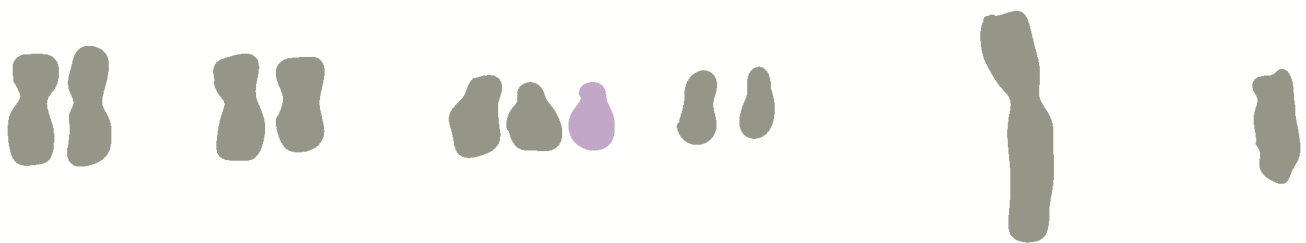
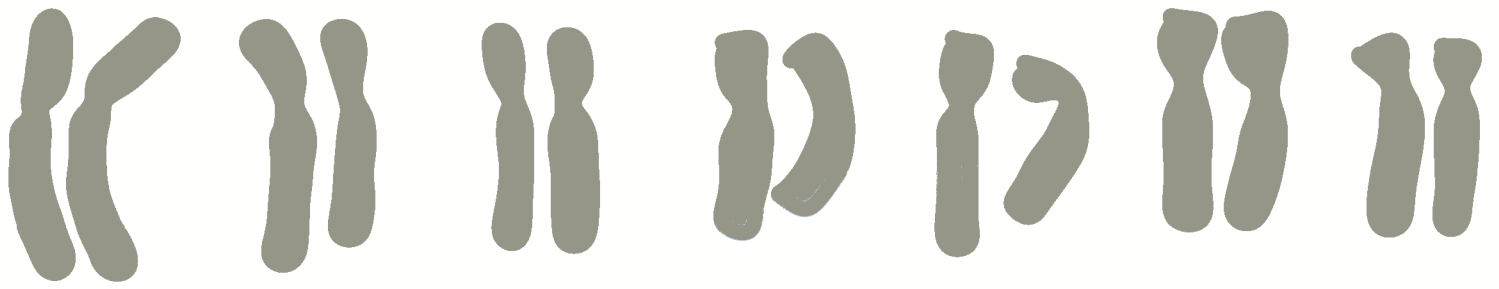




DOWN <sup>TO</sup> GET UP?





## RESEARCH PLAN

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Figure 1, Children with Down Syndrome (De Upside Van Down, E.Snoijink (2011))

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Figure 2, Children with Down Syndrome (De Upside Van Down, E.Snoijink (2011))

# DOWN SYNDROME

[ daʊn sɪndrəʊm ] • ENGLISH

(n.) a medical condition that some people are born with, caused by a fault with one chromosome, which results in learning disabilities.

Figure 3, Meaning Down Syndrome (Own graphic, source; Cambridge University Press, n.d.)

## INTRODUCTION

During high school, I worked in a restaurant where the owner of the place, Hans, had a brother with Down Syndrome. When we spoke about his brother, I noticed how much joy he brought into the family but also the extra energy it took his parents to provide him with the care he needed. Hans told me that, especially when his brother got older, his mother (father had already passed away) experienced much stress due to his future perspective and where he could live when she would pass away. When she passed away, he went to live with one of his sisters because there was no other place for him to go. Once they found a place for him, he only lived there for one year because it was an elderly home and not adjusted to the needs of people with Down. After he moved to a residential house with multiple living groups, he found the right place where he stayed until he died a year ago at the beautiful age of 62.

Years later, I started watching the Belgium show "Down the Road". People with Down Syndrome had to overcome fears and went without their parents on holiday with Dieter Coppens and Saar Pelgrims. During the first episodes of each season, I noticed that all of them lived at home with their parents, and this was their first holiday on their own. This left me wondering how people with Down might have lived so isolated at home, even though they could do much more.

This graduation project is the perfect opportunity to get an inside view into the lives of people with Down Syndrome and see what their needs are.

"I am a man with Down Syndrome,  
and my life is worth living"

- Frank Stephens

Figure 4, Quote Congressional Testimony - Frank Stephens(2017)



## PROBLEM STATEMENT

The world outside and society are disconnected from people with Down Syndrome due to their disability. People with Down Syndrome often are socially isolated, which causes slower personal development and adds extra stress to their families. Besides the disconnection, there is also the fact that people with Down Syndrome are living longer than ever before, which brings new, unexpected challenges for not only the people with Down Syndrome but also their caregivers and families. These challenges can be considered when designing for Down Syndrome, but given the existing literature, most buildings are existing buildings with a new purpose. This makes it difficult to adjust the buildings to the changing needs of people with Down Syndrome, which makes them move to another facility almost every time their care changes.

## GOALS

This research aims to understand better how we, as architects, can contribute to the needs of people with Down Syndrome and how a design can make their lives easier. To better understand their needs, in-depth observation of people with Down Syndrome and their surroundings will provide different design guidelines. These design guidelines will be used to design a lifetime-resilient form of housing for all generations with Down Syndrome.

## SCOPE

The scope of this research will be for young adults with Down Syndrome between 18 and 30. Nevertheless, the study and observation will have a wider variety of ages to notice the different needs of different generations. To make the end design adaptable to not only the target group in the age they are in now but for the rest of their lives.

The observations, interviews and survey will be held in Dutch, so it is accessible to the target group. The literature will be researched from different countries since there is already much research done in, for example, Canada, the USA, the United Kingdom and New Zealand.

## RESEARCH QUESTIONS

The main research question is the following: “Which housing typology is most suitable for the needs of young adults with Down Syndrome, in such a way the design is lifetime-resilient?”

To answer the main question, the research will be split up into five other questions:

1. Which typology of housings are there?
2. How do (young) adults with Down Syndrome perceive architecture?
3. What do (young) adults with Down Syndrome necessity during their lifespan?
4. What is “lifetime-resilient housing”?
5. How can architecture contribute to the connection between the outside world and (young) adults with Down Syndrome?

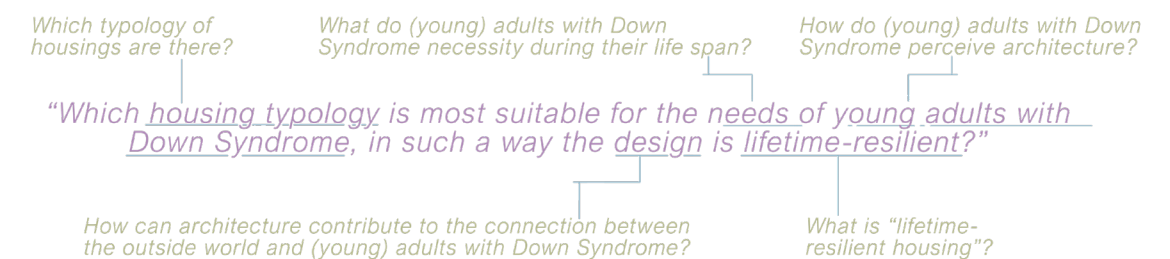


Figure 5, Research question explained (M.M. Hazenbroek, own graphic)

## DESIGN HYPOTHESIS

The stress on young adults with Down Syndrome will decrease when they can stay in an environment for the rest of their life span. This environment must be designed to their needs and liking and will provide care for each generation. This will decrease not only the stress of the person with Down Syndrome but also for the parents. They now have a secure place for their children to go and stay (even when they pass away).

## LITERATURE REVIEW

The theoretical framework describes literature and studies that have already been done on this research topic. The research can be divided into three subcategories connected to the main subject; Down Syndrome.

### DOWN SYNDROME &

Most Down Syndrome studies are about the medical conditions and treatments people with DS need or the different prenatal screening options to prevent having a child with DS. So this only covers the health part. Literature on the care of people with DS is about the pressure it has on caregivers and families instead of the changing needs of people with DS. For the social environment of people with ds, most research is about the social isolation of those who live at home or its effect on the parents. The last subcategory is architecture. A design might help ease the lives of people with DS and could be essential to consider when designing. Only a few studies show the impact interior architecture can have on a person with Down Syndrome, which is a good starting point for this research.

#### Health and care

Down Syndrome is one of the most common chromosomal malformations in Europe. In the last 20 years, a few things shifted for people with DS. The mortality rate in newborns with DS dropped from 7% in 1992 to 4% in 2003 in the Netherlands (Wijerman & Winter, 2010). Also, children with Down Syndrome now have an improved life expectancy, so they get older, which makes the population of people with Down Syndrome grow substantially (National Down Syndrome Society, 2013) (Wijerman & Winter, 2010). Long-term Down Syndrome morbidity brings new challenges, making us rethink the quality of their longer life span.

With ageing, an estimated 30% of adults with DS get Alzheimer's disease, which increases significantly, to over 50%, by their 60s (Lott & Head, 2019) (National Down Syndrome Society, 2013). Besides Alzheimer's disease, sight and heart problems are obstacles most people with DS encounter (Krinsky-McHale, et al., 2013).

Adults with DS get more social independence at an older age, whereas family members start passing away. Research shows that children with DS that had extra support in primary school are more social and capable of copying behaviour. However, most extra learning supports stop after primary school, and so does their personal growth (Wijerman & Winter, 2010).

#### Social Environment

In the Netherlands, half of the people with an intellectual disability live at home with their parents or relatives (Francke, 2007). Lunskey et al. research show that parents of children with intellectual disability have higher stress, anxiety and depression rates. Due to them planning for their child's future and, at the same time, facing their own ageing (Lunskey, Robinson, Blinkhorn, & Ouellette-Kuntz, 2017).

Another research gives a different inside in the social environment of a household with a person with DS. From 4924 households to whom the survey was sent, 2044 responded. 99% reported they love their child with DS, 97% felt pride, and 79% felt that their outlook on life was more positive. Joy, laughter and celebration were frequently used to describe the family experience. Another positive side effect was that most parents felt that their children without DS were more sensitive and caring because of the son/daughter with DS. Nevertheless also this research describes some of the struggles and challenges: "It will exhaust you. It will challenge you. It is the hardest job you will love (Household 1)" (Skotko, Levine, & Goldstein, 2011) (Wijerman M. E., 2011).

Hans van Pullen is the initiator of the concept of Thomashuis. A place where one family takes care of around seven people with Down Syndrome. A concept that already shows the care they give each other and the ease it gives their parents (Didden, 2022).

#### Architecture

Research on designing buildings for specific people with Down Syndrome is rare. Both observations were conducted for designing a building with an educational function. To provide a pleasant and meaningful environmental experience for students with Down Syndrome, it is essential to have a multisensory interior. The interior design has to stimulate their senses for better development (Suraini, Shahir, & Rahmat, 2019) (Febriany, Wardani, & Rizqi, 2018).

An online questionnaire by Suraini, Shahir and Rahmat showed that 89% of the respondents (all related to people with Down Syndrome) agreed that people with Down need a specially designed space. This is due to their lower muscle-built and lousy eyesight. Out of this questionnaire, we can consider that bright colours and organic shapes help support this (Suraini, Shahir, & Rahmat, 2019).

The observation by Febriany, Wardani and Rizqi found four main things regarding the perception of space for people with Down Syndrome. They had difficulty identifying boundaries between spaces when there was no clear division. Secondly, the privacy of a room can be a boundary between spaces. Thirdly their interest in light, windows and objects reflect light. Lastly, using the same material in different places provides peace and helps the adaptation process (Febriany, Wardani, & Rizqi, 2018).

## LITERATURE GAP

The literature gap is evident when looking at the existing literature. The connection between architecture and the social environment for people with Down Syndrome has not been researched in-depth. The longer-life span for people with Down Syndrome brings new challenges, and what those challenges can mean while designing lifetime resilient housing for DS is unclear. A new way of design can provide a peaceful life for adults with DS without worrying about the future.

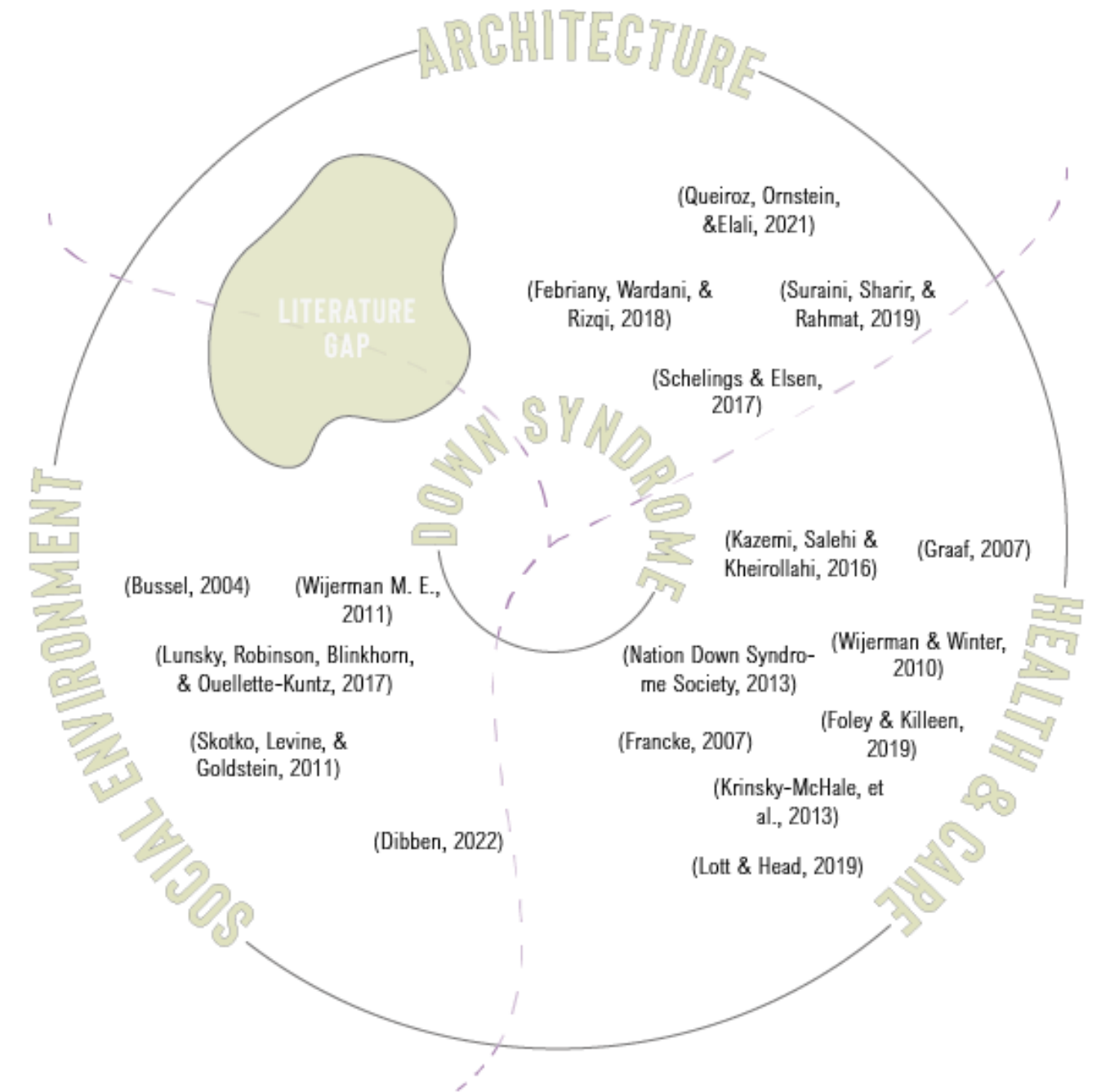


Figure 6, Framework sources (M.M. Hazenbroek, own graphic)

## METHODOLOGY

This research will conduct qualitative research, which helps to understand the theories in the literature better. This research is interesting for discovering the motivating factors behind human behaviour to grasp why people act or think in a particular way.

### LITERATURE REVIEWS

Researching, reading, analysing, evaluating and summarising scientific literature. To better understand the research that has been done in the past. Includes a more comprehensive range of related subjects, broader than needed. This will help during this research to get a better understanding of the possible outcomes for designing for people with Down Syndrome.

### SURVEYS

Surveys are used to conduct a vast amount of real-time data. This research will use two types of surveys; interviews and questionnaires.

#### Interviews

The interviews are in-person to reflect on feelings and experiences and explore issues. The interviews with the target group will be formal to make them feel comfortable. During these interviews, I will use different pictures of, for example, interiors and let the person decide which he prefers.

#### Questionnaires

There will be a few different questionnaires used for this research. The first is for the parents of the target group. The questionnaires will give an overview of the home situation and what parents have encountered during their child's childhood with Down Syndrome.

The second questionnaire will be for enterprises that work with people with Down Syndrome. To see if they considered the needs of people with Down Syndrome and if they made any changes regarding architecture to make it more accessible.

### CASE STUDIES

A few case studies will be conducted for the research. The case studies will give a better overview of the existing built environment for people with Down Syndrome. From these case studies, the pros and cons can be considered for the design guidelines I need to answer the research question. I chose the case studies: Thomashuis Delft Oliemolen, Brownies & Downies, Carefarm the Leemberg and Ipse de Bruggen, Hofje van Pauw.

#### Observations

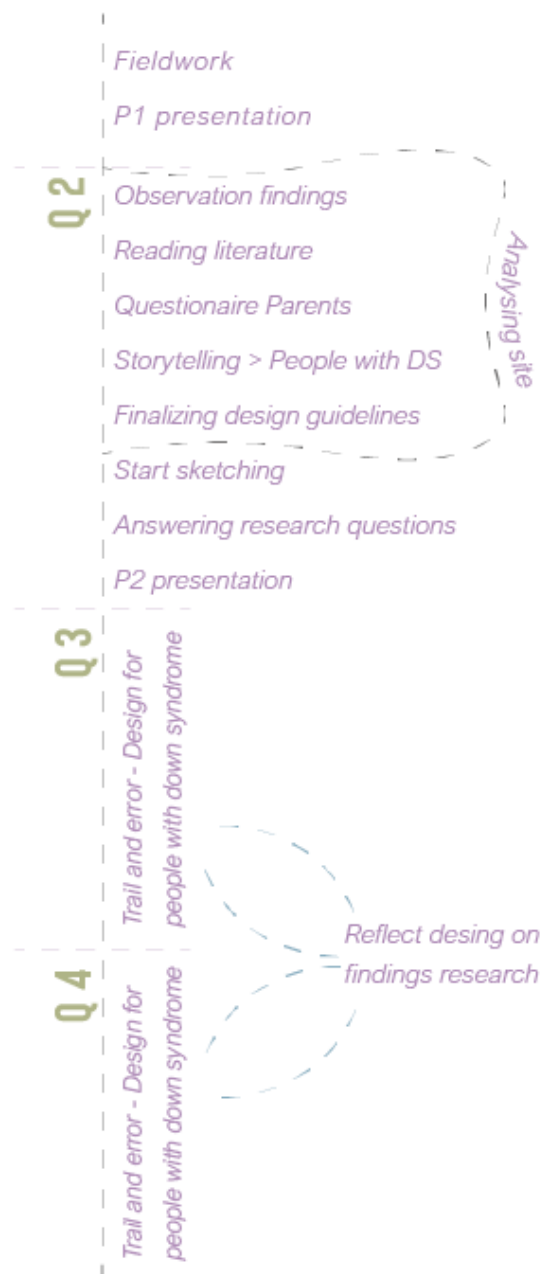
Besides looking into the architectural features of the case studies, there will also be an unstructured observation of the people working/living within the case studies. To obtain objective and naturalistic data by watching the target group during their daily routines. This method will provide natural habits without the participants being forced into doing specific things or answering questions.

#### Storytelling

To protect the target group, all the information directly from people with DS in the observations will be translated into storytelling. This protects the privacy of the person him/herself and still makes the information valid and valuable for the research. Storytelling means that the stories and reactions from the target group will be translated in a dairy style, which explains what they go through.



# PLANNING



## FINAL DESIGN

Figure 7, Planning Q2 (M.M. Hazenbroek, own graphic)

## WORKPLAN

The planning is made from Q2 till the end of the academic year. Q2 will start with analysing all the findings from the fieldwork and the feedback of the P1 presentation. Translating the findings into design guidelines and also into storytelling to get a better understanding of the people with Down Syndrome. The questionnaire will be sent to the parents of people with Down Syndrome after analysing the fieldwork to complement the findings and to get some additional information. Simultaneously with the questionnaire, the assigned site will be analysed.

After approximately six weeks, the research findings will be formed into the “final” design guidelines, which will help to start sketching for the assigned site for the P2 presentation. During the last four weeks, the research questions will be answered, and the main ideas for the design will be formed. The ideas for the design will be further developed in Q3 and Q4.

## FIELDWORK

The fieldwork will be done in different environments to observe and better understand how people with Down Syndrome react to architecture, their needs, and how they feel in different surroundings. Hofje van Pauw and Thomashuis are living facilities for people with intellectual disabilities (some of whom have Down Syndrome). Brownies and DownieS, and De Leemberg are daytime facilities for people with intellectual disabilities. The fieldwork will give a different perspective and help fill the literature gap.

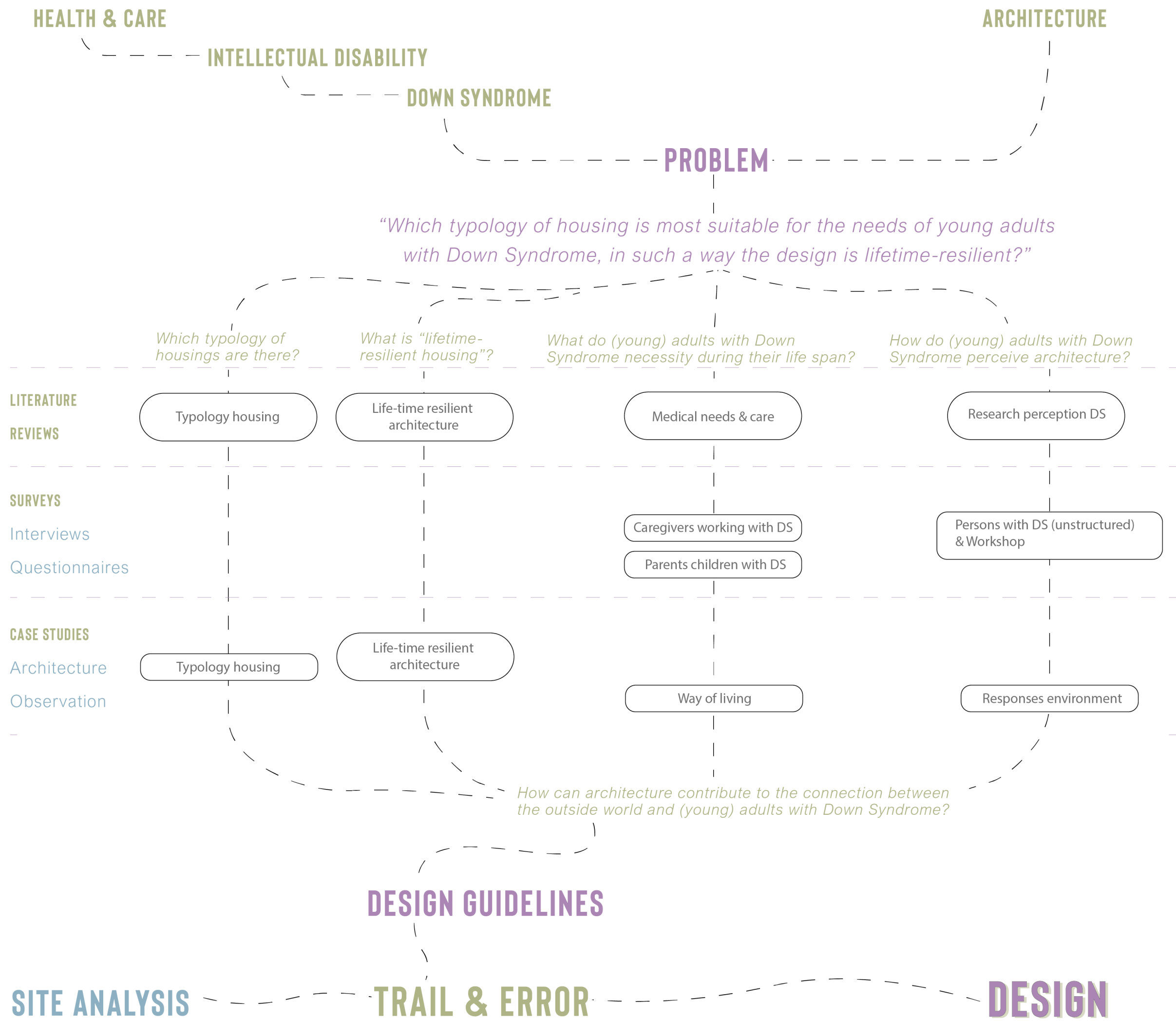
# FIELDWORK

31	Hofje van Pauw - Ipse de Brugge
01	Thomashuis & Brownies en DownieS
02	
03	Thomashuis
04	
07	Zorgboederij de Leemberg
08	Hofje van Pauw - Ipse de Brugge
09	
10	Thomashuis
11	

Figure 8, Fieldwork planning (M.M. Hazenbroek, own graphic)

Figure 9, Workflow diagram  
 (M.M. Hazenbroek, own graphic)

**METHODS**



## DEFINITIONS

*Brownies & Downies*

An enterprise where people with Down Syndrome get to work in a restaurant as a daytime activity.

*Down Syndrome (DS)*

Condition in which a person has an extra chromosome.

*Lifetime resilient housing*

Housing where a person can stay for the rest of their lives without encountering any issues with growing older.

*Thomashuis*

A house where around eight people with an intellectual disability live under the supervision of a household.

*Young Adult*

A person between the age of 18 and 30.

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