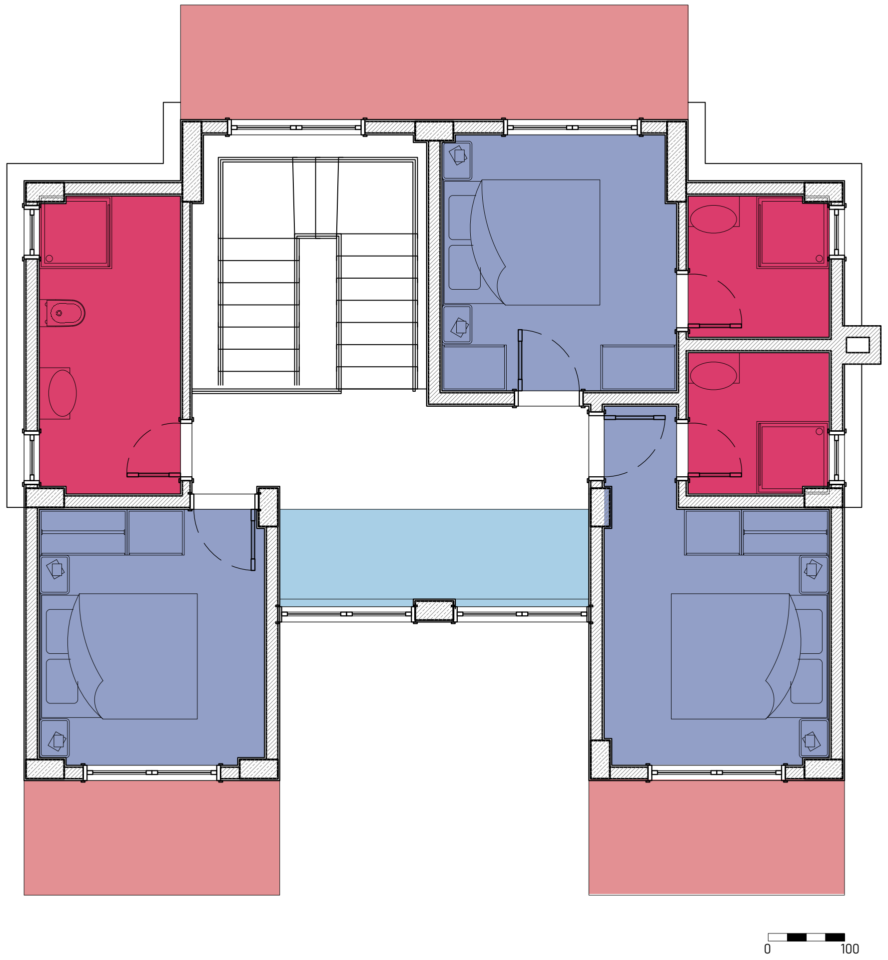
FUNCTIONS
Ground Floor Plan

The floor plans show a clear distinction between the two floors. Ground floor includes the collective living room space which is a flexible open area that can be used for any type of activity that the residents wish to do. There is also a large bathroom space and a large kitchen where all the food for all the residents and guests are prepared throughout the day.

On the first floor, there are three rooms that all have space for an individual or a couple to stay in. Each room has their own bathroom space and one of the bathrooms is larger than the other two, making it accessible for elderly visitors or residents that use aids to walk - such as wheelchair or a walker. Each room also has its own balcony which faces the forest nearby and also the collective garden which is situated on all four sides of the building, so visible from all sides.

Upper floor also includes a small kitchenette and office space in between the rooms. This space allows an extra workspace for residents that wish to work (but maybe not in the collective space) and also for residents to make use of the kitchen during the night instead of having to go downstairs for a glass of water.

Mrs. A mentioned that this configuration of rooms allow Hasbahçe to be a pleasant place to not only live but also to visit. Currently, two of the rooms are not occupied permanently so they get lots of visitors from all around the world and this is valuable for the foundation since with every guest, they learn something new and they explore a different activity. As an example, she mentioned a band that stayed and gave a few concerts during their stay.



FUNCTIONS
1st Floor Plan

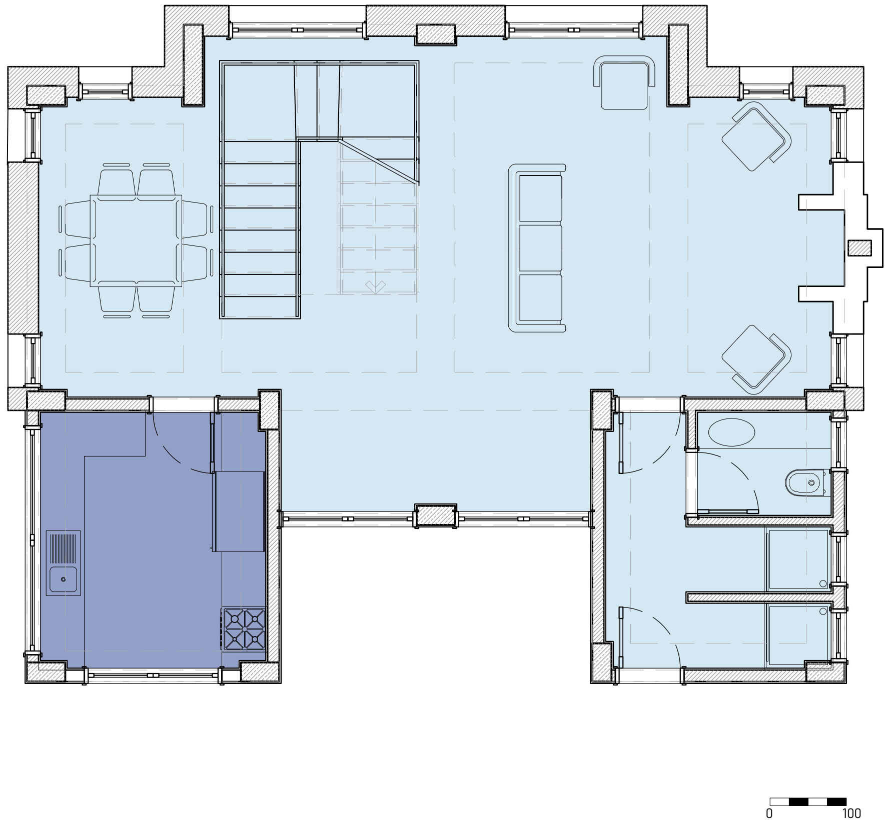
■ Bedrooms

■ Living Room

■ Bathroom/WC

■ Outdoor Space/Balcony

■ Collective Office Space

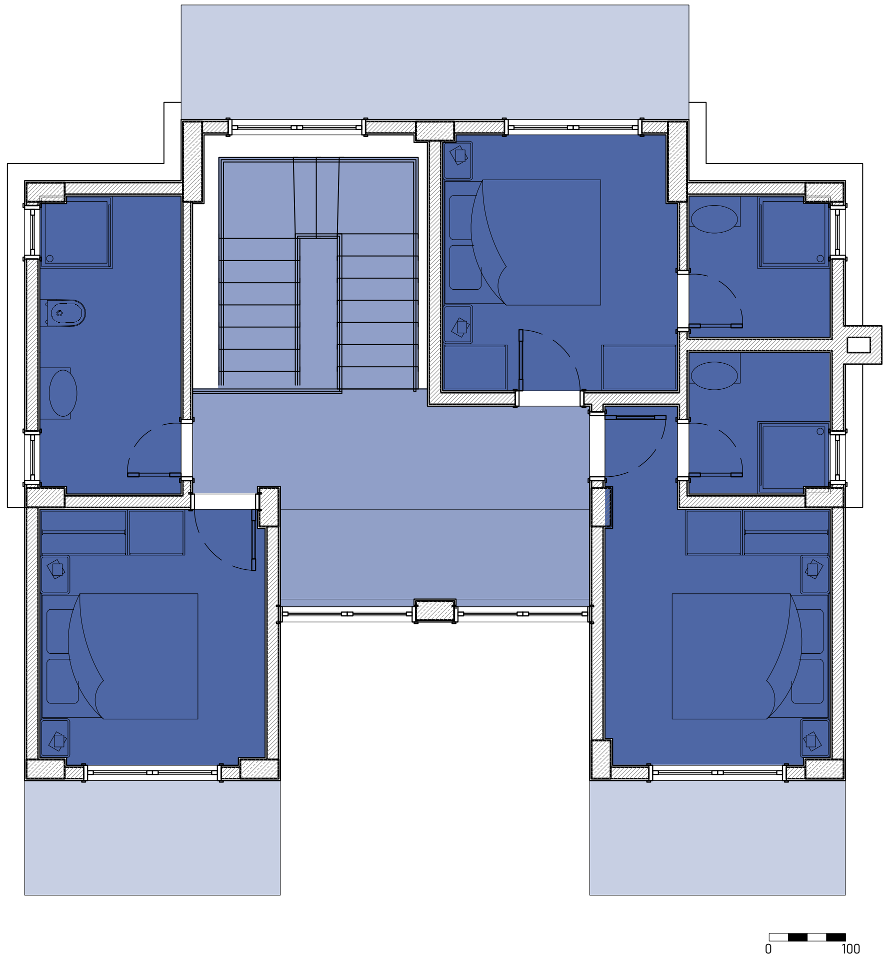


PRIVATE - PUBLIC
Ground Floor Plan

The functions that take place on each floor determine the nature of public and private for the living environment within the building. It is clear that ground floor is collective space that includes majority of the shared amenities while on the upper floor, the presence of the private bedrooms make the entire floor more private in character.

Mrs. A talked highly about the benefits of having such a large collective living room on the ground floor saying that it is where all the residents and guests come together and meet each other everyday. With loneliness becoming an issue, especially for elderly, it is vital to have such places of interaction and meeting in the residential context.

On this note, she also mentioned the lack of large private spaces as a negative point that they have started to realize as they start to spend some time at the house now. She said that sometimes, she just wants to spend one day without being obliged to see anyone - but they didn't think about this too much before the house was built.



PRIVATE - PUBLIC
1st Floor Plan

It has also been mentioned that when a variety of people who are unrelated to each othler live together in such a housing, it is more difficult to find common points. However, what they aim is to have small things that motivate people to come together and interact. For instance, the room being flexible is a great example of this - they use the table for dinners, but also for games and workshops, sometimes some guests use it to work on their computers, they always have card games and chess somewhere in the room, and there is also a piano in the corner waiting for someone to play it.

■ Private

■ Semi-Private (only available for people who stay/live in the building)

■ Semi-Public (only available for the people who can make use of the building - visitors from outside can access these spaces)

CASE 03: COOPERATIF SOUBEYRAN

Name: Soubeyran Project for the Cooperative Equilibre
Architect: ATBA
Location: Geneva, Switzerland
Date: 2016
Category: Residential & Collective Housing
Program: 38 housing units (3 to 6 rooms), commercial premises, a common room, a collective laundry room, guest rooms, independent rooms to be rented, roof terrace
Scale: ??

In September 2012, two cooperatives came together and started to meet regularly to develop a project for a new building and the construction began in june 2015 - finalized in december 2016. ATBA architectural firm was chosen for this building project dur to their various experiences with participatory projects and their previous projects aiming for lowering energy consumption.

Project consists of 38 HBM category housing units with 2 to 4 bedrooms and commercial functions on the ground floor. Building also has a common room for the residents to use, a collecive laundry room, guest rooms, independent rooms to be rented and a roof terrace which is made accessible for all residents - including wheelchair users.

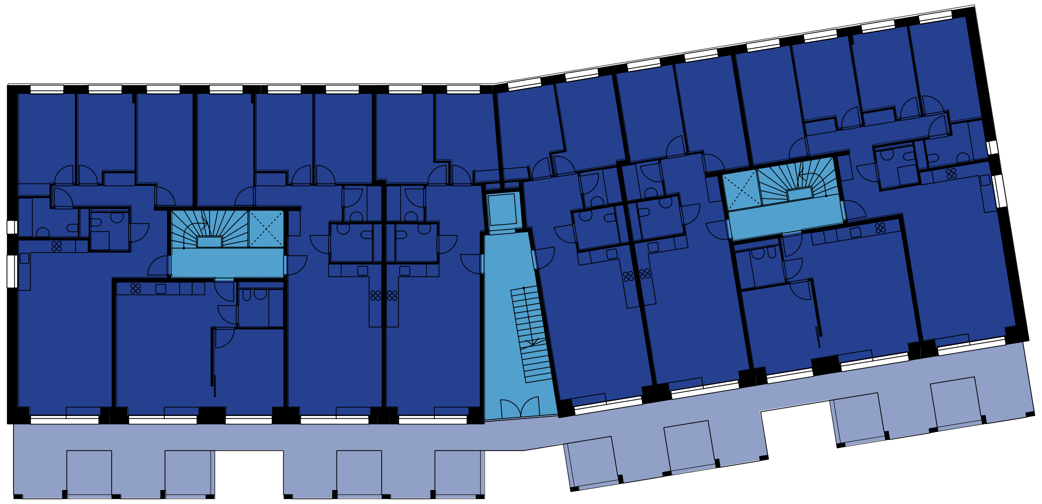
One of the focus points of the project is to create promote relations between residents by creating areas for exchange and meetings. Another focus point is low energy consumption by optimizing water management and heat recovery (Soubeyran - Coopérative Equilibre, 2021).

NETWORK IN NEIGHBOURHOOD

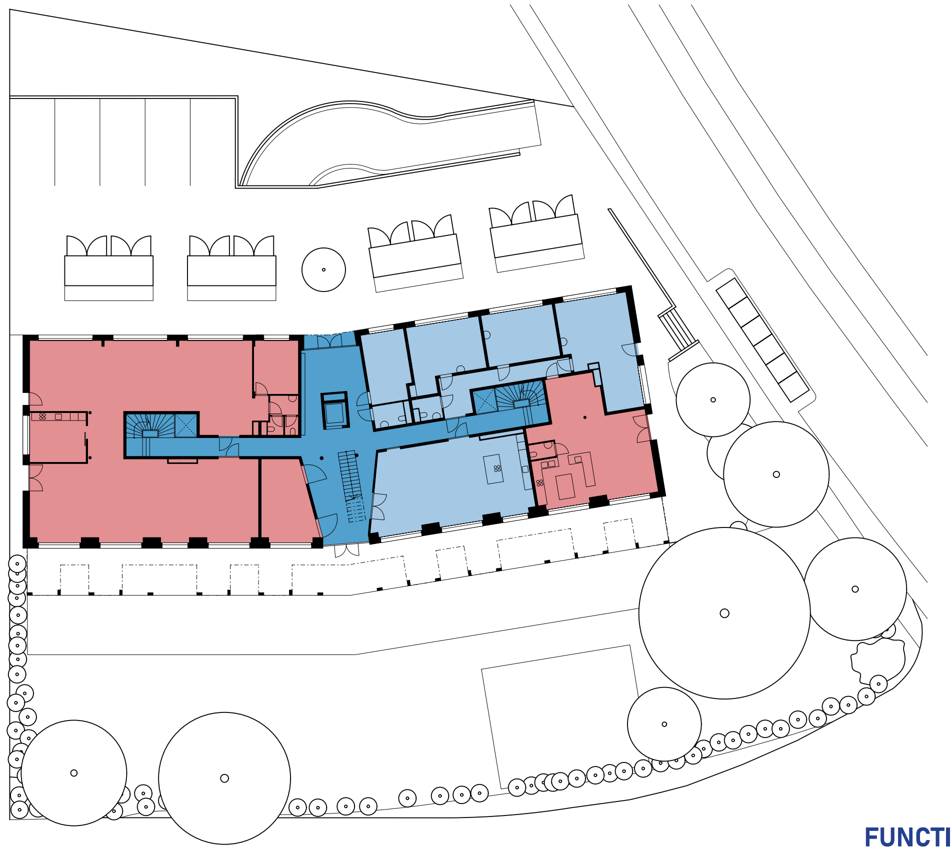
CONNECTED SPACES

SOCIAL CONTACT & SUPPORT

FUNCTIONS
3rd Floor Plan



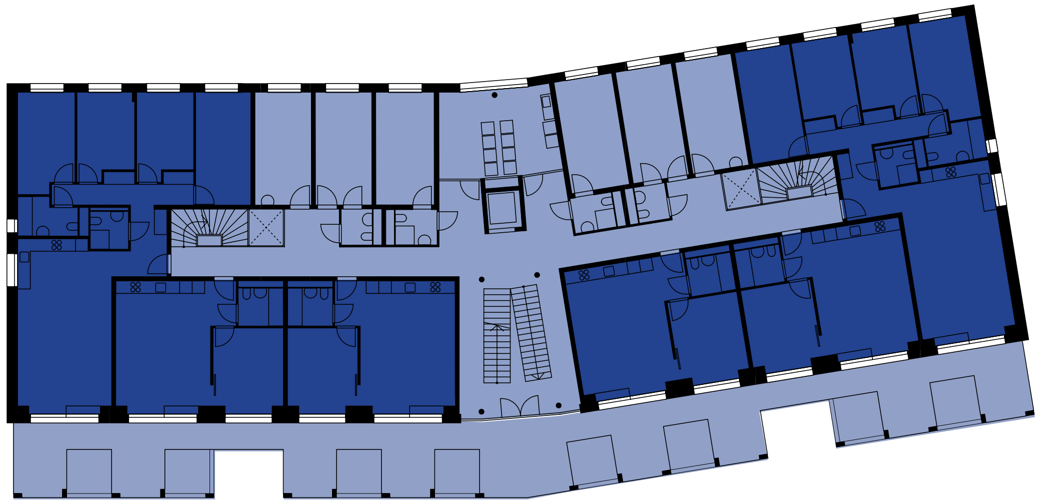
FUNCTIONS
Typical Floor Plan



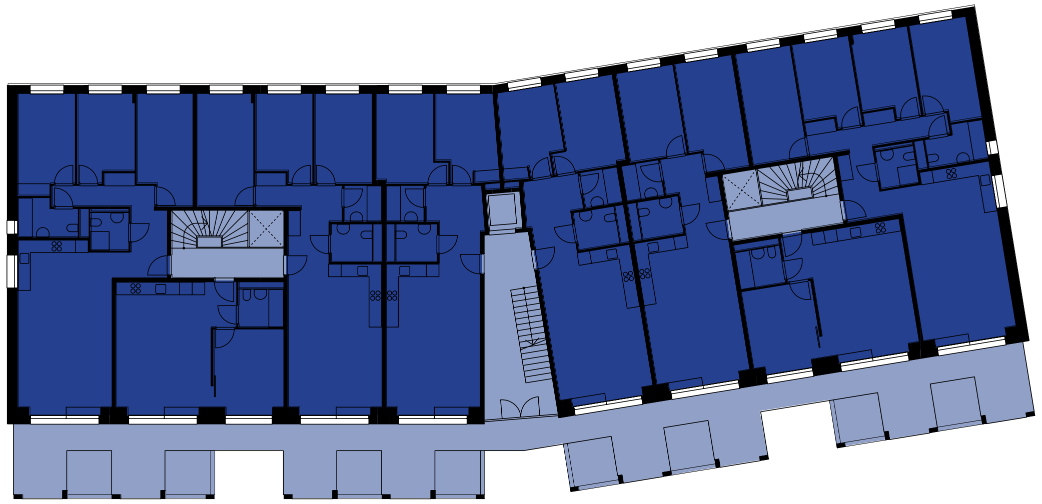
FUNCTIONS
Ground Floor Plan

🟥 Commercial Area
🟥 Independent Room
🟥 Guest Room
🟥 Laundry Room
🟦 Housing/Dwellings
🟦 Corridor/Circulation
🟦 Balcony
🟦 Common Room/Shared Space

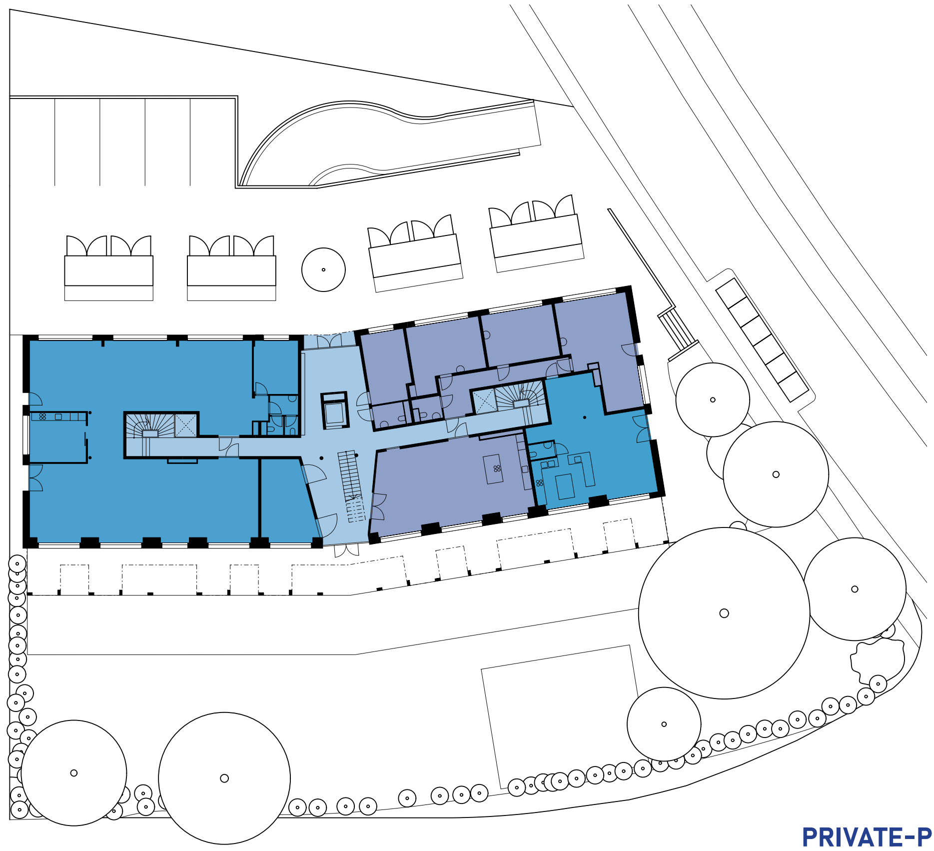
Commercial and public premises are located on the ground floor of the building, allowing for exchange between inside and outside by being a porous space. Ground floor also has the common room for the residents to meet. Typical residential floors consists of housing units only. On the 3rd floor, rest of the communal functions are located - which are a collective laundry room, guest rooms and independent rooms that can be rented individually by the residents. This layout of functions allow for ground floor to be the space where exchange between inside and outside is taking place and in addition to the ground floor, third floor being a collective backbone for the building allowing for exchange among residents. The roof terrace, which is designed to be accessible by everyone is another exchange point for the residents (Soubeyran - Coopérative Equilibre, 2021).



PRIVATE-PUBLIC
3rd Floor Plan



PRIVATE-PUBLIC
Typical Floor Plan



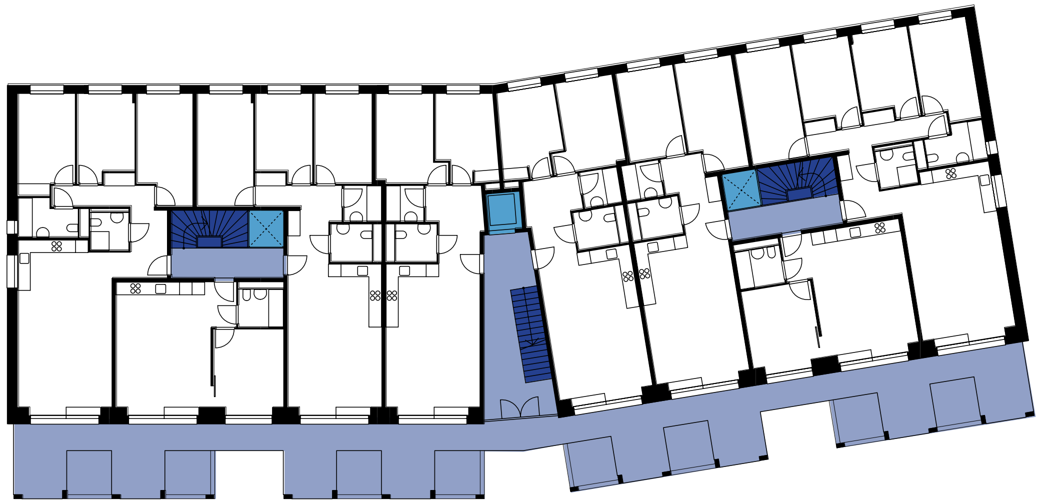
PRIVATE-PUBLIC
Ground Floor Plan

- ■ Private
- ■ Semi-Private
- ■ Semi-Public
- ■ Public

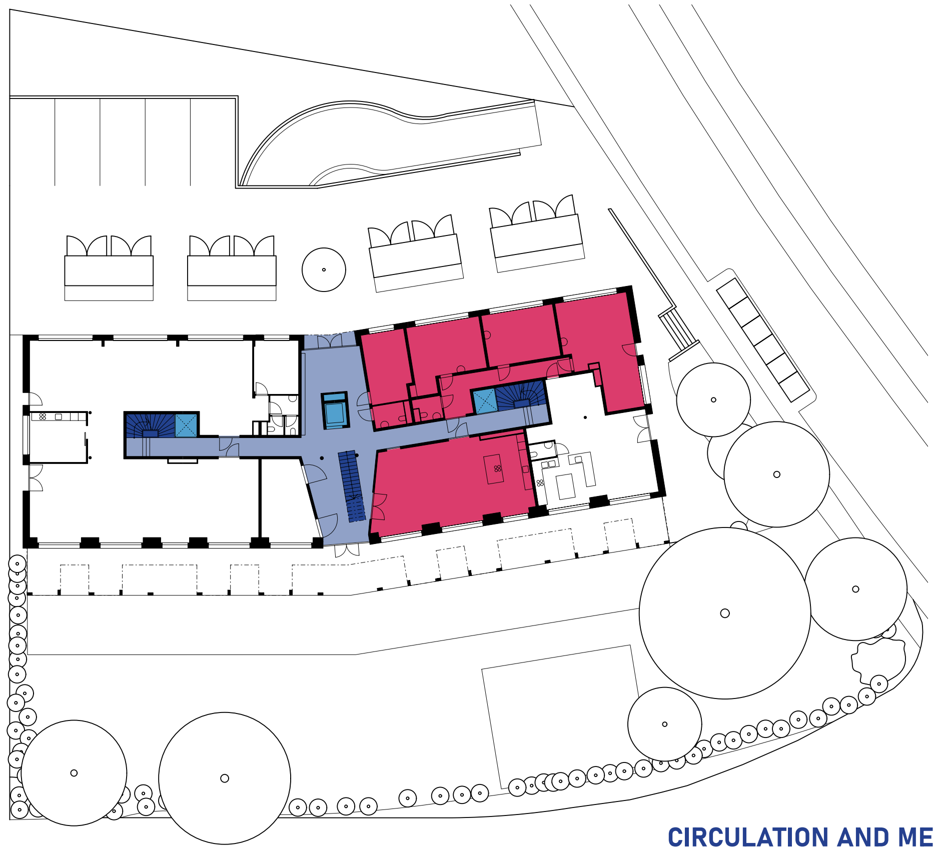
Functions that take place on each floor determine their public and private character. With commercial premises and flow of people going in and out, ground floor receives a public character for the most part - except for the communal space for the residents which is semi-public. As for the residential floors, the entirety of the floor space is private except for the circulation space, corridors and the balconies- which are semi-private.

3rd floor shows a more unique character by having a semi-private atmosphere by including the collective functions that can be used by all the residents (Soubeyran - Coopérative Equilibre, 2021).

CIRCULATION AND MEETING
3rd Floor Plan



CIRCULATION AND MEETING
Typical Floor Plan



CIRCULATION AND MEETING
Ground Floor Plan

🟦 Stairs, vertical circulation

🟦 Elevator, vertical circulation

🟪 Corridors, horizontal circulation

🟥 Meeting Spaces for residents

There are 3 vertical circulation points in the building (currently, only the central one is equipped with an elevator - but the rest will be too). On the ground floor, a horizontal link is created that connects the 3 vertical circulation routes by connecting the entrance, garden and the common room. On the 3rd floor, there is another similar horizontal connection that links the collective laundry room, guest rooms and independent rooms.

Balconies on each floor are facing the south and are 3 m deep. They are designed to be a natural extension of the private living room and all balconies on the same floor are connected with an exterior corridor to increase interaction and exchange among residents. This corridor provides an additional circulation path within the building that forms a meeting space for the residents (Soubeyran - Coopérative Equilibre, 2021).

04 CONCLUSION

In this chapter, the three case studies aim to show how projects tackle the topics of "independence", "adjusting to the new roles (control over life and routines)" and "interaction with the society" respectively. Each case demonstrates various design applications of the design guidelines identified in the previous chapter and these are shown below.

RAMPENHAUS

LARGE FLOOR SPACE AND OPEN FLOOR PLAN

EASE OF ACCESS AND MOVEMENT

VERTICAL TRANSPORT (WITH A RAMP)

CAPABILITY IN DAILY SKILLS

LIVING SPACE ELEVATED FROM GROUND LEVEL FOR A NICE OVERVIEW

CONNECTION TO OUTSIDE

HASBAHÇE

AREAS WHERE SPONTANEOUS INTERACTIONS CAN OCCUR

POSSIBILITIES FOR ACTIVITIES

(SEMI)-PUBLIC & POROUS SPACES INTEGRATED IN THE DAILY LIVING ENVIRONMENT

POSSIBILITIES FOR WORK

SPACES FOR INDOOR AND OUTDOOR ACTIVITIES TO TAKE PLACE

EXPLORING & IMPROVING SKILLS

SOUBEYRAN

(SEMI)-PUBLIC AND POROUS SPACES

NETWORK IN NEIGHBOURHOOD

CONNECTED PATHS IN VARIOUS PARTS OF THE BUILDING

CONNECTED SPACES

SHARED FACILITIES

SOCIAL CONTACT AND SUPPORT

06

CONCLUSION AND DISCUSSION

BRINGING THE FINDINGS TOGETHER

01 CONCLUSION

In this research, the research question **“WHAT KIND OF ARCHITECTURAL AND URBAN LIVING ENVIRONMENTS CAN BE INTEGRATED IN THE DAILY LIVES OF THE PHYSICALLY DISABLED ADULTS (PDA) AND THEIR FAMILY CAREGIVERS (FC) TO REDUCE THEIR SOCIAL ISOLATION?”** was formulated to find a solution to the co-dependence of PDA and FC that lead them to experience social isolation in their daily lives. It has been hypothesized that this social isolation is not only caused by the physical barriers but also by the social barriers in the society and it is possible to find a solution by adjusting and designing architectural and urban living environments suitable for PDA and FC to change the way they perceive their environments, their presence in the space and how others perceive their participation. To answer the main research question, four sub-questions are formulated.

The first sub-question **“HOW DOES A DAY IN THE LIFE OF A PHYSICALLY DISABLED ADULT (PDA) AND THEIR FAMILY CAREGIVERS (FC) LOOK LIKE?”** aims to understand the target group by exploring how a day in the life of a PDA and FC looks like and it is answered in chapter 2 through the findings of fieldwork which consist of observations and answers of PDA and FC to the interview questions. This chapter serves as the backbone of the research by providing an insight on how the daily life of the target group looks like and shows the locations that are significant for the daily life of PDA and FC. As a result, it has been discovered that the places that PDA and FC spend their times at as well as what they wish and need from their living environments vary depending on their level of disability but also from their familial and social situation. The second sub-question **“WHAT LIVING CONDITIONS MAKE PDA AND FC FEEL SOCIALLY ISOLATED IN THEIR DAILY LIVES?”** and the third sub-question **“WHAT LIVING CONDITIONS HELP PDA AND FC FEEL MORE SOCIALLY INTEGRATED?”** are answered together in chapter 3 through findings of fieldwork. There are 3 main findings out of this chapter: (1) It is unravelled that social isolation and social integration are inseparable from each other - absence of a living condition that creates isolation leads the target group to experience social integration or vice versa – and for this reason, the answers for these two sub-questions are presented together. (2) It has been found that the experience of social isolation and integration of the FC is highly dependent on the PDA (and same applies for the other way around as well), creating the need to see the two target groups as a whole that complement each other. Looking first at the living conditions that make the PDA feel socially isolated and integrated, structuring the findings using the three points mentioned in the theoretical framework as possible solutions for social isolation through the research of Freeman et al. (2018) and later doing the same for the FC by using the three points through the research of Gulwadi (2007), it has been discovered that the 3 points for the PDA are parallel to the 3 points of FC and can be seen as a whole. This brings up the following titles that help PDA and FC to combat social isolation and experience social integration: Overcoming Dependence, Control over Life and Routines, Interacting with the Society. (3) As the final finding, it has been found that these three titles are also connected with each other as making positive changes for one of the principles influence the other two as well: as the PDA and FC overcome their dependence on each other or to others, they gain the opportunity to have more control over their lives and can participate further in the society – increasing their interaction with others subsequently.

Altogether, by looking at the fieldwork findings, this chapter identifies 15 points (6 points under each of the three titles mentioned in the previous paragraph) as the living conditions that make PDA and FC feel more integrated with the society. These 15 points, also named as the design guidelines, form the basis for chapter 4.

The final sub-question **“HOW SHOULD THE ARCHITECTURAL AND URBAN LIVING ENVIRONMENT OF THE PDA AND FC CHANGE TO INTEGRATE THEM MORE IN THE SOCIETY?”** looks closely at the living conditions that lead PDA and FC to feel more socially integrated and explore how these living conditions can be reflected in the living environments of PDA and FC and it is answered in chapter 4 through combining the findings of the fieldwork with literature study. This chapter looks closely at the 3 titles (Overcoming Dependence, Control over Life and Routines, Interacting with the Society) and explains how the living conditions that lead to social integration of PDA and FC, which are the 16 points mentioned in chapter 3, can be implemented in the living environments of PDA and FC. The outcome of this chapter is the design applications of these living conditions, showing the ‘how’s of the design guidelines.

Combining all these results by looking at the design guidelines and their applications, it can be seen that the applications range from dwelling level to building level and even neighbourhood level in scale. Organising the guidelines based on the scale that they are relevant in, looking at the design applications revealed in chapter 4, a matrix can be created that shows which guideline is applicable at what scale and which applications are relevant for that scale and guideline. This opens up possibilities for the design of an inclusive living environment that supports independence, helps the target group to gain control over their lives and promotes social interaction between its residents. As hypothesized earlier, this research booklet shows the range of possibilities fathered through observations, interviews, and literature study for finding a solution to the issue of social isolation of PDA and FC by adjusting and designing architectural and urban living environments suitable for them which would change the way they perceive their environments, their presence in the space and how others perceive their participation. Full set of guidelines and design applications in the following pages could potentially be used by organisations and/or planners to ensure an inclusive living environment for all.

02 DISCUSSION

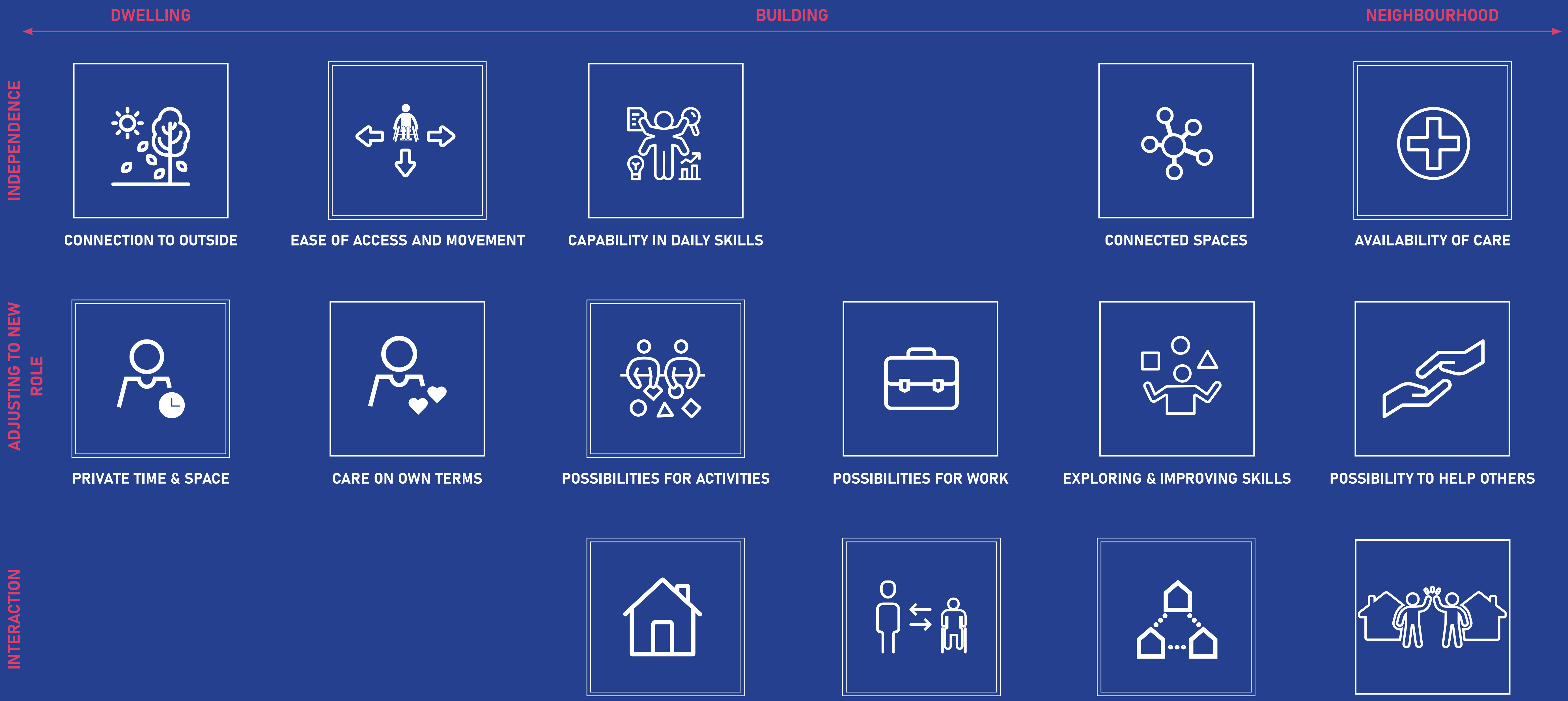
In this research booklet, the findings that were gathered during the fieldwork have been the main focus to answer the research questions. This is a conscious decision made by the author to keep the focus on the context of Netherlands and to understand the issues faced by PDA and FC more in depth. Majority of literature that covers social isolation problems for PDA and FC seems to be lacking the point of architecture or the impact of living environments on this experience. This research aimed to bring together the points about social isolation, mentioned in literature from a more psychological or medical perspective, and living conditions for inclusivity, mentioned in literature from an architectural and urban design point of view, to come up with design guidelines for an inclusive living environment for PDA and FC.

It is important to note that the guidelines and design applications gathered in this research booklet are 'without context', meaning that they should be interpreted as a collection of design elements that can potentially have an impact on the experience of the living environments of PDA and FC, depending heavily on the context that they will be applied at. Using these guidelines as 'guiding themes' instead of applying all the application methods mentioned without any evaluation can potentially bring better results by bringing the context and the design elements together.

There are several limitations to this research. Considering that the outcomes are heavily influenced by the fieldwork findings, arranging a different fieldwork could have led to different results and thus, a different set of findings. It is also worth mentioning that fieldwork was organized through the cooperation of several organisations and associations – which have a huge impact on the findings. Since the interviewees were recruited via the associations, a limited group of people that all belong to a similar social circle have been interviewed which might potentially have an impact on the results. Additionally, it is worth noting that the PDA and FC that were interviewed reached out to the author on their own terms, meaning that only the people who wanted to take the initiative to talk to someone about their living environments were interviewed which might impact the results since the PDA and FC who are heavily socially isolated were potentially not reached. It is therefore significant that further research explores ways to reach heavily socially isolated PDA and FC and conducts interviews with a bigger range of PDA and FC to generate variety in the findings.

03 DESIGN GUIDELINES

Full set of guidelines obtained in this research booklet are presented below. Guidelines are placed on a matrix with the three titles on the vertical axis and the scales of dwelling-building-neighbourhood on the horizontal axis. The guidelines that are repeated multiple times are shown with a thicker border to make a distinction.



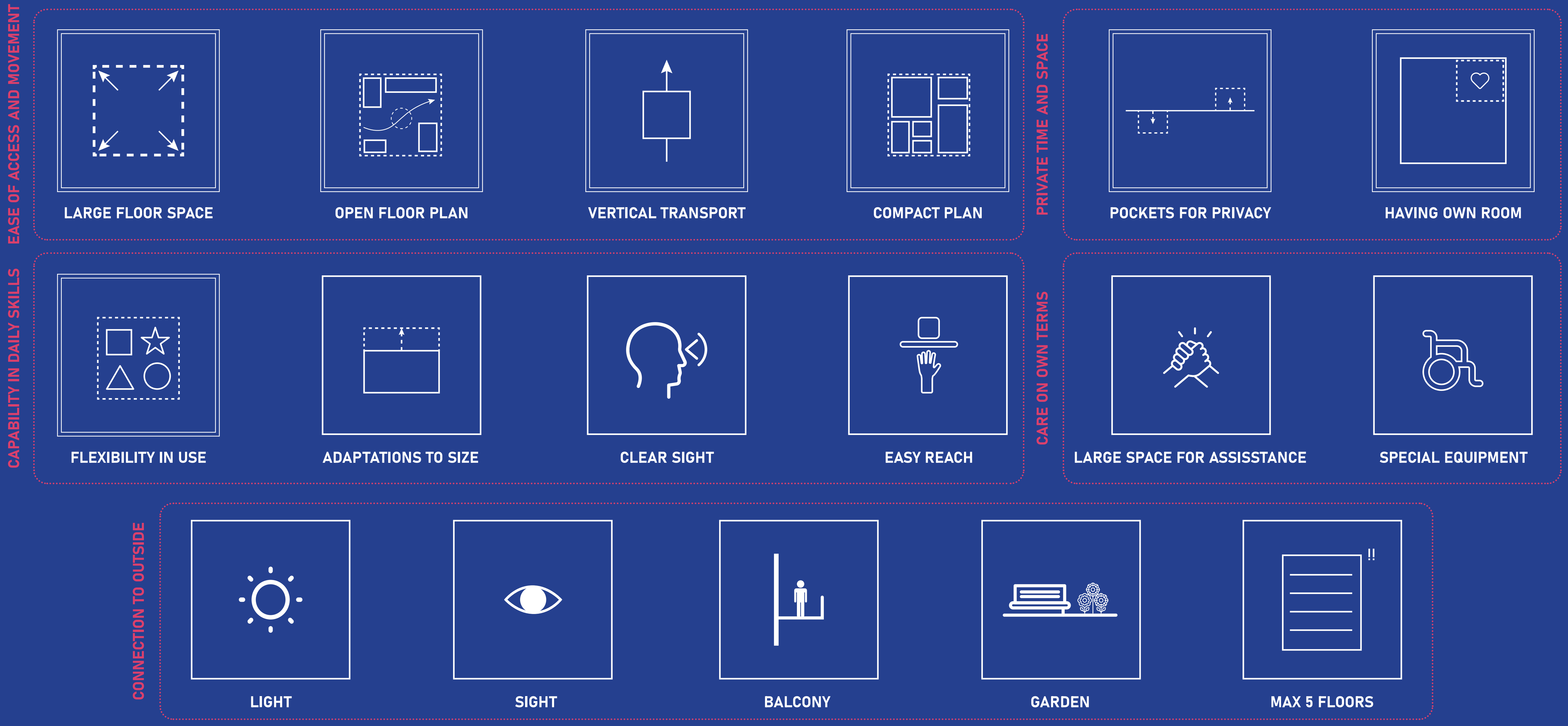
DWELLING BUILDING NEIGHBOURHOOD

INDEPENDENCE	CONNECTION TO OUTSIDE	EASE OF ACCESS AND MOVEMENT	CAPABILITY IN DAILY SKILLS		CONNECTED SPACES	AVAILABILITY OF CARE
ADJUSTING TO NEW ROLE	PRIVATE TIME & SPACE	CARE ON OWN TERMS	POSSIBILITIES FOR ACTIVITIES	POSSIBILITIES FOR WORK	EXPLORING & IMPROVING SKILLS	POSSIBILITY TO HELP OTHERS
INTERACTION			NON-INSTITUTIONAL LIVING	SOCIAL CONTACT & SUPPORT	NETWORK IN NEIGHBOURHOOD	LIKE-MINDED NEIGHBOURS

04 DESIGN APPLICATIONS

DWELLING

Design applications regarding the points under the dwelling level are presented below. Each application comes from a guideline and is explained in detail in chapters 3 and 4. The design applications with a thicker border below are the ones that are associated with the design guidelines that are repeated multiple times (as shown on the previous page) to make a distinction.



EASE OF ACCESS AND MOVEMENT

- LARGE FLOOR SPACE
- OPEN FLOOR PLAN
- VERTICAL TRANSPORT
- COMPACT PLAN

PRIVATE TIME AND SPACE

- POCKETS FOR PRIVACY
- HAVING OWN ROOM

CAPABILITY IN DAILY SKILLS

- FLEXIBILITY IN USE
- ADAPTATIONS TO SIZE
- CLEAR SIGHT
- EASY REACH

CARE ON OWN TERMS

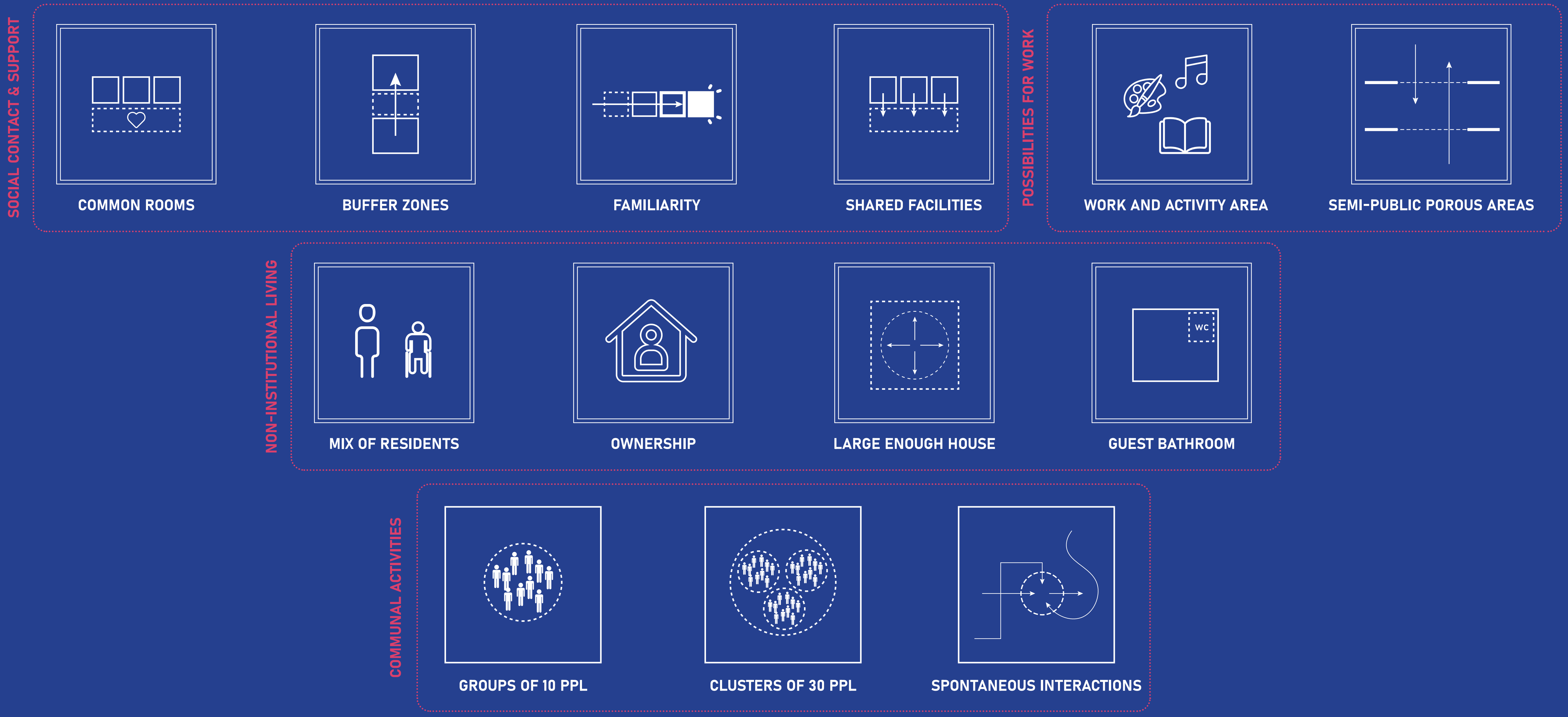
- LARGE SPACE FOR ASSISSTANCE
- SPECIAL EQUIPMENT

CONNECTION TO OUTSIDE

- LIGHT
- SIGHT
- BALCONY
- GARDEN
- MAX 5 FLOORS

BUILDING

Design applications regarding the points under the building level are presented below. Each application comes from a guideline and is explained in detail in chapters 3 and 4. The design applications with a thicker border below are the ones that are associated with the design guidelines that are repeated multiple times to make a distinction.



SOCIAL CONTACT & SUPPORT

COMMON ROOMS

BUFFER ZONES

FAMILIARITY

SHARED FACILITIES

POSSIBILITIES FOR WORK

WORK AND ACTIVITY AREA

SEMI-PUBLIC POROUS AREAS

NON-INSTITUTIONAL LIVING

MIX OF RESIDENTS

OWNERSHIP

LARGE ENOUGH HOUSE

GUEST BATHROOM

COMMUNAL ACTIVITIES

GROUPS OF 10 PPL

CLUSTERS OF 30 PPL

SPONTANEOUS INTERACTIONS

NEIGHBOURHOOD

Design applications regarding the points under the neighbourhood level are presented below. Each application comes from a guideline and is explained in detail in chapters 3 and 4. The design applications with a thicker border below are the ones that are associated with the design guidelines that are repeated multiple times to make a distinction.

NETWORK IN NEIGHBOURHOOD
ACTIVITIES AT ALL TIMES
NARROW STREETS
PEDESTRIAN FOCUS
CHOICE TO REACH HOME
DENSITY

AVAILABILITY OF CARE
CAREGIVER CENTER

CONNECTIVITY OF SPACES
CONNECTED PATHS
WIDE PATHS
NO LEVEL CHANGES
PLACES TO SIT AND REST
FUNCTIONS WITHIN REACH

CAPABILITY IN DAILY SKILLS
SPORTS FACILITIES

EXPLORING & IMPROVING SKILLS
FLEXIBLE COMMON SPACES
IN & OUTDOOR ACTIVITY AREAS

POSSIBILITY FOR WORK
CO-WORKING SPACES

POSSIBILITY TO HELP OTHERS
MEETING ROOMS

LIKE-MINDED NEIGHBOURHS
PDA IN THE NEIGHBOURHOOD
SHARED LIFESTYLE

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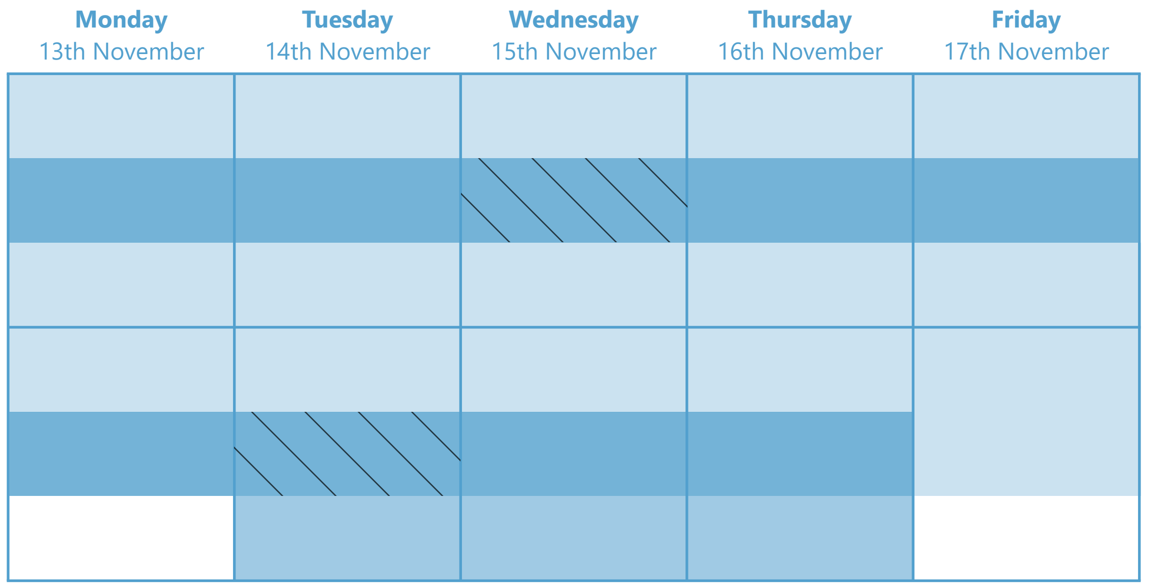
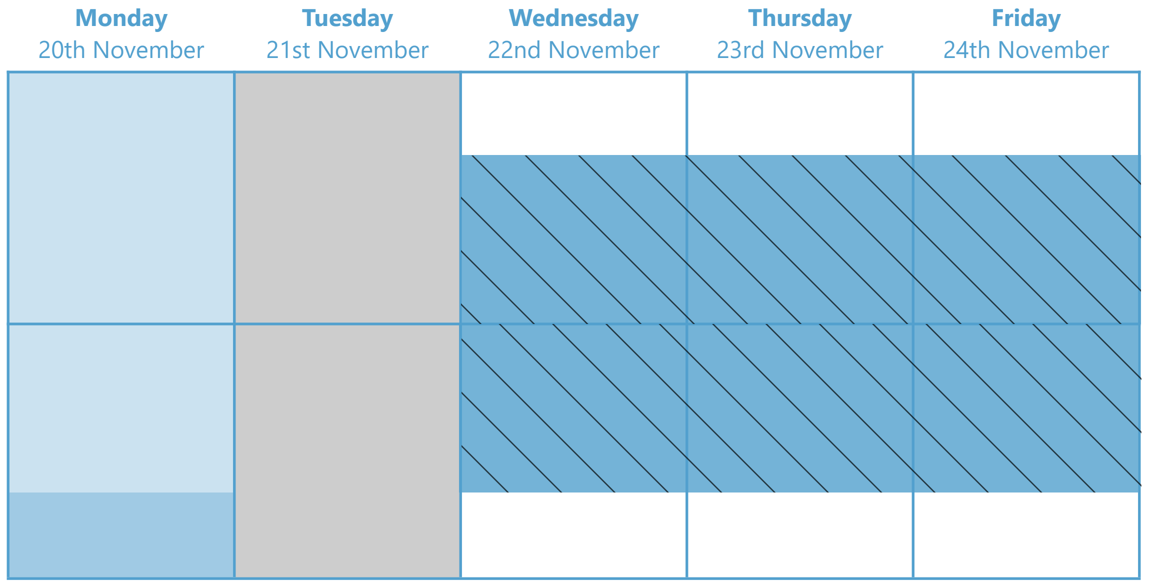
APPENDIX 1





- ▢ Observations
- ▢ Interaction
- ▢ Interviews
- ▨ Interviews + House visit
- ▢ Tutoring

FIELDWORK PLANNING

Fieldwork activities are planned in the 3rd and 4th week of November, between 13th to 24th. These two weeks provide the focused time needed to spend time with the target group and to get in contact with them. The methods to be used during the fieldwork is thoroughly explained in *Chapter 6* (pages 20-24). Fieldwork mainly consists of 3 elements: *Observations, Interactions* and *Interviews.* Although the diagram on the left and the text below describe them as separate elements, it is important to note that it is difficult to separate them from each other and in most instances, they will be intertwined. The diagram is a representation of the most prominent element at the given time-frame.

I. OBSERVATIONS

Observations will be done on PDA and FC while they are doing what they do in their daily lives. To make sure observations are authentic and a true representation of their daily routines, settings from their daily lives are chosen.

First week (*13th-17th of November*), a day-care center for physically disabled adults (aged 18 and above) will be visited. During the week, observations as described in chapter 6 will be realized while also taking part in activities that take place within the day care facility. At the beginning of the second week (*20th of November*), another day-care facility which is located in another city will be visited from the same organization to observe the differences and to gain a different perspective. It is also possible at this second location to take part in activities and events that take place at the day-care facility.

II. INTERACTIONS

During the two weeks, there will be several moments in which it will be possible to join specific events and to interact with the target groups. These interaction moments include having dinner at a housing facility for PDA and joining support group meetings where the PDA and FC of a specific condition/disease come together once a month*. For both instances, participants are informed about the presence and participation of the researcher and are aware of the situation beforehand. This allows them to prepare what they want to say if they want to discuss anything and to decide for themselves beforehand if they are comfortable sharing certain information during both the dinner and the support group meetings.

III. INTERVIEWS

Interviews are planned with the help of carefully chosen institutions and associations to get in contact with PDA and FC who wish to participate in such a research. They are all informed beforehand about what the research is about, what the researcher is looking for and how/when the interviews will take place. By signing up through the association/institution, they approved their participation and scheduled to a specific time slot. Some participants wanted to have the interview in their own homes and agreed to give a house tour and some wanted to meet at a public space or through online platforms (video call). These are scheduled all throughout both weeks.

**To protect the privacy of the interviewees, the names and details of the associations and institutions will not be shared in this research booklet.*

APPENDIX 2

INTERVIEW QUESTIONS

Interview will take approximately 30-40 minutes, depending on the interaction with the participant and the progression of the conversation. It mainly consists of 3 parts and each part corresponds to one of the topics related to the research question: *Daily Life of PDA and FC, Social Isolation, Living Environments*. Some of the questions are specifically formulated to conduct one of the methods mentioned in Chapter 6, where all the research methods are described in detail.

Part 0:

Interview will start with asking the participant about their ideal living situation with their current condition. This will be an "ice breaker" and will provide a preview to the participant on what they should expect from the rest of the interview.

Can you tell me how your ideal living situation would look like with your current health and/or care condition?
  What would you change?
  What would you keep as it is?

PART 1: DAILY LIFE

At this part, participant will be asked some questions about their daily life, their condition and about some basic information about them to provide background information.

Can you tell me a little bit about yourself?
Can you tell me about your living situation?
  Do you live alone? What kind of house? etc.
Can you tell me about a typical day in your life?
Can you take me through your day step-by-step?

At this point, participant will be asked to answer some questions regarding their most visited, favorite and least favorite locations to visit. This will help the researcher to form an understanding of the participant's judgment of a good and a bad place and where does this judgment come from.

Where do you visit most often?
What is your favorite place to visit?
What is your least favorite place to visit?
  What do you do there?
  Who do you go there with?
  How does this space make you feel?
  What do you associate with this space?
  Can you tell me a memory/story about this place (positive or negative)?

PART 2: ISOLATION & INTEGRATION

This parts aims to understand what "social isolation" and "social integration" mean for the participants. It is important at this step to understand what they can tell about their own experiences and what they see as isolation and integration.

Can you tell me what you understand from the word "social isolation"?
  Do you feel isolated from the society?
  What makes you feel this way?
  Where do you experience this the most?
Can you tell me what you understand from the word "social integration"?
  Do you feel connected to others?
  What makes you feel this way?
  Where do you feel this the most?

At this point, participant will be asked to answer some questions regarding a participant moment when they felt socially isolated and when they experienced social integration. This will help the researcher to form an understanding of the participant's judgment of social isolation and integration and the origin of this judgment.

Can you tell me a story/memory about a time when you felt socially isolated?
  Where and how did this happen?
  What and how did it make you feel?

Can you tell me a story/memory about a time when you felt socially integrated?
  Where and how did this happen?
  What and how did it make you feel?

PART 3: LIVING ENVIRONMENTS

This part will question the future and the expectations. Instead of asking about the present, the interview will aim to question the future and what does the participant need and want.

Can you tell me what comes to your mind when I ask you about being "socially integrated"?
  How is it different than how your daily life looks like now?

What do you need from the society (your community, your neighborhood, your work, your social circle, etc) to feel more integrated?
What does this mean for your living environments?
What do you think you miss in your daily life?
How do you think it can be introduced to your daily life?

This final question aims to tie the interview back together by asking the very first question once again. The changes in the answers will be noted and will be reflected upon together with the participant.

Can you answer the first question once again:
Can you tell me how your ideal living situation would look like with your current health and/or care condition?
  What would you change?
  What would you keep as it is?