Research Plan

Physical Disabilities and Family Life: Social Integration through Architectural and Urban spaces

Designing for Health & Care:
Towards an Inclusive Living Environment

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12%

of the people
in the Netherlands

People with motor disabilities and
impairments is the largest group

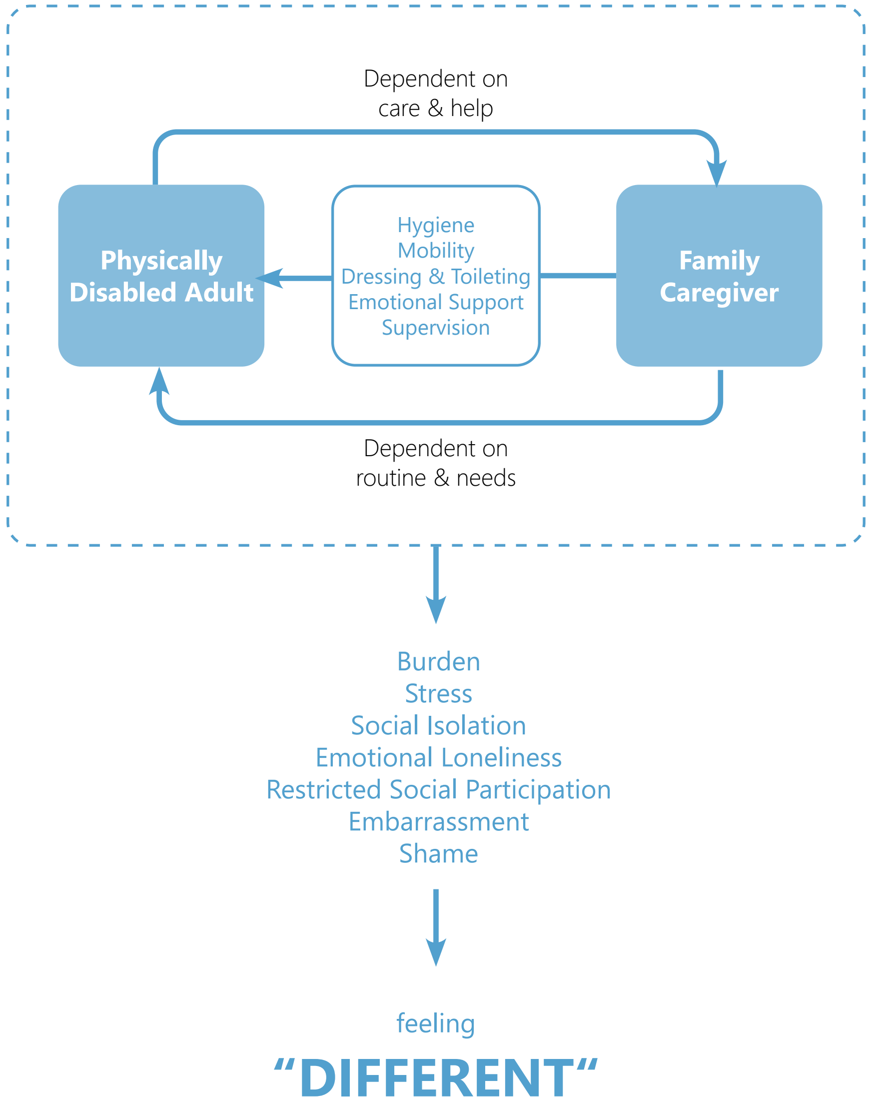
Family life and
continuing to live at home

1 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 as well as injuries to brain and spinal cord) 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).



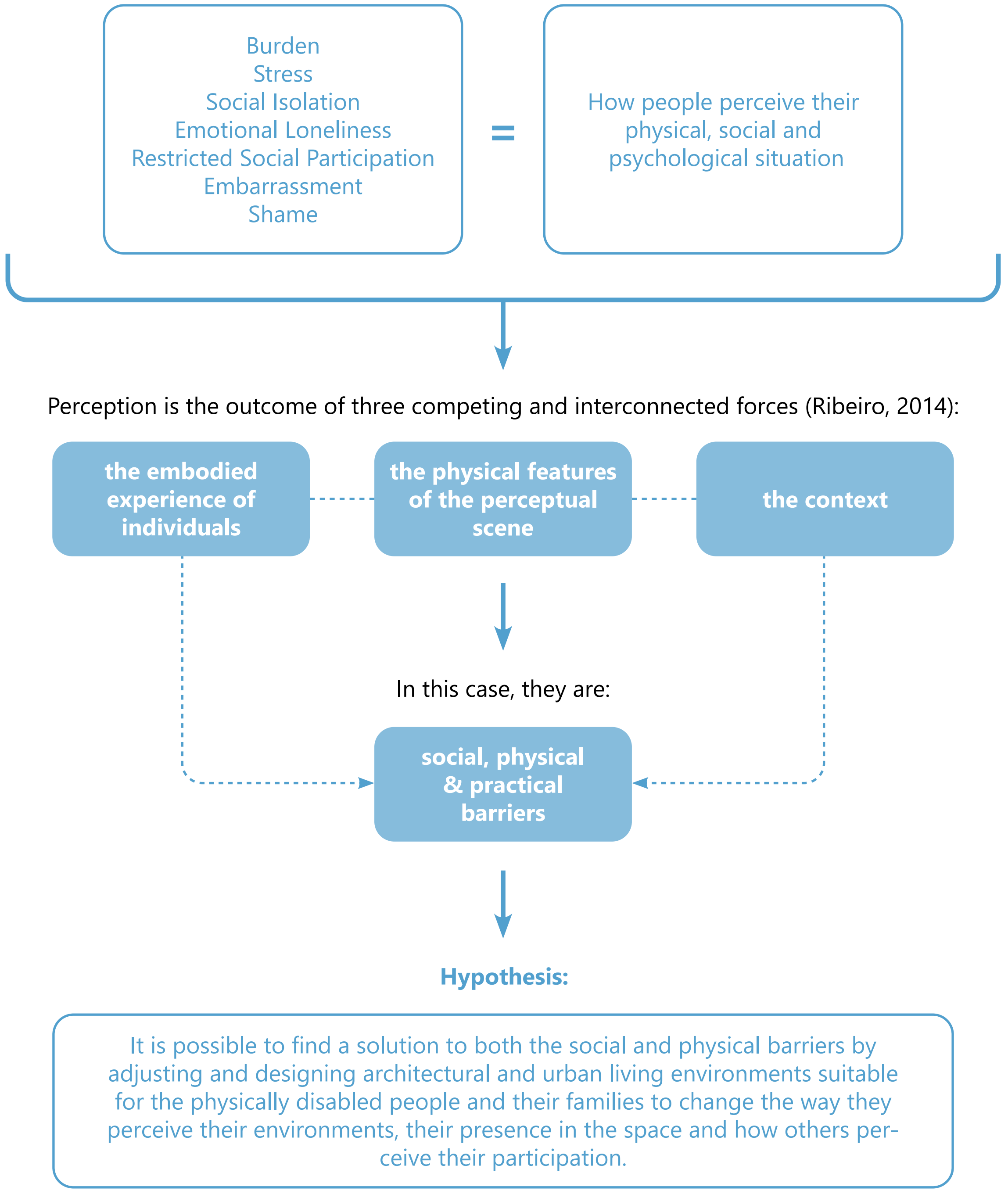
2 Problem Statement

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 is 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).



Perception is the outcome of three competing and interconnected forces (Ribeiro, 2014):

In this case, they are:

Hypothesis:

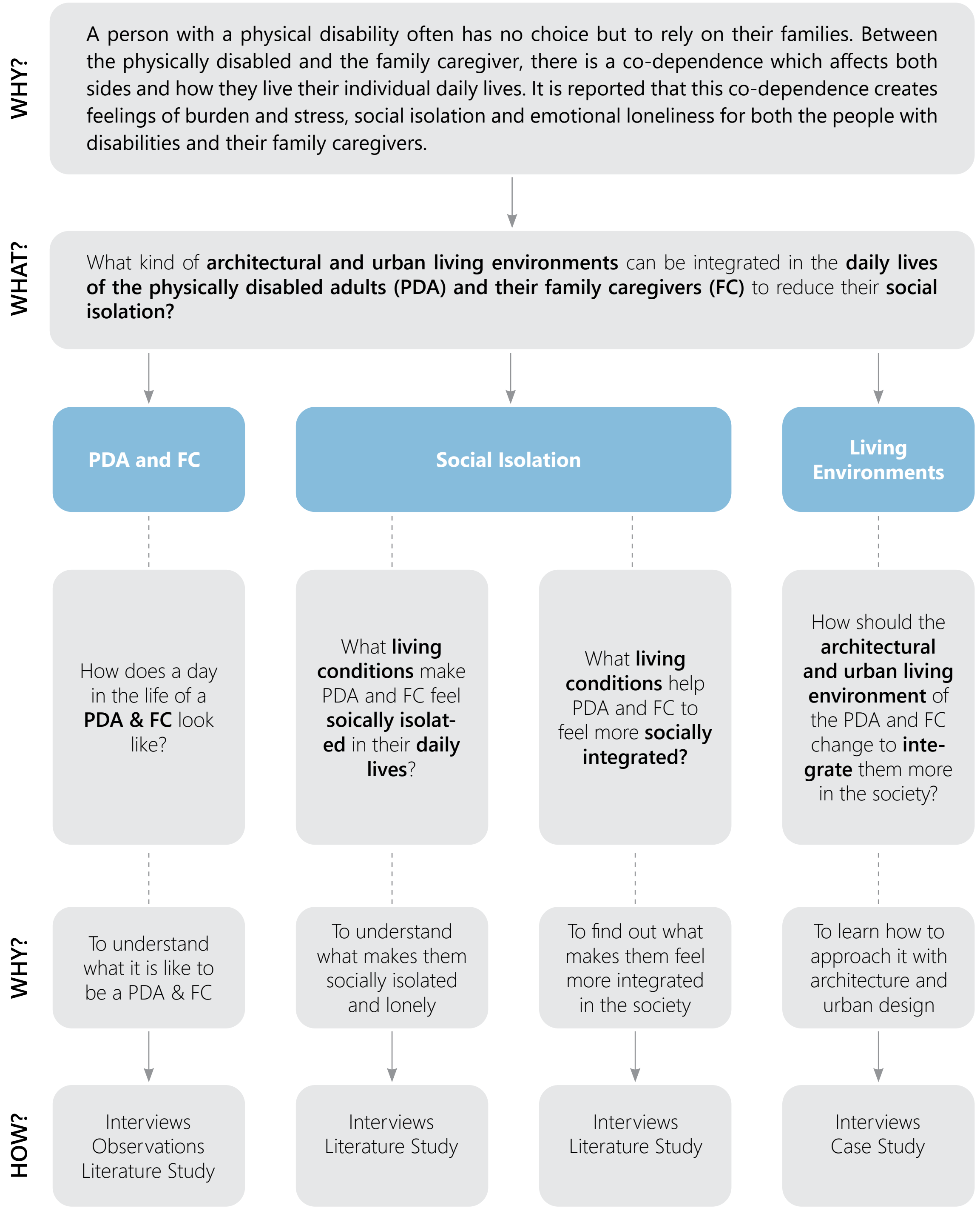
It is possible to find a solution to both the social and physical barriers by adjusting and designing architectural and urban living environments suitable for the physically disabled people and their families to change the way they perceive their environments, their presence in the space and how others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



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?**

PDA and FC

Social Isolation

Living Environments

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

What **living conditions** make PDA and FC feel **socially 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
Literature Study

Interviews
Literature Study

Interviews
Literature Study

Interviews
Case Study

3 Research

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)
- Conditions that make PDA and FC feel socially isolated and lonely
- 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?

**The terms "Architectural and Urban Living Environments", "Physically Disabled Adults", "Family Caregivers" and "Social Isolation" are defined in Chapter 4: Definitions.*

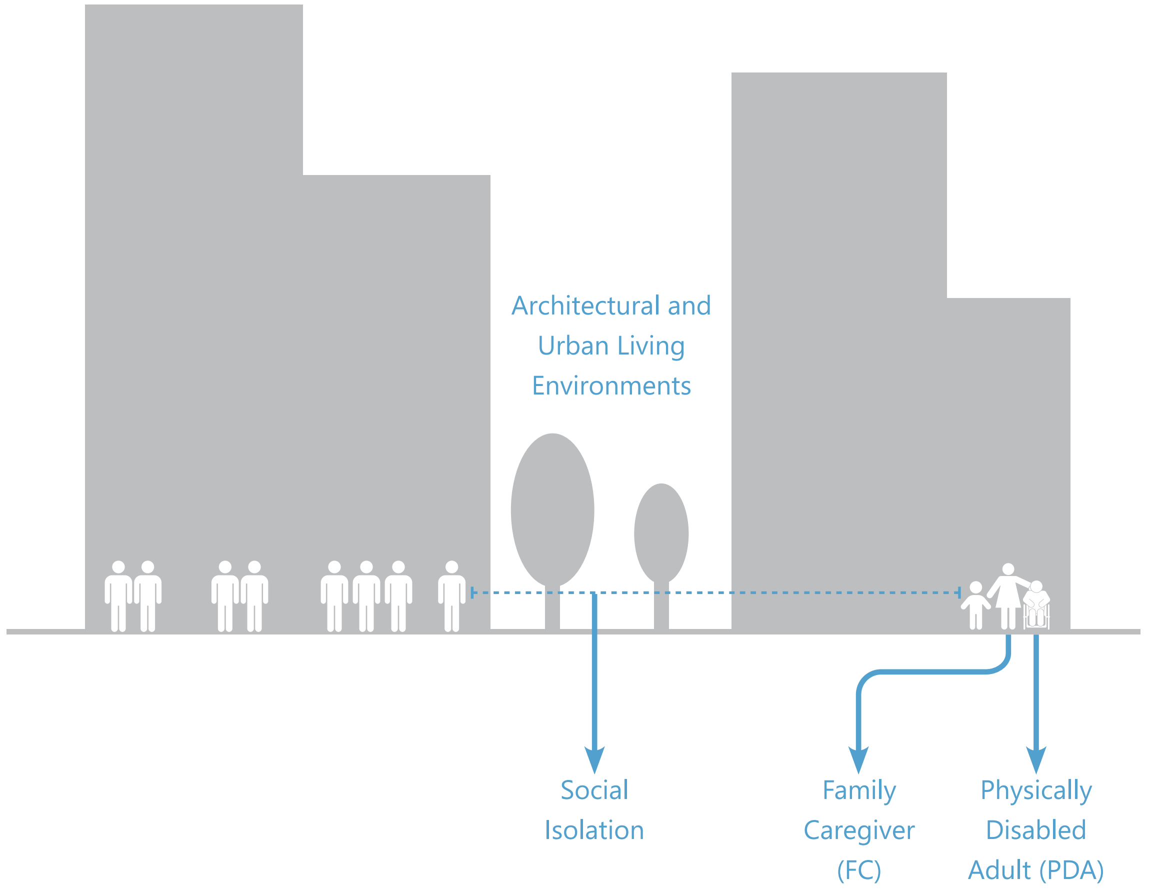
What kind of **architectural and urban living environments** can be integrated in the **daily lives of the physically disabled adults (PDA) and their family caregivers (FC)** to reduce their **social isolation?**

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?



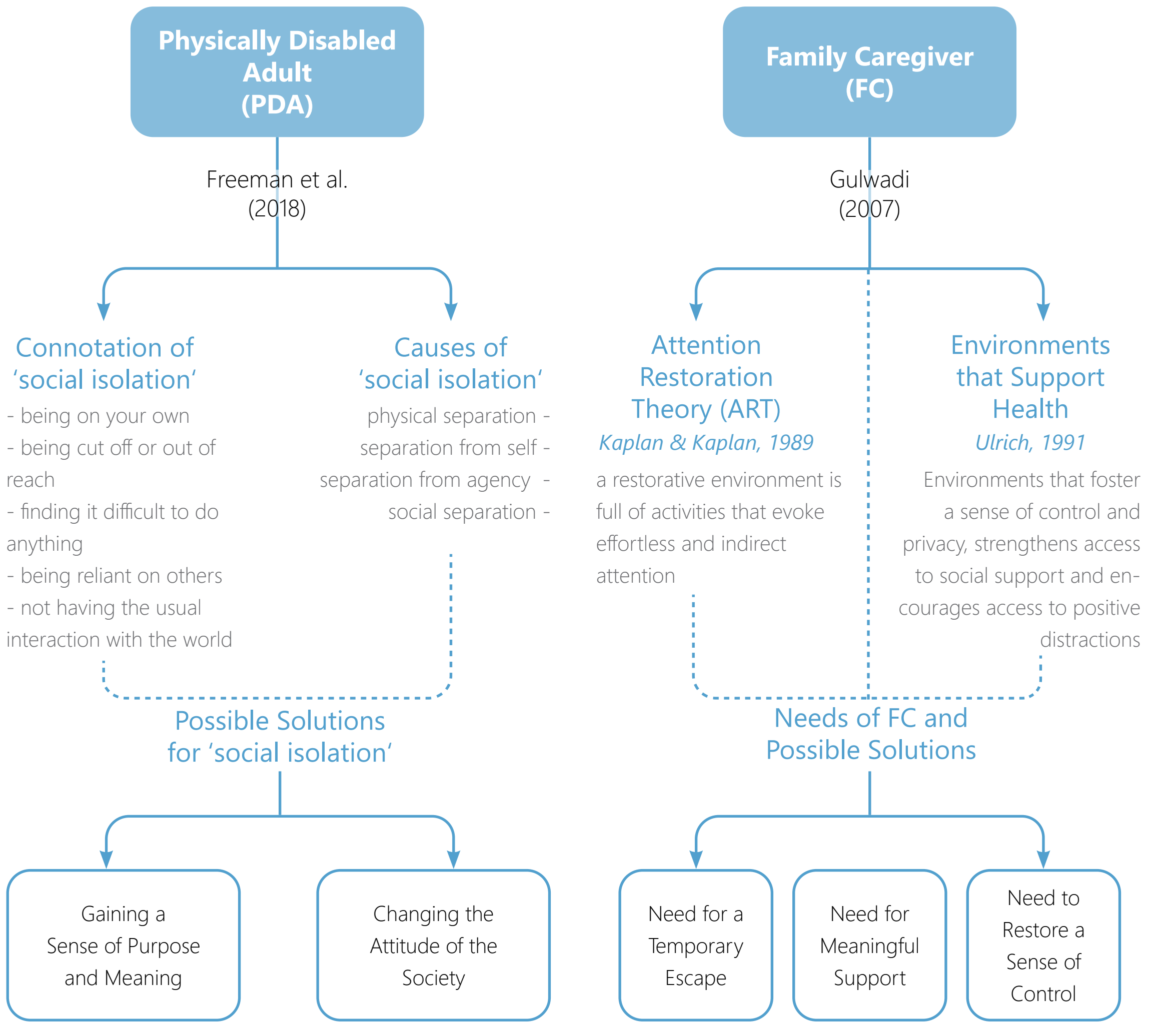
4 Definitions

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.



5 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 two key aspects to target for their social integration.

i. 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).

ii. Attitude of the Society

Being separated from agency for PDA - 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.

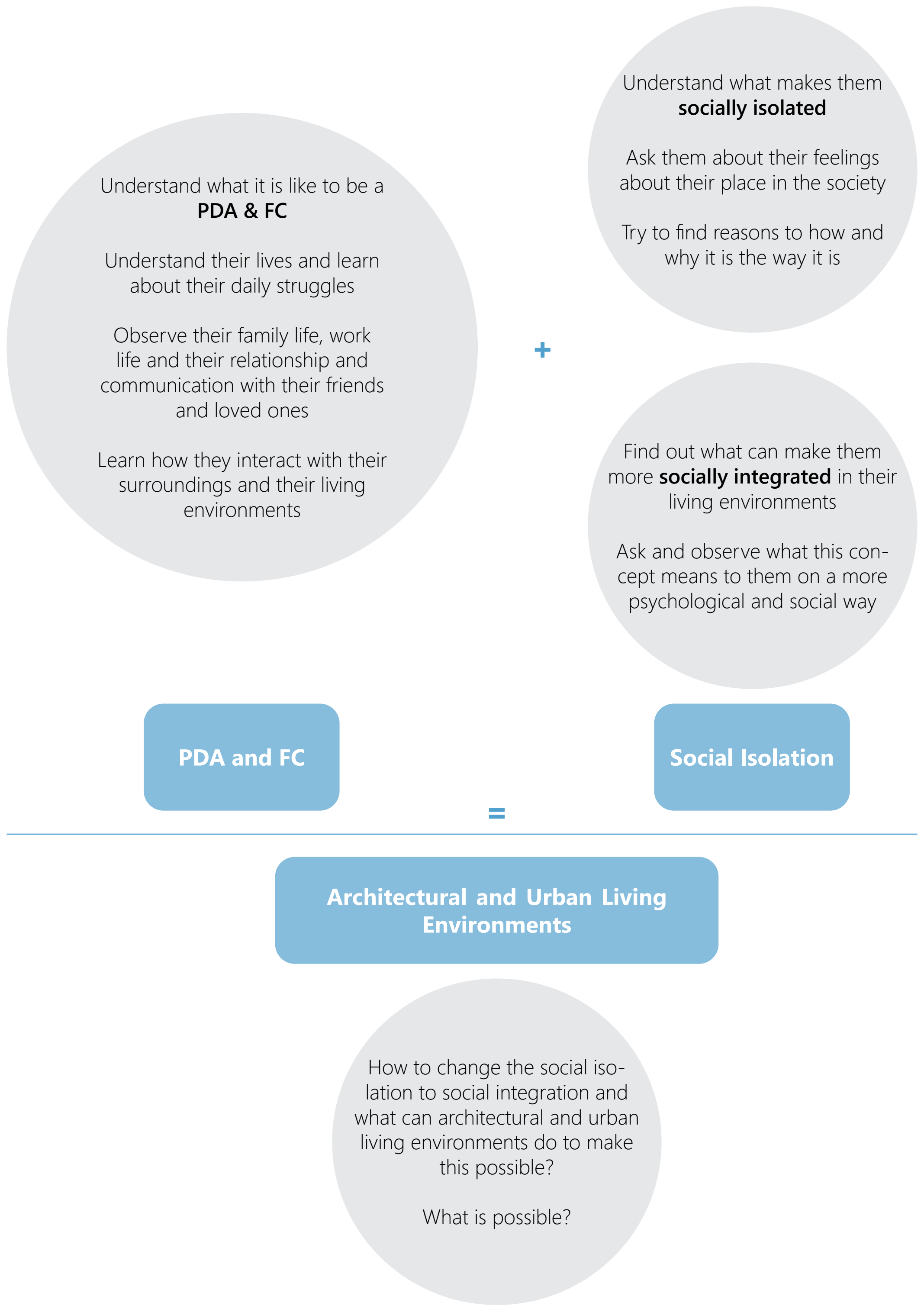
iii. Need to restore a Sense of Control

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 for FC.

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.



6 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

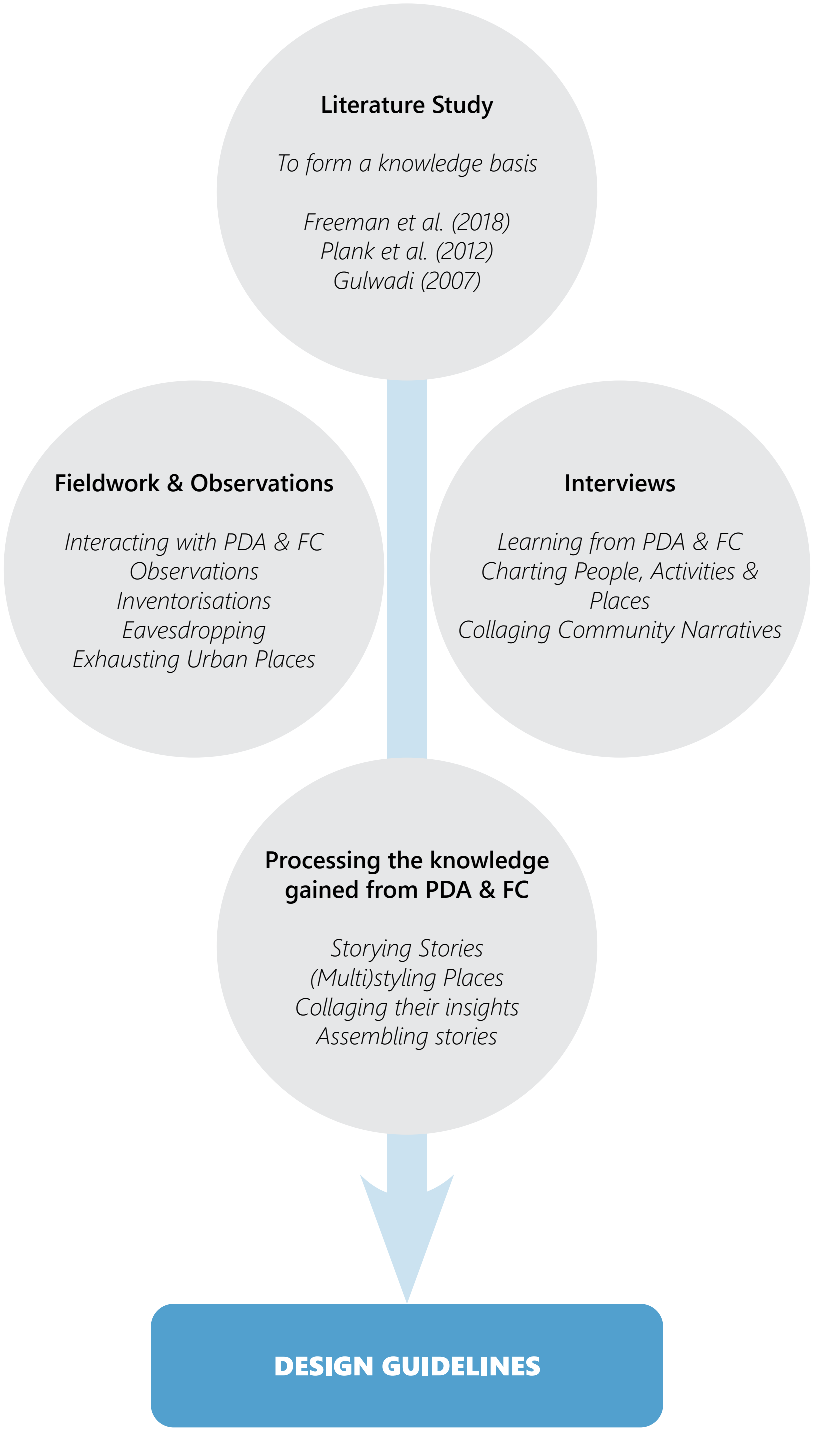
It is an essential part of this research to come in contact with the target group, PDA and FC, during the fieldwork*, which forms the basis of *Phase II*. Observations and inventorisations are the primary data to be obtained during the fieldwork, which will facilitate the understanding of daily life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

Main techniques/methods to be used during the interviews are “*Charting People, Activities & Places*“ and “*Collaging Community Narratives*“ as described by Havik and Moura (2023). *Charting People, Activities & Places* includes asking questions about their local environments that they visit in their daily lives through their memories and stories. *Collaging Community Narratives* includes asking all the participants to identify a specific memory from the same location/area to gather insight about this place.

These will help gather narrative interviews in which memories, experiences and feelings will be discussed. Interviews will be recorded (*if the participant is comfortable with doing so*) 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 the participants mentioned and 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:

- 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.)

**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** **Literature Study**	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** **Literature Study**	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** **Literature Study**	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** **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

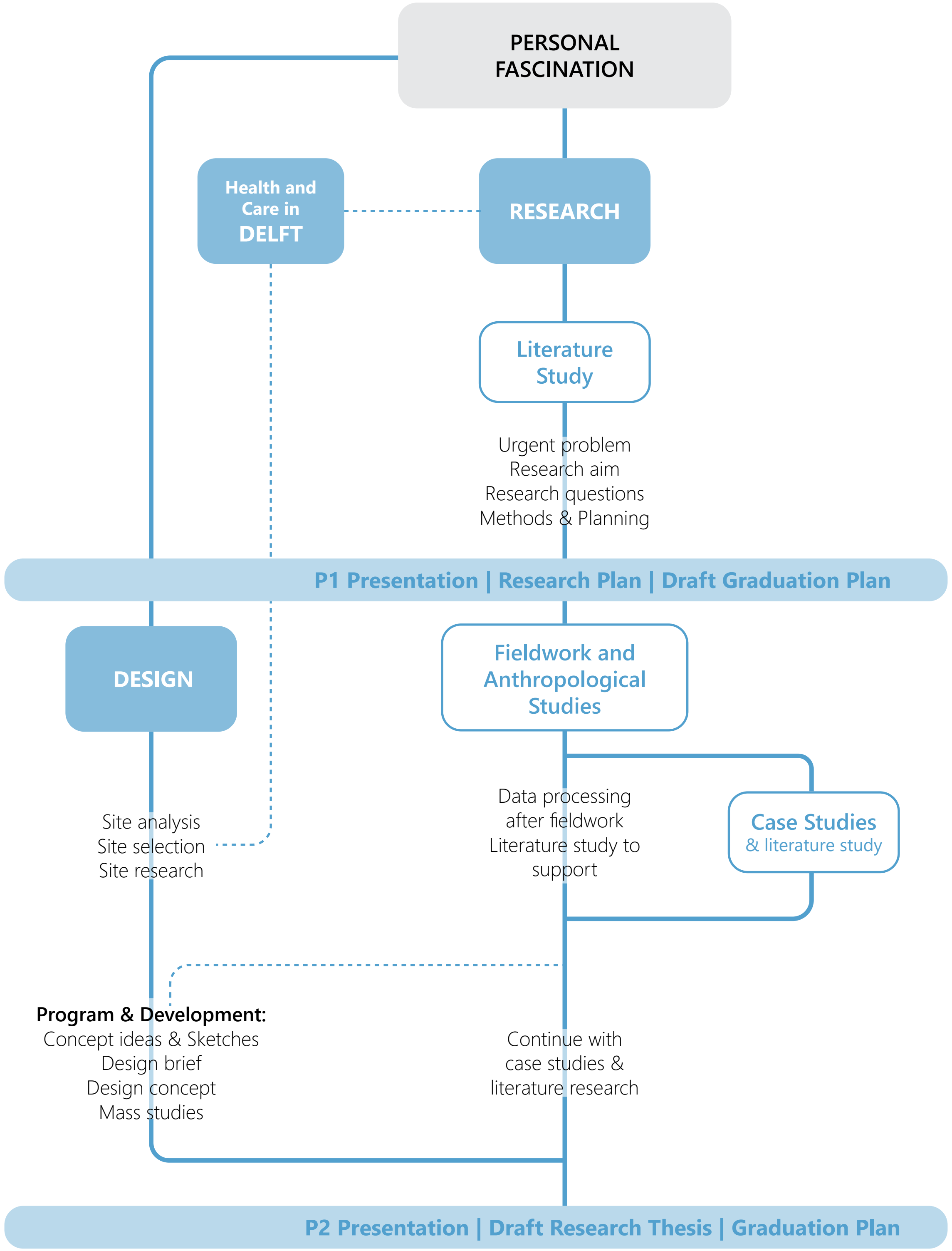
Limitations:

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.



7 Planning

Until P1:

At this stage, focus is on Research, informed mainly by literature study. Information regarding health and care in Delft supplement the research and act as a secondary fascination.

From P1 to P2:

There are two lanes to take into account between P1 and P2:

After P1, research continues immediately with fieldwork and anthropological studies. This is essential to gather information about the target group and their living environments. Afterwards, data gathered during the fieldwork is processed and supplemented with literature study. Case studies are done along the way to analyze real cases. This provides an outlook of the impacts and consequences of architectural and urban projects and to learn from such analysis.

On the other hand, personal fascination starts to slowly turn into design ideas and initiates the Design phase. Design phase starts off with site analysis, selection and research which is informed primarily by the city of Delft. Then it is time to develop the design brief, concept ideas and the main design concept. This phase is mainly informed by the findings of the Research lane.

As it gets closer to P2, the Research and Design lanes come closer together. The final result is the Draft Research Thesis and Graduation Plan, together with Final Design Concept acquired through *Research by Design*.

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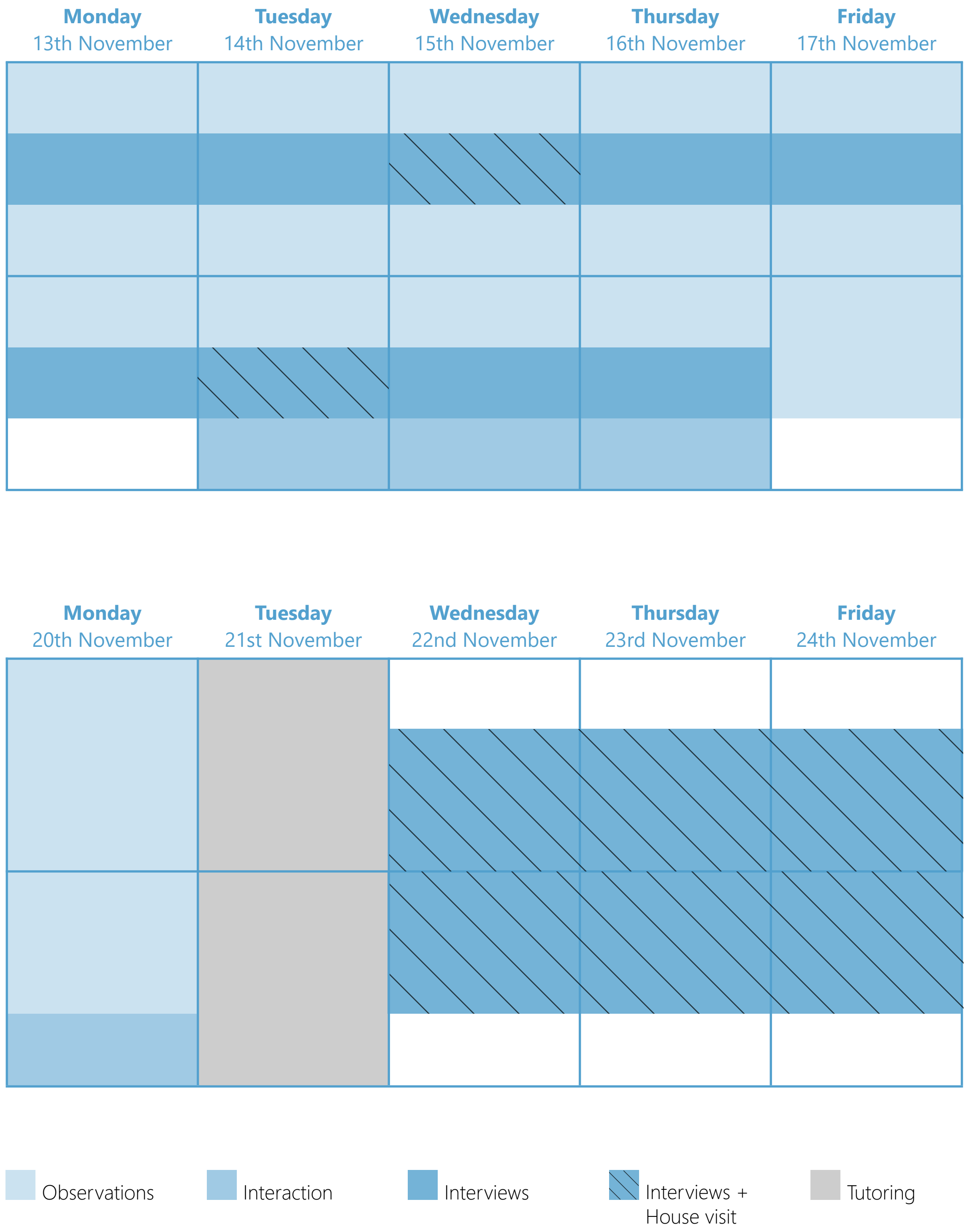

A1 Fieldwork Planning

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.*

A2 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: Social Isolation and 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?
  How did you react to it?

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?
  How did you react to it?

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?