

recess for families with chronically ill and/or disabled children

master thesis



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Designing for Health and Care
Towards a Healthy and Inclusive Living Environment
Dwelling Graduation Studio
TU Delft_Faculty of Architecture and the Built Environment
2022-2023

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Table of contents

| | | |
|--------------|---|-----------|
| i. | preface | 7 |
| | a. personal fascination | 7 |
| | b. acknowledgments | 7 |
| ii. | prologue | 8 |
| | a. abstract | 8 |
| | b. keywords and abbreviations | 9 |
| | c. declaration | 9 |
| | d. definitions | 10 |
| I. | introduction | 12 |
| | a. general topic introduction | 13 |
| | b. problem statement | 14 |
| | c. research aim & contribution | 15 |
| | d. research question & methods | 16 |
| | e. hypothesis | 18 |
| | f. research plan | 19 |
| | g. literature review | 20 |
| | h. theoretical framework | 24 |
| II. | the target group | 26 |
| | a. the family | 27 |
| | b. the fieldwork | 29 |
| III. | the past | 36 |
| | a. look back on past solutions | 37 |
| | b. reference project analysis | 40 |
| IV. | the present | 46 |
| | a. spatial needs of CID children | 47 |
| | b. needs and wishes of siblings and parents | 50 |
| | c. requirements for the surrounding | 52 |
| V. | the future | 54 |
| VI. | research results | 58 |
| | a. site criteria and choice of site | 59 |
| | b. design guidelines | 64 |
| VII. | discussion and conclusion | 66 |
| | a. discussion | 67 |
| | b. conclusion | 69 |
| VIII. | appendix | 72 |
| IX. | references | 84 |
| | a. reference list | 84 |
| | b. illustration credits | 87 |

i. preface

a. personal fascination

Stories of seriously ill children have always deeply moved me. Not only did they have to go through so much trouble in their young age, but they often never got to experience a carefree life, because they were born with the condition.

A friend recently told me about her weekly support for a family with a severely disabled girl. According to her, they really struggle to go on vacation for various reasons. To be able to unwind a little, the family needs to bring along someone else, whether it be a paid caregiver or a relative. However, they also need to purchase additional gear, such as a special foldable dining chair or a travel bed that can accommodate a five-year-old. Moreover, they have to cope with the eminent psychological strain. While travelling with such a severely disabled child, they unfortunately attract unwanted attention while staying in a nice environment.

Personally, my strongest and best memories of my childhood were made during the holidays and in child friendly environments, like indoor playgrounds or water parks. This is why I find it so important that every child gets the opportunity to experience those key moments that become core memories, together with their families.

b. acknowledgments

I wish to thank my Tutors Birgit Jürgehake, Lex van Deudekom and Frederique van Andel for their supportive feedbacks throughout the graduation year, as well as for their help in the research and design process. I also want to extend my appreciations to the Tricentenaire for welcoming me at their facility in Walfer, Luxembourg for my fieldwork and Nathalie for the extended interview on the travel situation with a CID child. Last, but not least, I want to thank my family and friends for their outstanding support during the whole year. Especially my brother Ben and my boyfriend Fränk, for the proofreading of this thesis.

ii. prologue

a. abstract

Due to the numerous problems families with chronically ill and/or disabled (CID) children encounter in their daily lives, taking a break from the ongoing care and worries becomes even more important for them than for “typical” families. However, travelling is related to many more complex difficulties since their sick child is usually reliant on very specific equipment. So far, the literature focuses on the consequence of the high care needs on the family system, the development of Dutch holiday parks and the spatial needs for the target group, but the combination of these elements has not been analysed in the architectural context before. Thus, this project’s goal is to provide caregivers with relief by creating an opportunity of real recess from constant care for the child, through architectural solutions and thereby improving their well-being.

This thesis investigates how the architectural environment of a retreat for families with disabled and/or chronically ill (CID) children can provide relaxing time together while supplying a potential benefit for the child.

To determine what a potential recess environment for families with CID children should look like, special attention is paid to the analysis of past architectural solutions, the spatial needs of the target group and on analysing how the architectural environment can provide a benefit for the child and its entourage. To that end, several methods were used. First and foremost, observations were made during a fieldwork at a daycare facility for disabled children in Luxembourg. During this fieldwork, the possibility was given to talk to staff members like therapists and nurses and see several treatment rooms for the children. Furthermore, talking to parents of CID children provided valuable knowledge and insights to their lives. Lastly through the use of surveys additional information for example regarding the well siblings needs were gathered.

The outcome of these investigations shows that several design guidelines can be developed. Those can be classified into different levels of detail, such as guidelines on an urban level, for the neighbourhood’s design and focussing on the interior, and they offer insights into the ideal architectural setting for a recess centre for families with CID children.

b. keywords and abbreviations

recess, retreat, vacation, holiday, trip

regenerate, relax, take a break, rejuvenate

family, parents, children, siblings, relatives [care givers]

quality of life (QoL), well-being

chronically ill and/or disabled (CID), chronic illnesses and/or disabilities

mental and physical health, disease, condition, burden

c. declaration

In this thesis, all survey or interview participants are kept anonymous and untraceable. Therefore, their names have all been changed. This is for the protection of all participants and their families.

d. definitions

Quality of Life

"Quality of Life [is] an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." (WHO, 2012)

Caregiver burden

Caregiver burden defines "the stress and other psychological symptoms experienced by family members and other nonprofessional caregivers in response to looking after individuals with mental or physical disabilities, disorders, or diseases" (APA, n.d.)

Disabled and/or chronically ill child

Childhood chronic illness refers to conditions in pediatric patients that are usually prolonged in duration, do not resolve on their own, and are associated with impairment or disability.¹ (Stanton et al., 2007)

Recess

Recess describes "a suspension of business or procedure often for rest or relaxation" (Merriam Webster, n.d.)

Retreat

A retreat is "a quiet or secluded place in which one can rest and relax" (OED, n.d.)

Shelter

A shelter is "a building where people or animals that have nowhere to live or that are in danger can stay and receive help." (Longman Dictionary, n.d.)

¹ the used formulation can be found on Wikipedia, under the following link. They cite the source of Stanton et al. (2007) to define disabled and/or chronically ill child (https://en.wikipedia.org/wiki/Childhood_chronic_illness, retrieved on 07.10.22)



Figure 1
vacation memories

I. introduction



a. general topic introduction

In recent years, the number of diagnoses of chronic illnesses and disabilities in paediatric care has risen steadily (Jansen & Illy, 2022). Therefore, late research started to focus on the long-term impact on the health related quality of life (QoL) of families with chronically ill and/or disabled (CID) children (Vonneilich et al., 2015).

According to Murray Bowen's Family system theory (1966) families are one emotional unit, where all the members are deeply connected on an emotional level. This connection is fundamentally based on the interdependence of family members. The moment one person within the system starts to malfunction, for example after receiving a diagnosis of a severe condition, the functioning of the whole system collapses and needs to be reorganised (zu Solms, 2022).

How the family unit changes in the wake of such a diagnosis and what can be done to generate positive effects are the questions that need to be answered. The focus of this research report lies on how families with CID children can recess in order to strengthen the connection between the various family members and what this means for the architectural environment of such a setting.

A trip to a generic hotel will most likely fall short of reaching these goals. The families would confront numerous accessibility concerns, and unnecessary complications. Furthermore, caring for disabled or chronically ill children is a full-time job that never ceases. How then can those families have a trip that will genuinely be enjoyable and where all of the family's needs will be met?

In the past, people dealt with the issue by sending their sick children to camps for people with special needs. The documentary Crip Camp (Lebrecht & Newnham, 2020) draws a picture of how grateful and jubilant the children were to spend some time among fellow patients. As several of the participants described later, Camp Janet was a utopia where their handicap didn't matter because there, they were all simply kids (Lebrecht & Newnham, 2020). At the same time, the parents got time to themselves to regenerate and retreat.

However, as mentioned before, the centre point of this problem has broadened. The realisation of how relevant the bond between every member of the family unit is, changes the view on those camps and raises a different question. The focus should therefore lie on how the family unit recesses together.

b. problem statement

Chronic illnesses and disabilities of a child does not only affect the health and well-being of the child, but also of their parents. They are constantly looking after their child and barely ever get a moment to themselves, which in many cases can lead to psychological problems. The caregivers often feel isolated and they suffer from a lack of social contact (Vonneilich et al., 2015). Recent studies have shown that it has several advantages when care is supplied by a third party, allowing the parents to spend time with the siblings, take care of other necessities, or simply take short pauses (Shelton, 2009).

The QoL of CID children is often lower than it could be. Since they hardly ever have peers with similar issues, they can only compare their situation to that of children in good health. They usually only get labelled as disabled or sick in their everyday life and they never just feel like a child. They are burdened by their condition and are unable to enjoy a carefree childhood (Lebrecht & Newnham, 2020). Bringing those children together and creating the opportunity for them to meet others with comparable issues, is therefore crucial for their mental health. This has been verified by analysing CID children that visited therapeutic camps. Allowing those children to participate in activities at their convenience, gave them the feeling of being like every other healthy child (Shelton, 2009).

These problems could simultaneously be addressed in spaces that allow the target group to experience family holidays in an environment that is tailored to their needs. However, the lack of architectural solutions that cater for them and that offer adapted environments, makes staying somewhere away from home unapproachable for most families with CID children.



Figure 2
work life balance

c. research aim & contribution

The overall goal is to give relief by creating an opportunity of real recess and break from ongoing care for the child for parents and caregivers through architectural solutions, resulting in general improvement of their mental and physical well-being.

The true moment of regeneration and retreat coupled with the obtained time to meet and connect with other families and patients will lead to a higher health related QoL for all family members. This research also aims to ameliorate the families social contacts through connecting them with other families that are facing similar troubles. This will contribute to an alleviated well-being of families with CID children.

Long-term and consistent visit of a centre, where this situation would be provided, will result in a more functional family system. Furthermore, the advantageous situation in which all relatives can spend a relaxing holiday together also leads to a strengthening of the bond between the siblings and their parents. The deep connection that often falters due to everyday life with a CID child is thus further stabilised. In more extreme cases, it can even be completely restored.

In addition, the design of the build environment, where we as people live in, influences our well-being and health. The creation of a space tailored to the specific needs of the target group in question and including the necessary programme, will therefore alleviate every family member. Through the introduction of specific design elements, the previously mentioned points can be reinforced which makes it possible to guarantee the providence of relief, improved well-being and social interaction.

d. research question & methods

How can the **architectural environment** of a retreat for **families with disabled and/or chronically ill (CID) children** provide relaxing time together while supplying a potential **benefit for the child**?

Thereof, three sub-questions have been derived. They read as follows and will be investigated through a diverse set of research techniques:

What kind of similar typologies or solutions have there been in the past and what design concepts can be integrated in such a retreat?

It is necessary to determine the drawbacks of and the solutions provided by those typologies. Furthermore, understanding how multiple typologies can be merged together is crucial to develop the desired outcome. This understanding is achieved by reviewing literature and analysing existing reference projects. Additional information on camps for CID children is gathered through documentations.

To conclude, it is important to determine what crucial elements are found in health care typologies, but are missing in vacation/retreat resorts and vice versa. Trying to figure out if and how they can be combined and what each typology is missing on their own leads to the conclusions necessary for determining first design parameters.

What are the specific needs for the different family members and how can they be addressed through design choices?

The visiting families should have all their needs covered. Therefore, infrastructure for every family member needs to be provided. Those needs are mainly addressed through the fieldwork that was carried out at a day care facility for children with special needs, called Tricentenaire in Luxembourg. This made it possible to gather information about the children's spatial requirements and how design may assist in supplying the required spaces and amenities. Furthermore, a semi-structured interview with Nathalie Schimdt, whose daughter Julie is disabled and chronically sick, helped determine what the needs of such a family are while travelling. A survey was carried out, which supplied answers to the posed questions about the needs of the well siblings. Additionally, the review of literature that analyses health care facilities or vacation centres will provide further information.

All of these findings are necessary to create an architectural environment fit to everyone's requirements.

What design concepts would need to be integrated to create relief for CID children?

Attaining a useful design, necessitates understanding about salutogenic design and what fosters a positive environment for CID children and their entourage.

Therefore, literature reviews and case study analyses need to be investigated. Reading about salutogenic or healing designs gives an insight on how architectural spaces can influence people's minds and therefore their mental well-being.

Additionally, the readings and analyses offer an understanding of the surroundings of the buildings which need to be included in a design proposal.

This information will provide the proficiency and design guidelines that are necessary to design a space that will benefit its users both physically and mentally.



Figure 3
methods scheme

e. hypothesis

An architectural environment where families with CID children can go for recess on a regular basis results in a significant increase in the health-related QoL of all family members.

It is valuable to develop a recess centre, where families can take a break from everyday life together without having to neglect the needs of the sick child. If the design is done right, this leads to an overall increase in parents' health, as they feel included and can interact with other families. In addition, the siblings of CID children also benefit from this, since specific design choices and the inclusion of certain program points give them the opportunity to spend some alone time with their parents, while the sick child is being taken care of.

The design itself will also help increasing the well-being of its visitors only through the application of the right guidelines and the integration into nature.



Figure 4
What is it going to look like?

f. research plan

WHY?

Problem:

Chronic illness and/or disability of a child affects the health and wellbeing of the children as well as their parents and caregivers. The families often feel isolated which in many cases leads to caregiver burden, depression or other psychological problems and lowers the health related QoL of all the family members.

Hypothesis:

The possibility to have an architectural setting where families with CID children will go for recess on a regular basis will result in a significant increase in the QoL of all family members as well as their physical and mental health.

Aim:

Create an opportunity of real recess and break from ongoing care for the child for parents, resulting in the general improvement of their mental and physical well-being.

WHAT?

How can the **architectural environment** of a retreat for **families with disabled and/or chronically ill (CID) children** provide relaxing time together while supplying a potential **benefit for the child**?

locating what is already there and determining the lack of potential

What kind of similar typologies or solutions have there been in the past and what design concepts can be integrated in such a retreat?

identifying what the specific needs of every target group are

What are the specific needs of the different family members and how can they be addressed through design choices?

analysing how the built environment can influence a child's wellbeing

What design concepts would need to be integrated to create relief for CID children?

HOW?



THIS!

design tools, parameters and guidelines leading to an **architectural environment proposal**

Figure 5
research plan scheme

g. literature review

Interesting studies that have already been conducted on the subject of this inquiry are described in this literature review.

We can highlight three related streams of studies: impact of caregiver burden, vacation centres and camps throughout history, and the spatial needs of target groups.

impact of caregiver burden

Vonneilich et al (2015) studied the care related effects on parents of CID children. In their research paper, the authors used data analysis to identify a relationship between caring and the parents' health-related QoL. The results of their study show that a lower health related QoL is the direct consequence of a higher care need of the child. The medical sociologists concluded that future interventions need to target the whole family and not just the child in question.

The work by Bluebond-Langner (2000) also highlights the influence of a sick child on the entire family. In her book, Bluebond-Langner draws portraits of nine different families that have a child with high care needs. Therefore, this work helps to understand the load and impact of care on these families, which gives a better insight on the families' internal functioning and what might provide them with alleviation.

In her study, zu Solms (2022) examined the effects of stress on parents of CID children and how this stress can be the reason for depression and anxiety. The research proved that the parent's psychological distress negatively influenced the assessment of individual family functioning. It also showed that the use of social support had a positive influence on the family functioning, which helps us to understand how important it is to create an environment where those people can meet.

The study, which is positioned between two topics, by Shelton (2009) covers the needs and daily hurdles of a family with a CID child, as well as the extent to which camps for children with disabilities bring relief for the family. The author highlights moments of respite for the children during such camps and explains why these moments of relaxation for the parents, are crucial. That is why his work is so valuable for this thesis, as it already combines two of the topics to be dealt with. Nevertheless, the aspect of how an architectural environment or specific design elements allow families to relax together, has not yet been analysed therein.

Vacation centres and camps throughout history

The PhD dissertation by Mieke Dings (2015), provides a complete overview of vacation habits in the Netherlands over time. This research provides necessary knowledge on how Dutch people have spent their free time at holiday parks in the past. Furthermore it contributes to the learning of how the travel

behaviour of the Dutch population changed in the past and it enables us to make a prediction for future needs and what families would look for in an architectural environment providing retreat.

Furthermore, the documentary movie Crip Camp (Lebrecht & Newnham, 2020) will give more insight about the functioning and evolution of these camps and parks. This documentary is told and led by disabled people, who talk about their personal and ground-breaking experiences at Camp Jened, one of the first camps for disabled children that took place from the 1950ies to the 1970ies in the United States of America. The documentary therefore gives insight on the importance of a "normal" vacation for these children but also on how to address the organisation of such a place.

the spatial needs of target groups

Bloom et al.'s paper (2011) analyses if everyone experiences a beneficial effect on their health and well-being while taking a break from work and going on vacation. The authors investigate six factors such as health status or energy level, in employees before, during and after their vacations. Their goal is to learn more about how vacations can enhance health and well-being and what factors affect how someone perceives their vacation. The needs for parents of CID children, who frequently shoulder the double burden of caregiving and working a full-time job, can be related to this paper's discussion of employees. The research conducted by Tyrväinen et al. (2014), investigates the psychological and physiological influence of weekend getaways in a rural or suburban setting. Their results show that even a brief trip to nature can have major benefits on the overall well-being of a person and reduces their perceived stress significantly. This allows us to determine a set of criteria for the chosen site in order for it to be beneficial to its visitors. Moreover it helps to understand how and why these stays away are urgently needed by families with CID children.

Lastly, Borowczyk (2019) describes in his recent work, the required conditions for spaces designed to rehabilitate CID children and how a carefully designed environment can be beneficial for those children. It gives the required input that helps determine design tools and criteria for the architectural response developed in this thesis. It especially provides information about the spatial needs for CID children and how spaces can be designed accessible to the broadest spectrum of disabilities and conditions possible.

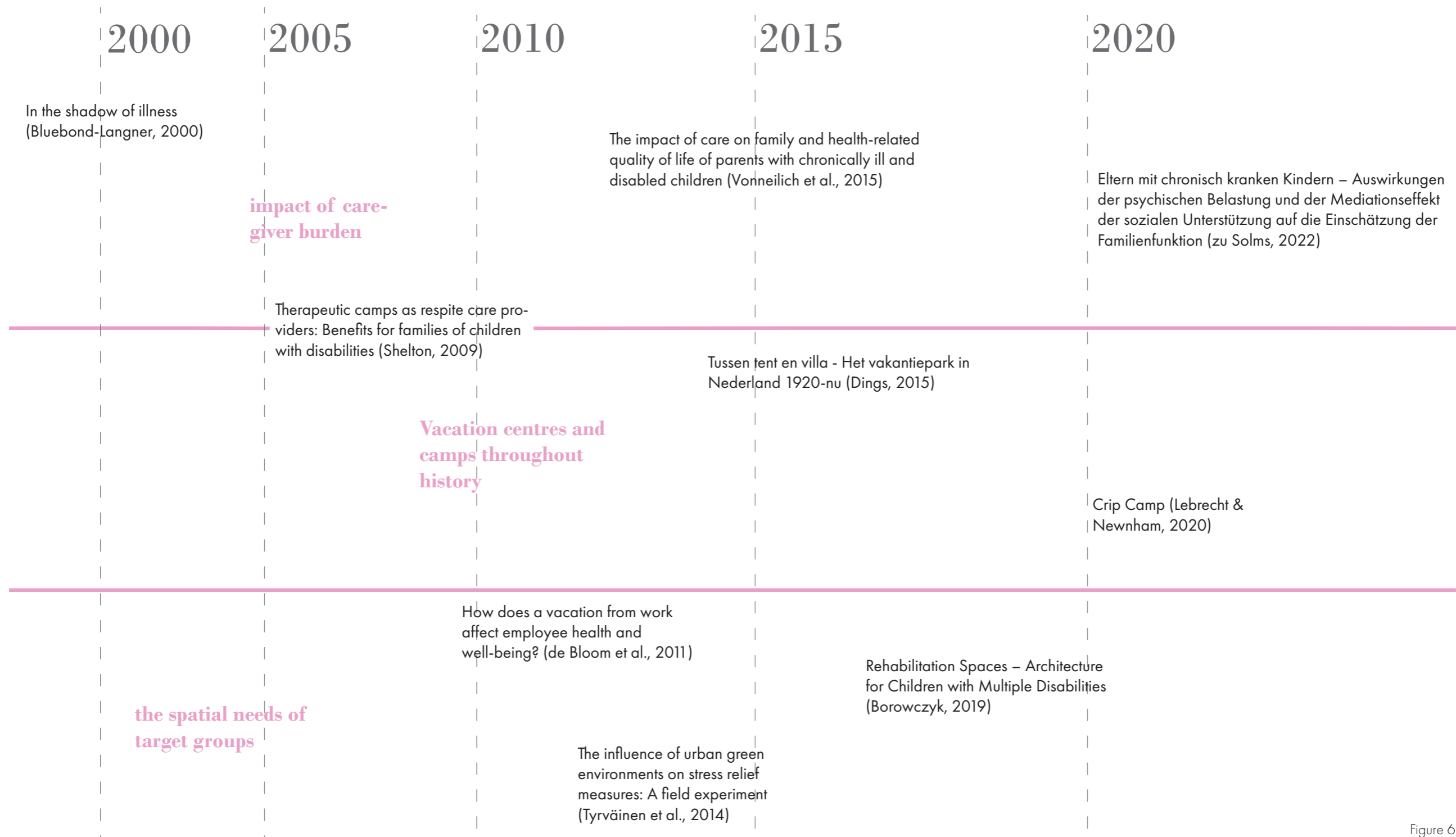


Figure 6
theoretical framework scheme

h. theoretical framework

Several theories are being used to build the framework around this research to determine how the build environment of retreats for families with CID children needs to look like. Those theories are mainly being used, both in research and design, to determine the spatial composition and the qualities of a recess centre for families with CID children. They help to understand the spatial requirements of the target group and they provide the needed boundaries to build the guidelines on.

One of those theories is built upon the importance of **salutogenic design**. The immense effect that the quality of surroundings has on the users of buildings and designed spaces is clarified through this notion (Dilani, 2009). According to Shepley & Pasha (2017,103) salutogenic design can be defined as “the foundation for psycho-socially supportive design, resulting in improved health and well-being. The framework for salutogenic design emphasises an ecological and holistic approach by embracing interconnections between people, events, procedures, and places”.

Until recently most buildings with public functions have been designed with the function and efficiency as a priority. Often these buildings, like hospitals, focus mainly on healing patients and therefore neglect patient’s psychological, social and spiritual needs. Those environments do not include psychosocial supportive design strategies that would stimulate and engage the users, support their sense of coherence and reduce anxieties. Healing processes could even be reinforced and accelerated through the implementation of salutogenesis in the design process (Dilani, 2009). This sense of coherence can for example be guaranteed by elements that can help create a context where people have a proper feeling of orientation like the introduction of landmarks, easy way findings or a well-developed colour palette (Gattupalli, 2022).

This aim, of creating pleasure, creativity, satisfaction and enjoyment through the build environment, is

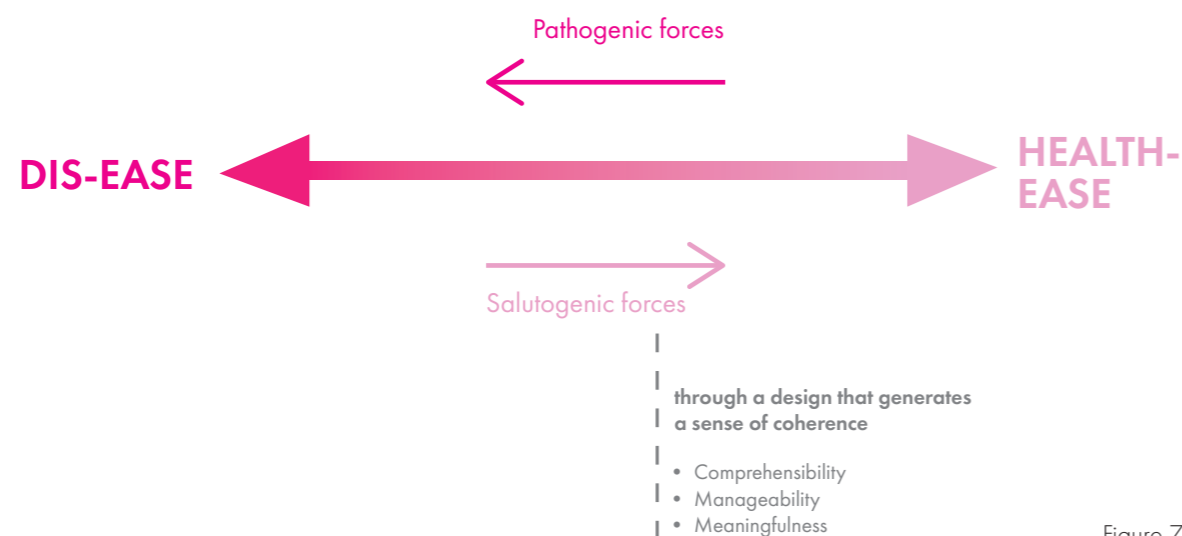


Figure 7
salutogenesis

exactly what this research is trying to reach as well. In the context of designing for CID children and their families those aspects should not be forgotten and therefore this theory is indispensable to this research.

The **seven principles of universal design** that have been developed by North Carolina State University in 1997 also contribute to the framework of this research. Universal design aims to design products and environments that are usable to as many people of all ages and abilities.

Prior to the development of these seven principles, the quality of usability was usually determined by comparing it to other examples that had proven to work well in practice. To determine the seven principles of universal design, the working group evaluated consumer products and architectural environments, through which they determined characteristics of optimal performance and what elements made products usable by the greatest diversity of users possible. With the introduction of these seven principles, design processes can now be easily guided and designers can be educated and trained about characteristics of more usable products and environments (Story et al., 1998).

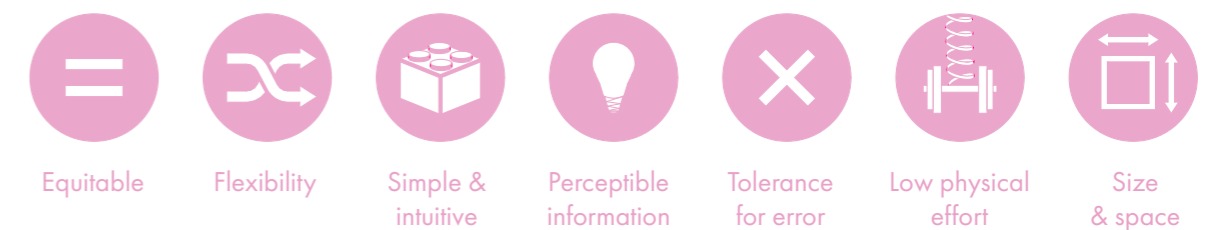


Figure 8
7 principles of universal design

II. the target group



a. the family

In order to understand how limiting a life can be if your child gets diagnosed with a chronic illness or a disability and to emphasise the severeness of the problem, the author felt the need to start this report by introducing the people in question. This will additionally answer first questions such as in what way those families' lives are limited and what the illness of a child means for the physical and mental health state of other family members, in particular the parents.

In 2011, 2-3% of all children in the Netherlands experienced serious limitations in daily functioning due to a chronic health condition. (Wijga & Beckers, 2011).

The degree of limitation in the children's everyday life is as varied as those conditions. Some of the most prevalent diseases, such as asthma, cystic fibrosis, diabetes, epilepsy, cerebral palsy and autism spectrum (Amnie, n.d.) should be mentioned to provide an overview of how the lives of families with CID children are impacted.

Apart from the parent's obvious concerns and fears towards their CID child, the everyday life of these families is branded by multiple difficulties. Part of these struggles are frequent hospitalisation, social isolation, and economic stress to name only a few (Vasconcellos et al., 2022). The seriousness of the circumstances becomes even clearer if the family members have no support from a social entourage. Those parents frequently find themselves in critical situations where both work a full-time job to resist the economic strain, but the ongoing double burden causes psychological stress and health related issues. As zu Solms (2022) claimed, especially mothers who suffer from psychological distress, depression and anxiety, primarily negatively influence the assessment of the family functioning. Therefore, multiple aspects quickly affect the whole family which makes a "regular life" with ordinary habits impossible for them.

As mentioned in the introduction, every member is affected if the proper functioning of the family system is not guaranteed, especially the well siblings. As the research from Bluebond-Langner (2000) shows, well siblings, from a young age on, perceive their parents' struggles and sense the seriousness of their sibling's condition. They struggle with thoughts and feelings that are not easily managed. From young ages on, they spend a lot of time in hospitals, where they are confronted with the severe diagnoses and heavy treatments of their CID sibling, in turn causing them to be worried and concerned. They often are confronted with the possible death of their own sibling due to the life-threatening conditions.

Additionally, they suffer from the lack of time and capacity of their parents to look after them and spend exclusive time with one of their parents. As multiple conversations with affected families showed, even on rare occasions, like family trips to please the well sibling, the situation usually turns out to be the latter's disfavour. For instance, a mother mentioned her last trip to the water park where her well son wanted to go on the water slides with his mother, but she could not leave her disabled daughter behind, nor could she take her to join them on the slide. They ended up staying in the baby pool, where the seven year old son was bored and wanted to go home after twenty minutes.

This shows that not only the sick child's life is very different and branded by their condition but it affects every family member in a different way. Both parents and their well siblings suffer as well under the difficult circumstances and daily activities that are normal for other families are big hurdles for them that they have to overcome again and again. Thus, the challenge lies therein to create adapted architectural settings that help the families to lead a more flexible life.



Figure 9
family with CID child

b. the fieldwork

The author of this research conducted fieldwork at the daycare facility of the Tricentenaire in Luxembourg, to personally get acquainted with the CID children and their support system. During that time, the gathering of answers to several questions, tackling the following main topics was the main focus:

What does the everyday of CID children look like?

What are the most common therapies for children and what spatial requirements do they imply?

How can the architectural environment be adapted to respond to the specific needs of CID children and their families?

How do the children and their families experience holidays and social life activities in general?

To get those answers the children were observed during their stay at the day-care facility and different people that evolve around CID children on a regular basis, were questioned. From therapists, nurses and caregivers to some of the children themselves and their parents, the author tried to get in touch with a variety of different people and experts of the target group. To complete the picture of the CID children and their spatial needs a quick recap of these two weeks and the answers we gathered are worth mentioning here.

The first realisation came quickly. Most of the children at the facility cannot do much on their own. But with only two professionally trained staff members, we were only three adults to look after five to seven children. On the first day, we decided to go out for a walk but only two of the children were able to move alone in their wheelchairs. So one of us ended up having to push two wheelchairs at once. Another day, we only took a part of the group for a walk simply because those children are dependent on another person. This is an issue that cannot be solved architecturally; however it may influence some architectural decisions.

Some further observations that quickly became apparent and were mentioned multiple times by staff members, are that corridors and door openings can never be wide enough if the majority of people using a space are sitting in wheelchairs.

Furthermore, heights and reachability are a big issue as well. For instance, not one of the children was able to grab their own coat from the rack simply because it was installed too high up.

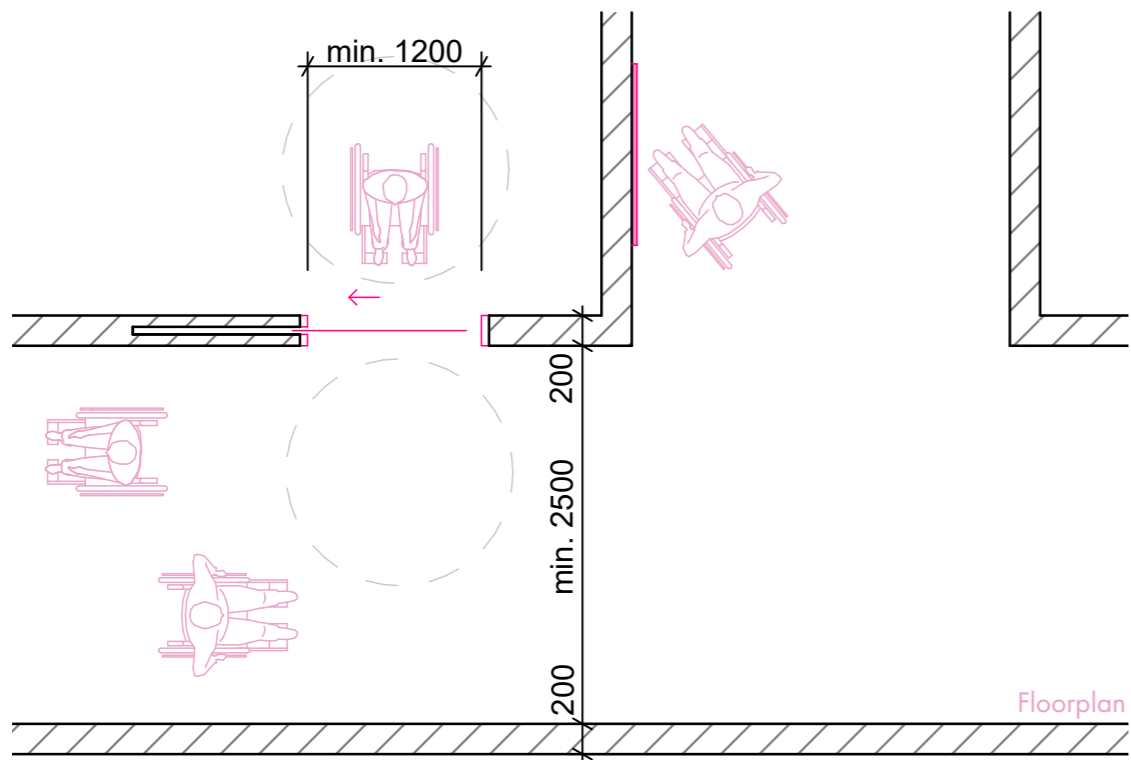
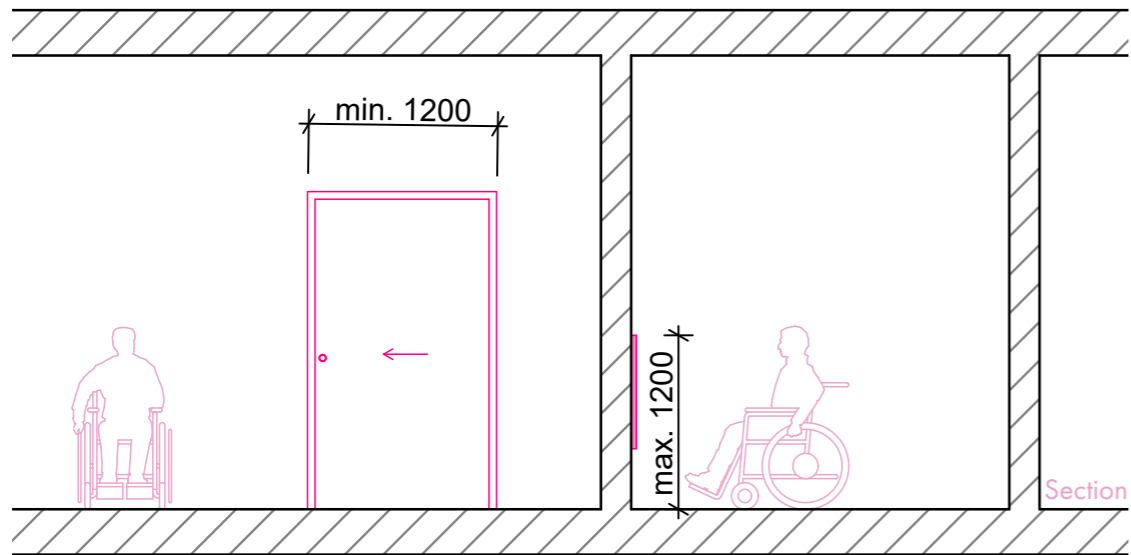
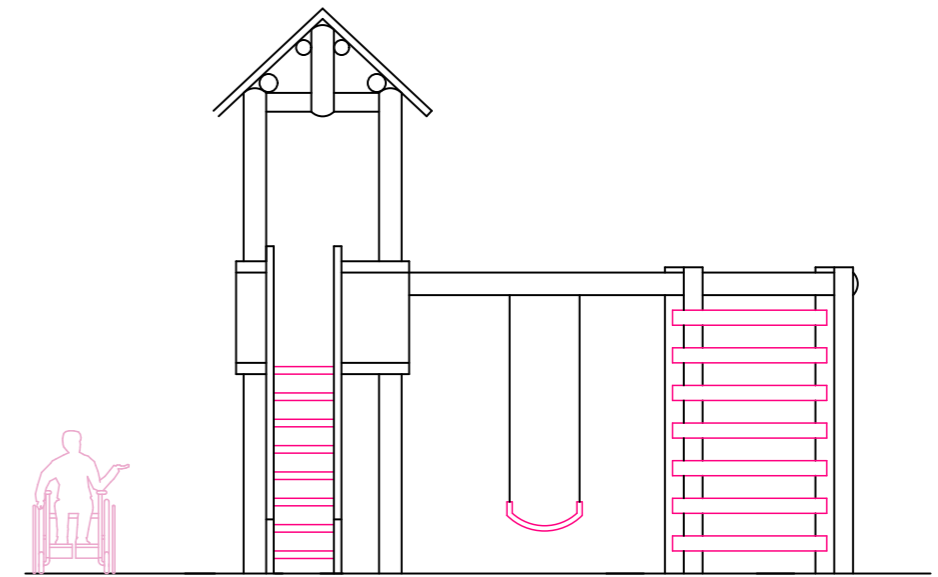
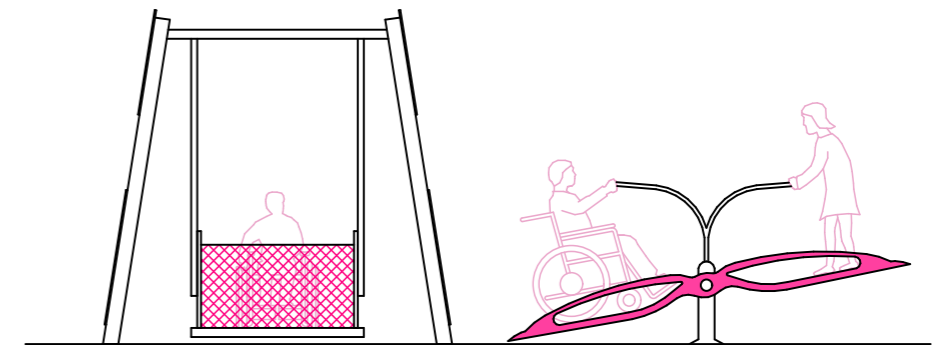


Figure 10
corridor widths and reachable heights



situation as-is



ideal situation

Figure 11
playground situations

The way the kitchen was planned made it impossible for the children to really take part in everyday tasks. The possibility for a walk outside was only a small circular path around the building with no real input for the children. Weirdly, there was a small playground that was not accessible for CID children on the premises. The importance of sensory input came clear after spending some more time at the facility. For most of these children sensory activities are the only ones they can actually participate in. Some really loved to listen to music, others liked to look at turning and colour changing lights. What almost every child loved was baking. During these weeks we baked several times and the children loved listening to the different sounds of mixing and pouring, looking at how the dough changed consistencies, feeling the heat of the oven or the citric smell of the lemon muffins. Also tasting the raw dough was a huge hit.

The Ergotherapist also confirmed how important sensory stimuli are for those children. Furthermore, she gave me some input on spatial qualities and needs for the sake of therapy in facilities where CID children stayed. Next to the obvious therapy rooms equipped with a practitioner's table, a room for intense sensory input for snoezeling, an activity room and a therapy pool would be great additions to such a place. She pointed out how a week of intensive care can be very beneficial for the children and that they regularly have temporary patients at the facility to benefit from such a week. She specified that therapy for children should always be playful and educational so the rooms should probably already reflect this through their design.

After having the first lunch at the facility it became clear how messy and hectic that time of the day can be if one spends it with multiple CID children. First of all, most children need to be fed by an adult with the necessary expertise. They have issues swallowing, that's why every child has to follow their own strict diet and have their food prepared in a different way with varying consistencies. Some children cannot even swallow anything too liquid, so their juice or water had to be thickened with a chemical additive. The need for many napkins and bibs got very clear at this point as well. At least once a day, the caretakers ran out of clean bibs and had to rush to the laundry room to get fresh ones. This made clear how important a well-organised laundry system at such facilities is.

While asking some parents about their participation as a family in everyday social life and how well vacations work for them, the replies were diverse. One of the mothers told me that her actions in dealing with her disabled daughter are usually judged hastily and negatively by the public. Most of them would not be able to estimate the extent of caring for an impaired child, which can quickly lead to unpleasant situations in everyday life. Travelling is also very difficult and she fears that this will be even more difficult in the near future. Since her daughter is still quite small, some things are still rather easy to do, because her husband would still be able to carry her in situations that cannot be overcome with the wheelchair. But she also told me that they need to care for their daughter at all times and that "normal" childcare services, such as those found in hotels, don't dare to take on the task. Therefore, there was never any exclusive time for her relationship with her husband during her holidays.

A Tricentenaire's staff member, whose daughter is also physically impaired, rather only told about the hurdles and obstacles they encounter in many city trips when visiting restaurants, the theatre and cinema. She finds it very unfortunate that most public places are still not accessible enough for wheelchair users. However, she also said that her daughter has now learned to cope with her situation and she knows how to adapt to many circumstances. But it should be the other way around.

Overall, a number of observations were made while conducting this fieldwork that have already shaped and influenced first architectural guidelines for a retreat centre for families with CID children.



Figure 12
sketch of a snoezel room



Figure 13 observations from fieldwork

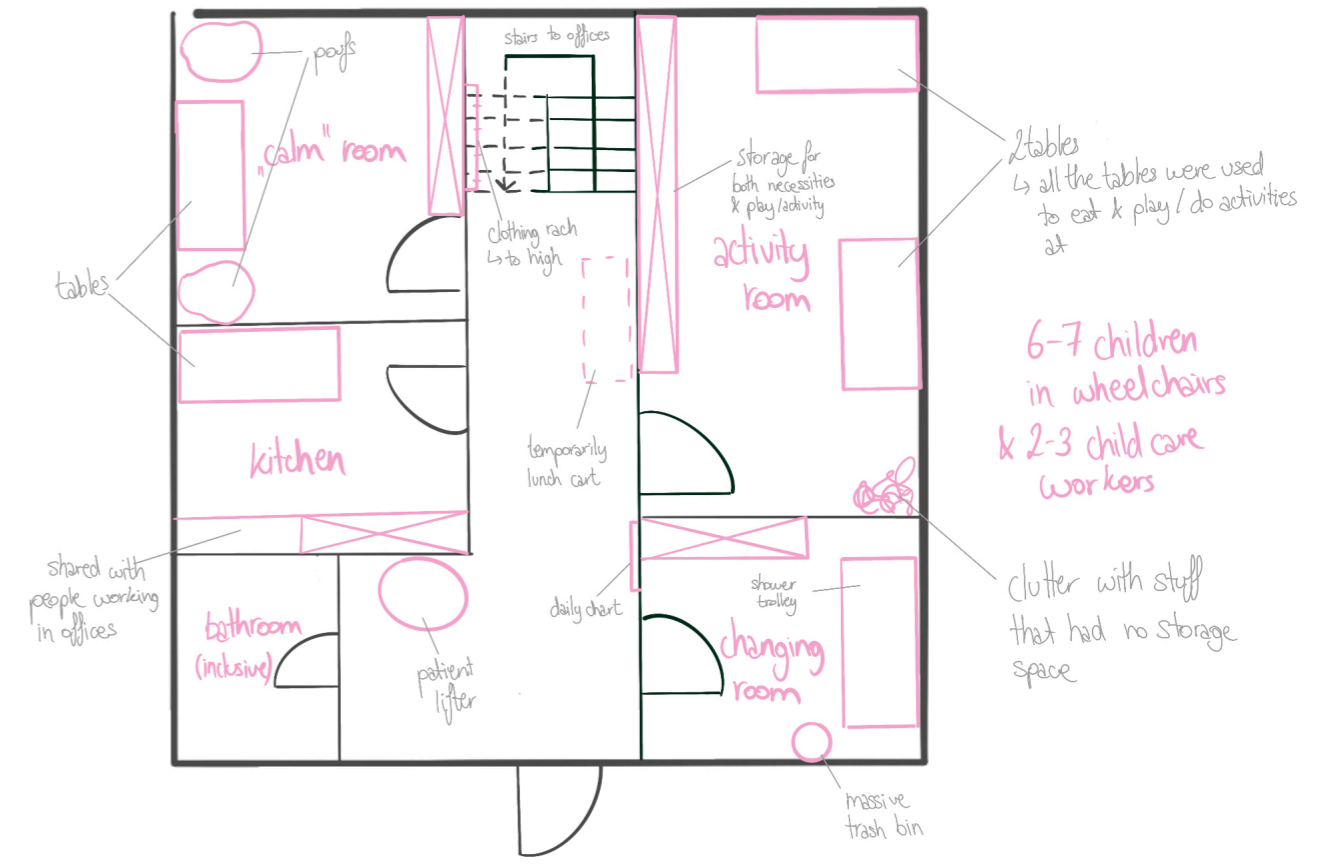


Figure 14 floorplan sketch Tricentenaire

III. the past



a. look back on past solutions

The focus of this chapter lies on answering two questions: what similar typologies there have been in the past and what design concepts could be integrated in a retreat for families with CID children. An analysis on past facilities gives clues on how to create a calming environment and to determine the necessary elements. Up until this point, no facility has been identified that applies all the requirements of such a retreat. Therefore, looking into different solutions that cover at least one of the required aspects is a logical approach.

We start our discussion with a detailed investigation of camps for CID children. While those camps appeared in the 1950ies to 1970ies in the United States of America, the benefits of bringing those children together became clear. The children, growing up in isolation up until that point, described these places as utopias, where they were finally like everyone else and where they got to simply be children (Lebrecht & Newnham, 2020). For the first time in their lives they were not seen as objects of fear or pity. In their teenage years, most of them started first romances here, while they have never experienced this outside of the camp. Back then, this was even more important as it might be today, because handicaps and illnesses were not as accepted and recognised in society (Lebrecht & Newnham, 2020). As Selton's research (2009) shows, those camps have a massive impact on family functioning. Studies have shown that these positive effects have maintained until one month after the end of a stay at a camp.¹ Thus as Shelton (2009) claims in his conclusion, that most of the available services still seem to be unable to meet the families' demands. While sending their CID child on camp, parents usually stay at home and face their everyday life like a "normal" person. So they still do not recess completely and have no real time to relax and have some time off. He also points out the importance of giving those families the sense of integration. By connecting with other families facing a similar situation, they can stop feeling alone.



Figure 15
accomodations at Camp Jened

Figure 16
children at Camp Jened

¹ for this information, Shelton (2009) cites Smith, Gotlieb, Gurwitsch, & Blotcky (1987) which is a work that was not used in the context of this research.

A feeling that arose due to some discussions with parents of CID children and was proven by Shelton (2009) is that the child's safety while being taken care of by a third party is most important to the families. So they are willing to pay a bit more if they can be sure that the capability and professionalism of the staff is guaranteed.

Therefore, it can be said that those camps are undoubtedly the start of a change in how families with CID children spend their free time while rejuvenating, as studies have shown that parents can re-energise and spend time with their well children if care is provided by a third party for a longer period of time. However, they still lack some characteristics, like the ability for the family to join their child and stay away from home together.

This is where carehotels started to pop up. One that was closer analysed as a case study is the Hotel Middelpunt in Middelkerke, Belgium. Their aim is to create a place where families with disabled members can have a carefree holiday, "because everyone is entitled to it" (Dertien 12, 2022). The architects furthermore strived to create an uplifting place by eliminating the visual presence of care. It is important to them to create a space to relax and regenerate which is impossible if the room one is staying in resembles a hospital room. They tried to fit as much functionality as needed into the rooms while still aiming for the most comfortable and appealing look. This care hotel offers 44 rooms that can be booked with a full care package or without, according to the personal preferences of their clients. This makes the Hotel Middelpunt a place where disabled people can spend a holiday on their own or accompanied by their loved ones. One downside is that it is not very attractive to families. The hotel does not offer any activities, treatments or entertainment tailored to the needs of both sick and healthy children. Apart from being close to the sea it also lacks more programs for the rest of the family, for example a place where the parents can retreat and relax undisturbed while the children are cared for.



Figure 17
Hotel Middelpunt

Since it is important to make the families with CID children feel as "normal" as possible and offer them the same possibilities as they would have with healthy children, it is necessary to mention holiday parks, as they are the most popular accommodation for Dutch families during their holidays (Dings 2015).

Mike Dings (2015) researched the evolution of the holiday parks in the Netherlands and tried to determine why they got so popular. They first developed according to the Dutch living environment and proposed a similar scenery, with single family housing with a private terrace, in a more nature-based setting and offering some family oriented amenities. Then the parks evolved, inspired by popular foreign holiday destinations to a spectacular staged exotic experience. Now, next to luxurious themed houses, they offer unique bad weather facilities like indoor play jungles (Dings, 2015). This also shows in the picked cases studies, analysed for the purpose of this research. The Recreational Park Roompot in Zandvoort for example offers next to the staged dune setting different amenities like a kids club, playgrounds, a mini market and a bistro. It even has four extra-large cottages that are designed according to four different themes (2by4-architects, 2020).

This lookback gives a good overview of what different types of environments have been created so far. From the development of vacation parks to the so-called care hotels and the camps for children with special needs, the perfect solution for family retreats could not be found yet. It seems however, that the answer would lie somewhere in between those concepts. Furthermore, this investigation helps to create design guidelines that lead to the best possible outcome of the desired environment, such as the combination of private huts, typical for the vacation parks, with a central building that accommodates a health care program as it can be found in the care hotels.



Figure 18
Recreational Park Roompot



Figure 19
Holidaypark Ridderstee

b. reference projects analysis

As part of the used methods an analysis and comparison of different reference projects has been made. The chosen projects include a variety of different typologies, that were estimated to cover different aspects of the researched subject. This also was a way to evaluate if holiday centres that claim to be inclusive and family friendly, actually are fully accessible for a range of disabilities and the limitations they imply. Next to three vacation parks (Ridderstee, Roompot and Punt West), a care hotel (Middelpunt), a private holiday house and a care facility for disabled people (Balans) were chosen. The combination of the different typologies, give the information that must be gathered to create and determine the desired environment.

In order to be able to compare this diverse range of projects to each other, some criteria needed to be developed first. Based on preliminary findings from the literature review and the fieldwork, the thirteen following criteria points were established:

| | |
|----|--|
| 1 | the presence of private and individual huts or apartments |
| 2 | separated bedrooms for the healthy and sick children |
| 3 | the family friendliness of the place based on presence of playgrounds or child activity offers |
| 4 | a direct access to nature |
| 5 | access to swimmable water |
| 6 | wheelchair accessibility of all amenities |
| 7 | adaptation of private and public bathrooms |
| 8 | presence of treatment rooms or offers |
| 9 | possibility for relaxation for the parents |
| 10 | sensory stimulation offer for CID children |
| 11 | activities in the surrounding of the facility |
| 12 | presence of a restaurant |
| 13 | shared facilities like a laundry room or kitchen where the families can meet |

The Punt West Hotel and Beach Resort is a showcase example of a vacation park that is really integrated in its natural surroundings with the recreation of the historic dune landscapes and the use of natural building materials. However in terms of accessibility and family or child friendliness, it has nothing to offer. The Holidaypark Ridderstee is more adapted to accommodate families. With the offer of a playground, a theatre and a swimming pont, it feels much more pleasant to children. But it is not at all adapted to disabled people. Not only are the bedrooms placed on a second floor, but also the bathrooms are so small that entering with a wheelchair would be impossible.



Figure 20
Punt West Hotel and Beach Resort

The Recreational Park Roompot in Zandvoort is the only one that offers special units that are wheelchair accessible and have inclusive bathrooms. However unfortunately the inclusive design has not been coherently continued to the public areas like the playgrounds, the restaurants and so on.



Figure 21
bathroom at Recreational Park Roompot



Figure 22
floorplan at Recreational Park Roompot

The care hotel Middelpunt offers the complete care package that can additionally be booked by its visitors. Also in terms of space adaptation, it includes everything that is needed to guarantee an easy and comfortable stay. Unfortunately it has less to offer when it comes to family friendliness. The main design focus did lie on the inclusiveness and adaptivity of the space and this does show. While it might be the perfect place to stay for a disabled person in their adulthood, it lacks the most crucial aspects to be attractive to accommodate families and especially their healthy children.

The Holiday Home in Texel, designed by Orange Architects, and the care facility Balans, both gave additional input on program points or space adaptability. However, they would both not individually fit as an architectural environment where families with CID children could stay and spend enjoyable and relaxing holidays.



Figure 23
interior at Hotel Middelpunt



Punt West Hotel & Beach Resort

- 72 villa's & 20 suites
- max. of 2 storeys
- cluster arrangement with central beachclub

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ✓ | ✓ | ✗ | ✓ | ~ | ✗ | ✗ | ✗ | ✓ | ✗ | ✓ | ✓ | ✗ |
|---|---|---|---|---|---|---|---|---|---|---|---|---|

Holidaypark Ridderstee

- 104 holiday homes
- max. of 2 storeys
- organic, scattered arrangement

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ✓ | ✓ | ✓ | ✗ | ✓ | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ~ | ✗ |
|---|---|---|---|---|---|---|---|---|---|---|---|---|

Recreational Park Roompot

- 100 cottages
- max. of 2 storeys
- organic, scattered arrangement

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ✓ | ✗ | ✓ | ✗ | ~ | ~ | ~ | ✗ | ✗ | ✗ | ✓ | ✓ | ✓ |
|---|---|---|---|---|---|---|---|---|---|---|---|---|

Hotel Middelpunt

- 44 rooms
- max. of 3 storeys
- 1 building with inner courtyard

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ✗ | ✓ | ✗ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ | ✗ | ✗ | ✓ | ✗ |
|---|---|---|---|---|---|---|---|---|---|---|---|---|

Holiday Home

- 1 house
- 2 storeys
- building in grid organised neighbourhood

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ✓ | ✗ | ✗ | ✓ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ |
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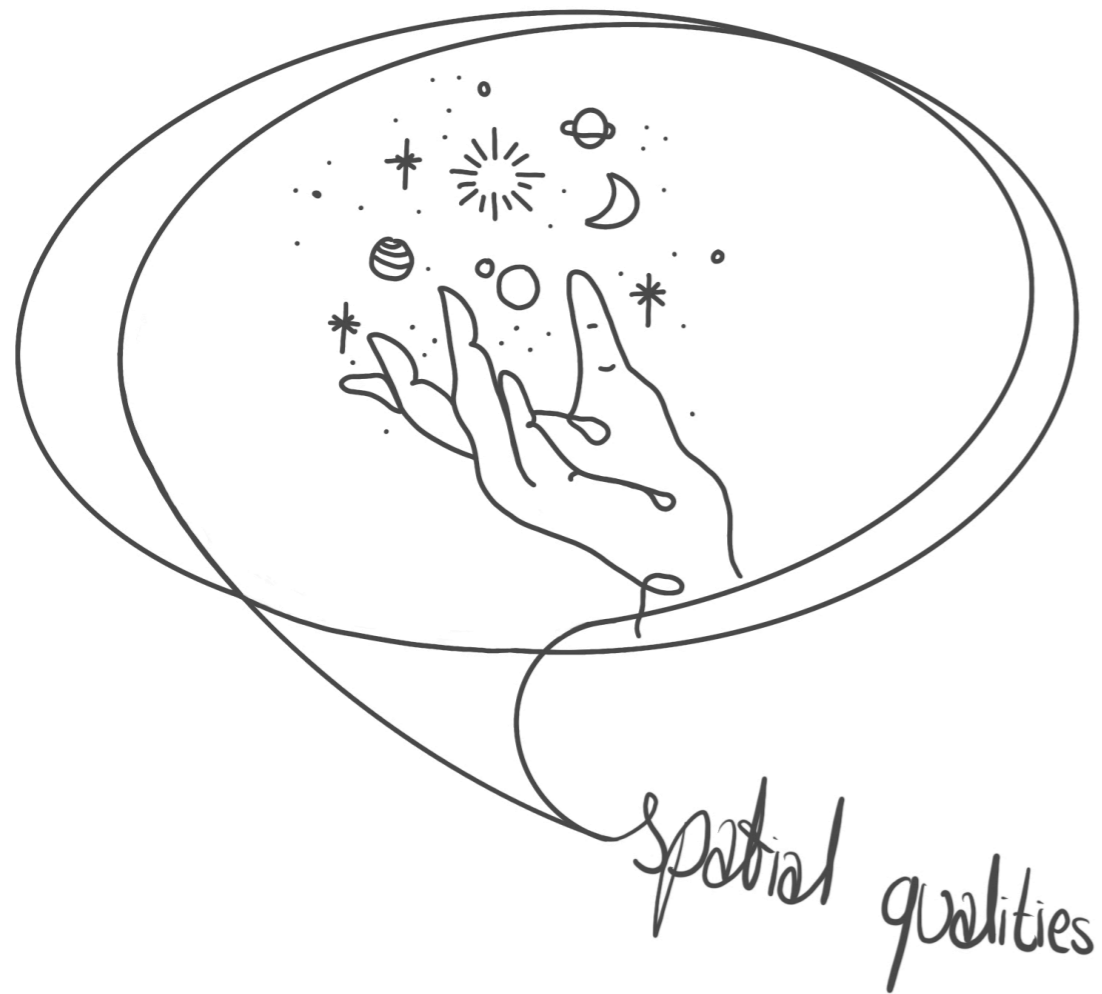
Balans Residential Group

- 7 rooms
- max. 2 storeys
- 1 building with inner

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ✓ | ✗ | ✗ | ✗ | ✗ | ✓ | ✓ |
|---|---|---|---|---|---|---|---|---|---|---|---|---|

Figure 24
reference projects check list

IV. the present



Another main objective of this research is to answer the questions about defining the specific needs for the different family members and to determine how they can be addressed through design choices. To do this, different factors need to be considered. First - what might be the most obvious one - is the question about accessibility and treatment needs of the sick visitors and how they affect and shape the architectural environment. The needs and wishes of the healthy siblings and the parents also need to be addressed and analysed. Included in this will be the analysis of how and when people start to relax and recess and how this can be accomplished through architectural design. Finally, we should look at requirements for the surroundings of such a centre and how different settings influence their residents.

a. Spatial needs for CID children

Designing for people with disabilities has been extensively studied in the past. For instance in 1997, the North Carolina State University developed the seven principles of universal design (Story et al., 1998)¹. However, designing for CID children has not been studied as considerably, although it is even more specific. Defining clear rules or guidelines for their architectural environment is a task of high complexity, since children with multiple disabilities show a very diverse and broad variety of symptoms that lead to loss or limitations of particular functions or skills. This even has an impact on their psychological well-being or their social skills (Borowczyk, 2019). So, guidelines like the seven principles can definitely be used in the context for children, but they need to be supplemented by additional factors.

Principle 1: Equitable Use.

The design is useful and marketable to people with diverse abilities.

Principle 2: Flexibility in Use.

The design accommodates a wide range of individual preferences and abilities.

Principle 3: Simple and Intuitive Use.

Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills or current concentration level.

Principle 4: Perceptible Information.

The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

Principle 5: Tolerance for Error.

The design minimises hazards and the adverse consequences of accidental or unintended actions.

Principle 6: Low Physical Effort.

The design can be used efficiently and comfortably and with a minimum of fatigue.

Principle 7: Size and Space for Approach and Use.

Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture or mobility.

(Story et al., 1998)

¹ the original source leading to an unexistent website, therefore the work by Story et al. form 1998 used as a source, since a lot of the original authors worked on this as well and they cited the original work of the seven principles form 1997.

A key element for a successful design where CID children can move around independently are simple methods of clear navigation within the building and its surroundings. The use of colour contrasts and tactile tiles as well as the elimination of elements which complicate the space in an unjustified way, are some design choices that need to be taken into consideration to make sure this is guaranteed (Borowczyk, 2019). More obvious choices are to eliminate steps and replace them with mild ramps and slopes or install sliding automatic doors with a wide opening instead of manual hinged doors. Moreover, because such a space will be used by multiple people in wheelchairs, even wider corridors and passageways need to be considered in order to have two wheelchairs pass each other without collision (Borowczyk, 2019). Also, reachability can pose a big problem to CID children. At this point the experience and observations collected during the fieldwork will give some examples of bad design decisions. For example, the coat racks were hung too high, which made it impossible for the children to get their own coats. Furthermore, the countertops in the kitchen were installed at a regular height and all had cabinets underneath, which makes it impossible to even wash hands there, let alone assist at the meal preparations. Also some children could not reach the magnetic board, which they use to create the morning board and where they put information like which caretaker is working on that day, the weather, and the childrens' individual schedules. Moreover, the children could not open or close the blinds according to their needs, since they were manual blinds. Also the problem of narrow hallway and door openings mentioned by Borowczyk (2019) could easily be experienced here. The caretakers often first had to move around one or two other children in their wheelchair when they had to go to the toilet with a third child.

Some of the holiday park case studies, that claimed to be both family friendly and inclusive, usually had at least one playground, but it was not accessible to disabled children. The same was sadly also the case at the daycare facility where the fieldwork was conducted. In general, the offer of outdoor activities in which those children can take part of was quite narrow for both fieldwork and the analysed holiday parks. Apart from walking around the circular path, which even had considerable slopes up and down and that led around the building of the Tricentenaire, there was not much to do. However, there must be a way that the several important sensorial activities that are offered inside could be translated to outdoor activities as well or that playgrounds in all their extent could be made accessible. This aspect needs to be considered and developed through designing the surrounding of the retreat centre.

What is shown by the case studies and was also mentioned multiple times during the fieldwork is the presence of vast bathrooms. Not only does the shower need to be big enough to be accessed with a shower trolley but also the area around the toilet needs to be big enough to be reached with the patient lifter. The presence of large bins is indispensable, because some children need to wear diapers at all times so the amount of waste in the bathroom is bigger than it would be under different circumstances. Another aspect that was mentioned during the interview, is that some children might be screaming or crying a lot. A positive experience that Nathalie had with her daughter was the stay at a hotel with

soundproof walls. That way both her and the other visitors at the hotel could stay more relaxed, because no one complained, which apparently happens a lot if sound proofing is not present or simply insufficient. Nathalie also pointed out that she usually checks if a bathtub is present since bathing Julie is easier than taking her for a shower.



Figure 25
patient lifter



Figure 26
shower trolley in inclusive bathroom

b. needs and wishes of siblings and parents

Designing a place to spend the holidays for the surroundings of a sick child is not equal to designing for a “regular” family. However, some aspects can be translated one to one from principles and guidelines used for designing holiday parks or hotels for families. As the analysed case studies showed, the proximity and the addition of activities like water sports, kids clubs and even a cinema or theatre are in trend while designing a holiday park for families. A playground is usually to be found on the premises of the hotel. This wide range of program points allow the parents to make the holidays as varied as possible for their children. But what are the indispensable spatial conditions that are necessary to create unforgettable childhood memories of their vacations? A micro survey of 20-35 year old volunteers, showed that their most vivid memories are either tied to some specific playground, being in or outdoors or in pools and water parks. Some participants mentioned waterslides or meeting other children while playing at the beach or being in a kids club.

And this is also what the author of this paper feels like. The best personal memories have been made in hotel’s play areas or pools and themed water parks. One very vivid personal memory is strolling around in an Alice in Wonderland themed maze that was made of hedges. Hours and hours were spent outside trying to get out of that maze and everyday we got lost in a different part of the maze. Therefore outdoor activities, indoor playgrounds and a pool or sea to swim in seem indispensable while trying to design a place where the children can make key memories.

As the interview with Nathalie showed, the moments that are really relaxing and that she is seeking for during holidays are the ones where she can just quietly sit down and read a book or go to the beach. She did not mention any specific spatial requirements. The only requirements that she stated are that she wanted both of her children to be taken care of and to be reassured that they are safe. Therefore it might be sufficient to create a calm and cosy space both in and outdoors, where the parents can withdraw. Maybe adding some coffee and vending machines or installing a library to borrow books and magazines form, might add additional attraction to the space.

Rancic et al. (2013) However mentioned the growing importance of a well planned wellness facility of high quality in hotels. More and more people are adding saunas and hot tubs to their criteria list while planning their vacations. However we need to consider if this is the case for everyone and if this also applies to the target group in question. Thus it might definitely be worth considering and having a closer look at.

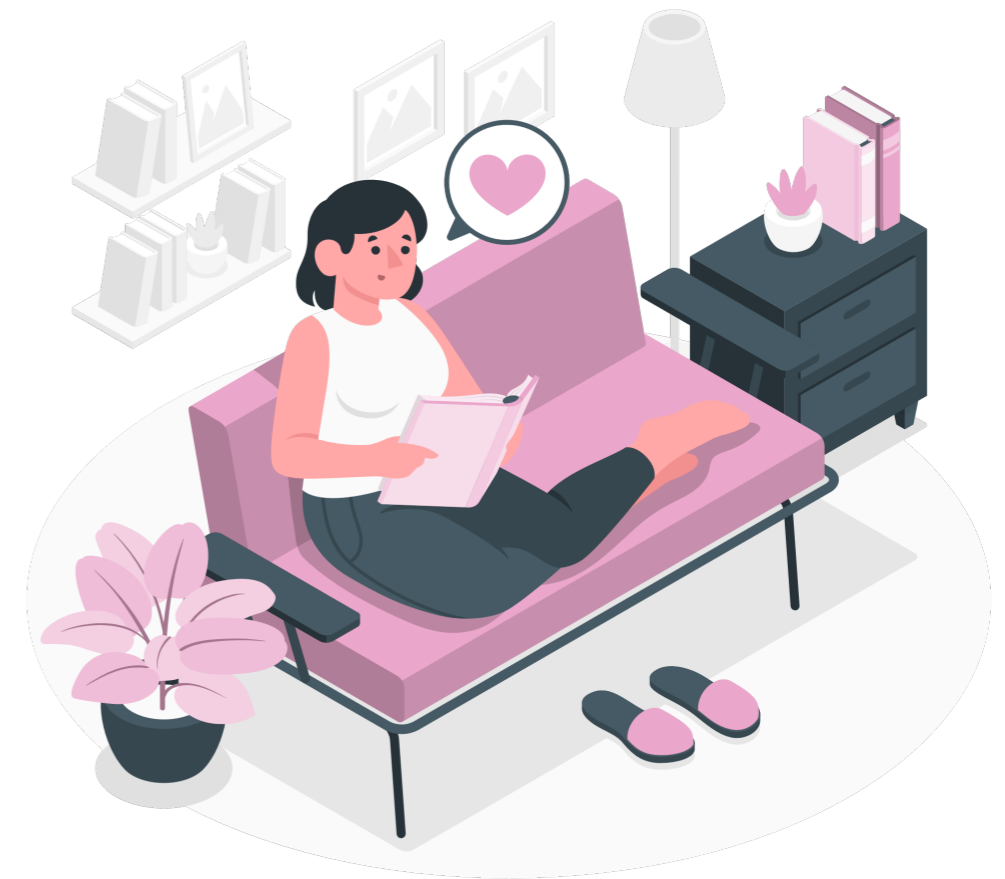


Figure 27
mother reading

c. requirements for the surrounding

As Dings (2015) pointed out in her research about the history of holiday parks, the surrounding of such a place is a crucial point, since their development is tightly connected to it. Therefore, it is important to carefully think about criteria that should be met by the chosen location.

Research has shown that green spaces help to reduce and they help to enhance psychological recovery. Some research investigating whether nature might be able to cure stress-related diseases such as depression has even been conducted in the past. As mentioned earlier, especially the parents who are mostly the caregivers to their CID children are exposed to an immense amount of stress and burden (Tyrväinen et al., 2014). Therefore, a location in a stress reducing setting like nature is even more important for them than for any other person. Tyrväinen et al. (2014) show that even a short stay in a natural setting is more restorative than an equally long stay in an urban setting would be. This fact makes the presence of green surroundings even more indispensable, as the planned retreat centre should also be possibly used for short week-end getaways. Furthermore, the analysis of the case studies showed - and got backed up by Dings (2015) - that holiday resorts often pop up in more natural surroundings rather than in an urban context.

The proximity to water has shown to be of a big advantage. Not only could the water be used for bathing and fun activities like water sports, but water therapy is also a very common therapy when it comes to CID children, as the Ergotherapist explained during the fieldwork. Most children feel a lot more free while they are floating in water compared to while they sit in a wheelchair. As sensory input is so important for disabled children, the addition of an accessible water source would be super beneficial to them.

The natural setting would also allow for the installation of a little barn with some animals. As the Ergotherapist stated a donkey or a horse could be used for sensorial or contact/social therapy. Since the conducted survey showed that outdoor activities are well beloved, this barn could be home to a variety of typical farm animals. In addition, it would double as a fun activity for all children at the retreat centre. The children could pet the animals or in little workshops learn how to feed them and care for them.

Therefore, the perfect location for a retreat for families with CID children would be in a rural surrounding with connection to and views of beautiful landscapes and the proximity to accessible water in the form of a lake or the sea.

V. the future



possible benefits of a retreat centre

Given that simply going on vacation has a favourable impact on most people's health and well-being (de Bloom et al., 2011), the question arose as to whether such a stay away from home could even further benefit the CID children due to the architectural design of the space and/or the amenities offered by the retreat centre. While talking about architecture that can have a positive effect on someone's health or well-being, we can rely on the theory of salutogenic design. To ensure the development of this approach in a design proposal, it is important to first determine the essential components of salutogenic design and how they can be incorporated into a retreat centre for families with children with impairments or chronic diseases.

A key element to salutogenic design is to include the sense of coherence to the architectural environment. This sense of coherence is a scale that determines how people view life and a tool for them to maintain their health through optimization and control (Gattupalli, 2022).

From the notion of coherence, the psycho-socially supportive design was derived by Dilani (2009). In this paper, the author mentions the positive health outcome of the presence of several elements like windows in a room. Not only does a window allow for natural lighting, but also for fresh air and views of nature. Especially, if the lighting conditions can then be individually controlled by the person using the space, a positive effect on his attitude can be recognised.

The introduction of "wellness factors" that eliminate anxiety in the user through the physical design of a space are another way to design a beneficial and safe environment. A way to accomplish this feeling of "wellness" is by designing the surroundings in an ordered, structured and clear way with accentuated intuitive paths and way findings. Other additional elements to create this ideal interior are elements of the internal environment such as smell, proportion and rhythm, together with sound, texture and materials. It has been proven that they can offer powerful healing and therapeutic benefits to varied patient groups (Mazuch, 2017).

Mazuch (2017) furthermore states that the healthy living environment for people with ever-changing needs in healthcare, should be designed in an innovative, elegant, supportive and exciting way rather than in a visually debilitating, degrading and stigmatising way. In other words, he states that the typical healthcare and hospital look of a living environment is not promoting benefits and well-being in its users. In order to create an uplifting interior, the hospital beds, slow moving stairlifts and cold, metallic handrails need to disappear.

In order to supply development for a CID child, the creation of a safe and inspiring environment is required, since the conditions decide on the effectiveness of the child's improvement (Borowczyk, 2019). A place where the children and their families stay to spend their holidays should therefore strive to create this ideal and safe environment while translating the previously stated themes.

The children's independence should always be considered while designing, so that the sense of coherence is created as well as the wellness factors can be applied. This means, for instance, that the previously mentioned reachability of appliances like coat racks or switches for lights and blinds should be guaranteed. Furthermore, clear wayfinding through the use of easy symbols or a system of letters and numbers should be used on directional signs. This way even small children that cannot read yet will be able to move around by themselves which gives them the feeling of self-control in the safeness. If every child is given the opportunity to do certain things by themselves and carry out their own initiatives, their confidence is being supported, which can directly impact their health and well-being (Gattupalli, 2022) As the connection to nature is so crucial for a salutogenic design, it can be suggested that the design of the interior of the retreat centre might even try to reflect the nature on the inside through the use of natural materials and colours as well as the use of many big windows allowing for stunning views.

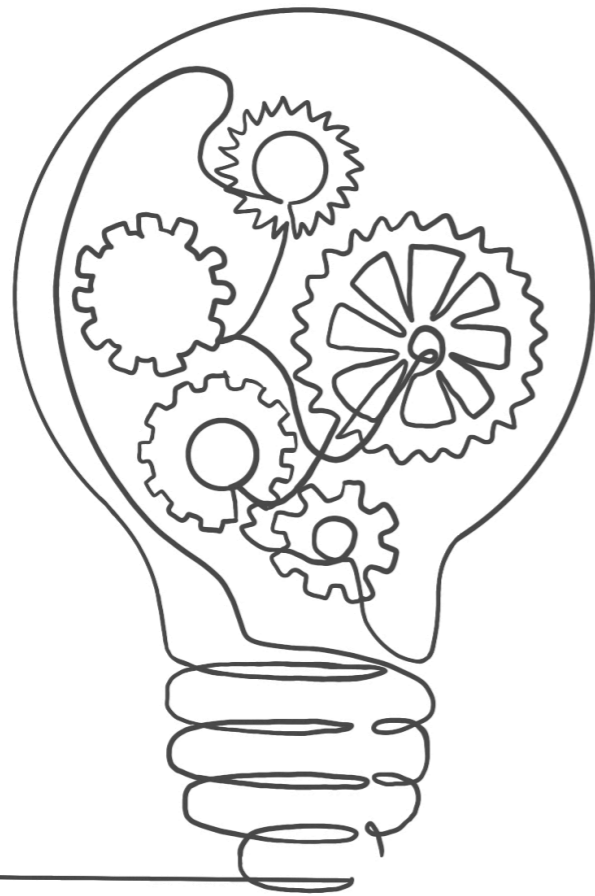
To ensure the creation of a sensitive design, the interior should be designed in an aesthetically pleasing way while avoiding a typical hospital look. This calls for a redesign of certain appliances or furniture, like special beds for the CID children with adjustable bedrails, that still look as close to a normal bed as possible.

A stay at a retreat centre can therefore definitely also have beneficial effects on CID children and their entourage, if the guidelines and framework of a salutogenic design are applied to its design. Not only will these aspects potentially increase the well-being of the children, but they will also help reduce the stress level of the parents and caregivers. Additionally, this might even have a positive effect on the people who will be working at the retreat, since they will also be exposed to its design.



Figure 28
nature integration in architecture

VI. research results



a. site criteria & choice of site

Several criteria that had to be provided by the site, can now be developed through the outcome of this research. As a summary we can state that both the analysis on former developed holiday parks as well as the analysis of the target groups' needs, proved the importance of nature's presence. The desire to make the recess centre extend those basic needs and provide deeper benefits makes the presence of the green environment indispensable. The views that a centre in such a setting will provide have an instant relaxing impact on everyone - from staff to clients. The proximity to water should also be guaranteed. Not only would this provide multiple activity offers, like canoeing or other water sports, but it could also be used for the CID children's therapies. Furthermore, the chosen site should be able to create privacy for the living units, while supporting the inclusion of all the families in the more public areas. The transition from public to private should therefore be easily adaptable to the site. Lastly since most CID children have mobility issues and are therefore sometimes dependent on a wheelchair, the chosen location should be mostly flat.

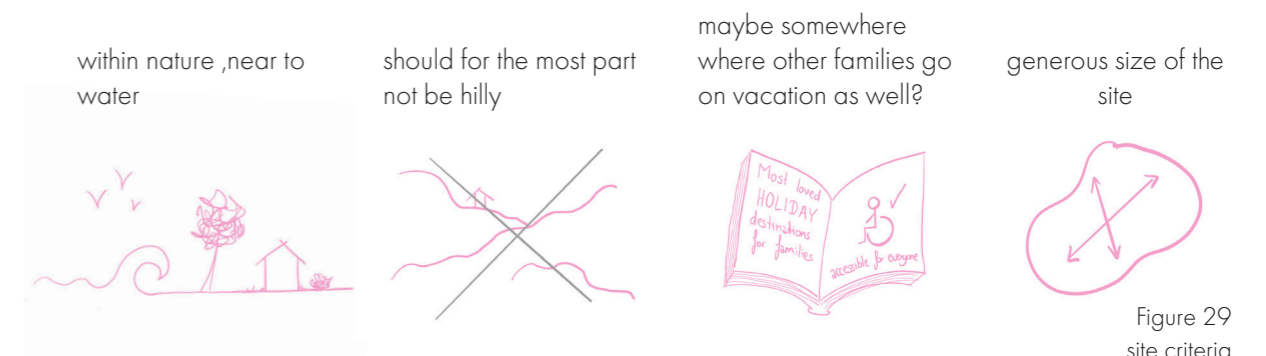


Figure 29 site criteria

From the three provided locations, Laakkwartier in the Hague, Driebergen and Warande in Lelystad, the latter is the best fit according to the previous conditions. But while exploring and analysing the location, it is clear that the nature park adjacent to Warande would be an even better fit. After closer examination, the perfect place in the middle of the forest and directly adjacent to the shore was found. The future development plans for this area include many attractions in the vicinity. Even now, there are already some offers in the immediate vicinity, such as canoeing, hiking trails and a beach with beach volleyball, which can be used by the healthy siblings or the parents. Another plus point is the presence of the campsite right next door. This can help to give the families a sense of integration, as they can spend their holidays in the same place as others do.

As the site is big enough to also allow adding additional activity offers both in- and outside, this site, in the middle of nature and greenery, seems to be the perfect fit for a recess centre for CID children and their families.



Figure 30
impressions of the site

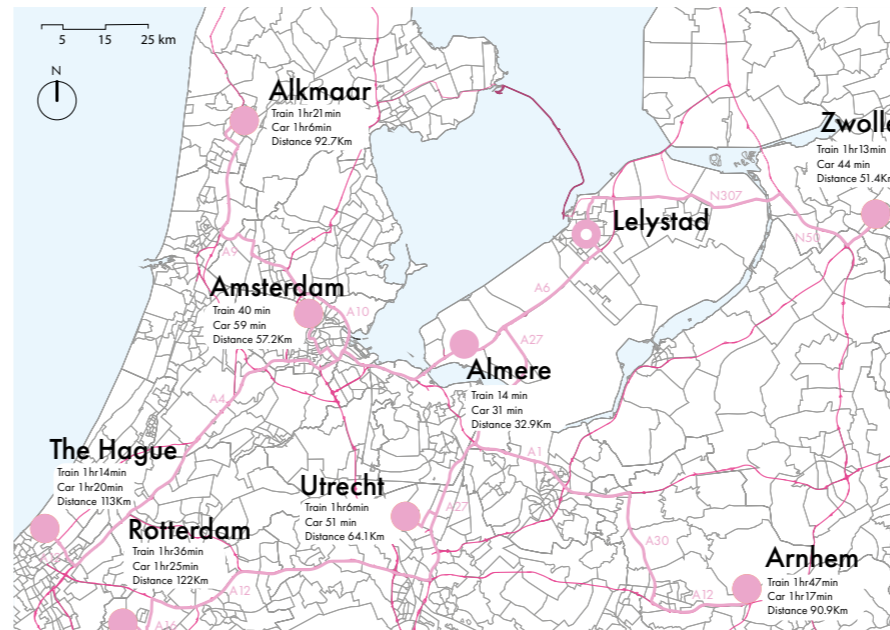


Figure 31
surrounding cities



Figure 32
figure ground plan



Figure 33
contextual situation

b. design guidelines

First design guidelines for a retreat centre can be derived from this research. Starting with guidelines concerning the masterplan and the surrounding of the design. The nature provided by the chosen site now needs to be integrated into the design in a way that it gets accessible to its visitors. For example creating a swimming area in the water and creating a beach like area at the shore would be first steps to make. Also trying to maintain as many trees as possible so that they create the perfect situation of blocking off the view for privacy's sake and at the same time enabling beautiful views on the waterfront. This transition from private to public might however not only be provided through the presence of trees. The way the buildings will be arranged and what elements will be added will determine how good this transition will turn out. Finally the masterplan should support the feeling of integration for the families. This will also be guaranteed by how the buildings will be organised and by providing some facilities that will be used together like laundry rooms and eating facilities or the places that offer multiple activities.

Secondly on the level of the neighbourhood, the creation of little clusters with one storey houses is aimed at. It would not make sense to design the units with multiple floors since it would be impossible to guarantee a wheelchair accessible transition to the upper floors for every unit. Furthermore every unit will be equipped with a spacious adapted bathroom with a big shower and adjustable sink heights. However to keep the costs low these accessible bathrooms should be shared by two to three families that will temporarily inhabit that unit. Every family room will additionally be equipped with its own private bathroom that just might be of a reduced size and therefore will not be very practical for using with disabled children. Furthermore, these units should, on the outside, fit into the natural setting and blend into the forest to disturb the views as least as possible. Therefore, the use of a natural and reduced material pallet should be thought through meticulously.

Last, for the unit and interior scale, we should strive for appealing and welcoming interiors. The aim should be to eliminate the typical hospital look, while still maintaining the usability and practicality of the elements. For instance, a thoroughly designed bed with nice railing made out of wood or a net-material will be much more appreciated than a metal or plastic hospital bed. It is also important to try and consider different disabilities and the restrictions they provide. It should therefore be considered to either have adaptable interiors or to design different units to particular illnesses and disabilities. Furthermore all units should provide sound proof walls in order to guarantee a stress less stay for everyone. They should also have separate bedrooms. It is best if the CID child gets their own bedroom in case it needs treatments during the night. That way not every family member gets distracted and the child can be cared for in her own private space. One last guideline is to create as many windows as possible that can be manipulated independently. Both opening a window, to let fresh air in, and closing shutters to make a room darker, should be possible to be done by every visitor. This enhances the feeling of independence and will help subconsciously in the well-being of the children and their parents.

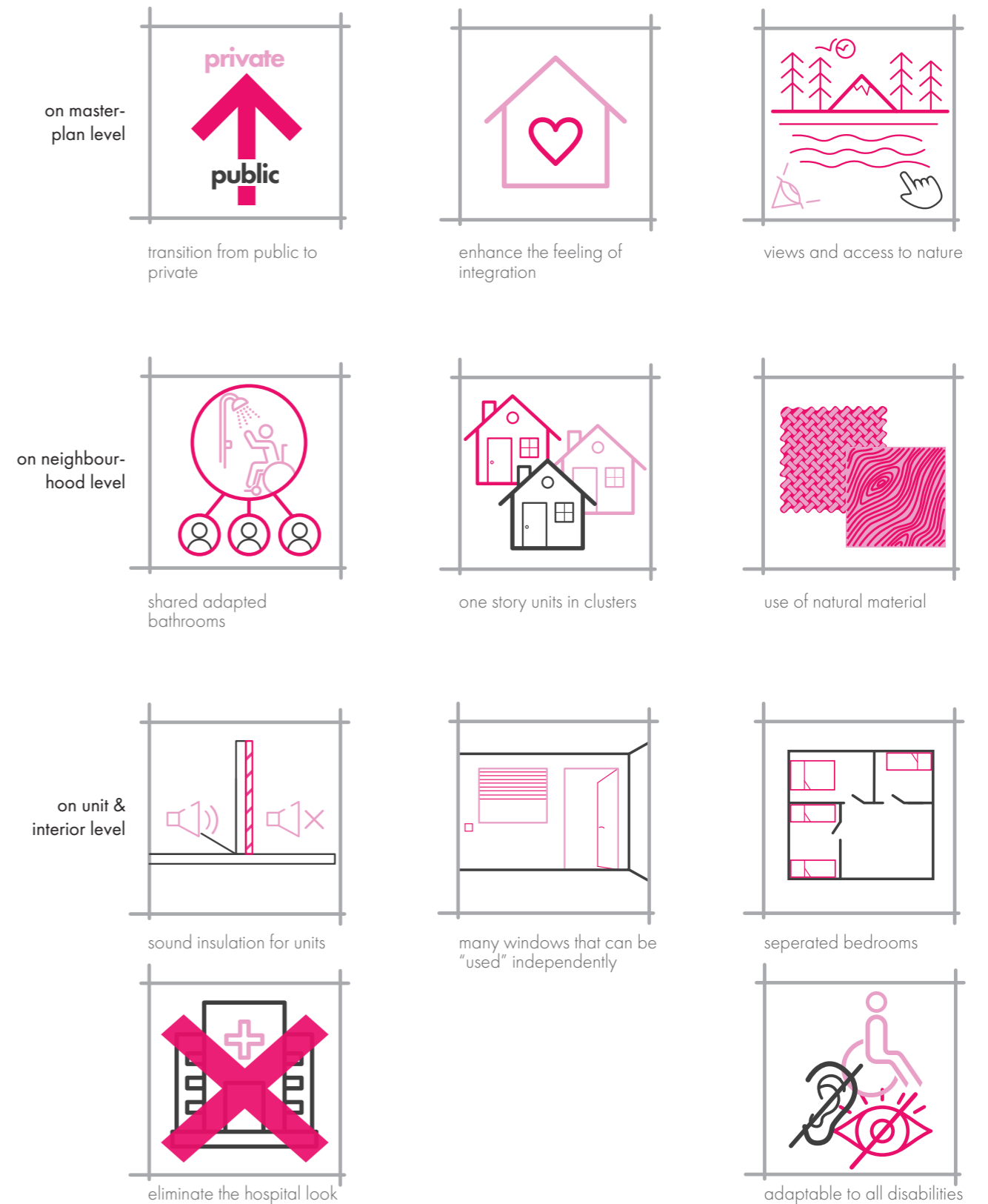


Figure 34
design guidelines

VII. discussion and conclusion

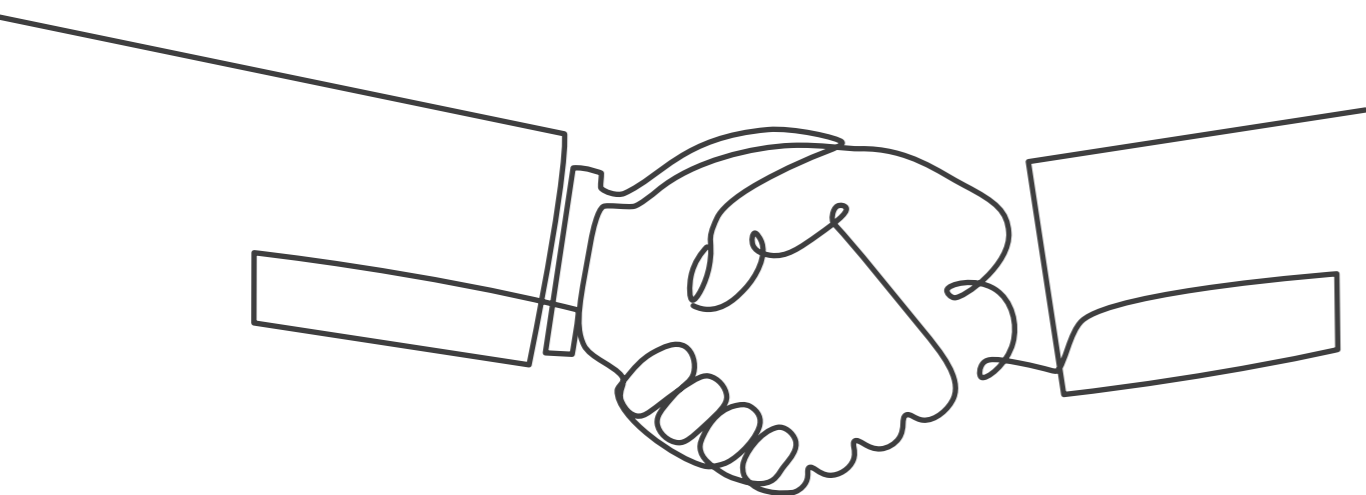
a. discussion

Looking at the current situation involving inclusive holiday solutions and architecture has given clues on what should be included in a design proposal and how the environment should be designed. Not only is it important to create a safe environment for the CID children, but it is equally important to design meeting opportunities for the children as well as for their parents. Therefore, the private family units should be arranged in clusters that share some amenities like a kitchen, to enhance the feeling of integration. As the parents often suffer from the care they provide, opportunities of real recess are indispensable for them. Those moments of respite should be designed in such a way to also support the connection to other parents that stay at the facility. During this time their children need to be taken good care of, therefore the creation of a vast programme of child entertainment should be set up. On the other hand, a potential one-on-one care should be made possible for the CID children.

As architects, we should furthermore strive for the creation of a coherent environment. The existing care hotels can be an inspiration of how this can be done. The next step is to make these designs appropriate and welcoming for families and their children. Implementing the accessibility and inclusivity into a vacation park would help to lessen the burden of everyday care at home. Further, being surrounded by families with CID children might provide a relieving feeling of compassion and normality, which is often hard to encounter in their usual environment. So combining options from camps and care hotels into the well-known Dutch vacation typology seems to be the most fitting option in order to reach the aim of this research.

Defining the specific needs of every family member has helped illustrate the importance of having multiple accessible programme points for the CID children. This spreads from accessible bathrooms with large showers and bathtubs to accessible playground and activity offers. Creating a space where the children can move around independently and have everything they need at reachable heights is very important for them. They should furthermore be able to adapt the spaces, like shutting the blinds or switching on the lights, on their own. Their parents mainly need calm areas, where they can lay back and read a book or simply relax, as well as areas to improve their physical health and let off steam. This could potentially be provided through a wellness and fitness room or an adult-only café. To provide the parents with some free time, a vast offer of play time options should be provided not only for the CID children, but also for their well siblings. Both them and their sick siblings need to have the opportunity for safe and guarded playtime and amusement.

To provide relief to the CID children as well as to their families at the facility, the integration of salutogenic design needs to be guaranteed. Not only does this mean that a sense of coherence should be provided to ensure a psycho-socially supportive design, but also that the surroundings and the integration into a natural setting should be carefully considered while designing. As it is suggested by the theory of salutogenic design, this coherence can be achieved for example by using a thoroughly considered material and colour palette, or by integrating easy to follow wayfindings.



Furthermore, the proximity to nature and access to bodies of water should be used to create an inspiring environment that generates improvement for the child and its entourage.

Finally, it is safe to say that a lot of factors must come together to create a safe and healthy retreat centre for CID children and their families. While designing this recess centre, the guidelines laid out in this thesis should therefore be considered to create this new typology of a family care and vacation park. This then makes it possible to take all of its users into consideration and create the healthiest possible design proposal for the target group of families with CID children.

b. conclusion

In this thesis, we have investigated how the architectural environment of a retreat for families with disabled and/or chronically ill children can provide relaxing time together, while supplying a potential benefit for the children. After having looked into past architectural solutions, the spatial needs of the target group, and the potential benefit that the architectural environment can provide for its users. It can be concluded that the only way, in which a vacation for a family with CID children can be relaxing for everyone, is if the necessary programme points and guidelines are integrated in a coherent design. The results show that the most fitting typology is very close to the typical holiday parks, but it needs some adaptations and the adherence to a set of rules that are determined in the previously stated design guidelines.

While the overall used methods seem to all have brought valuable input to the research, the personal experiences gained through the fieldwork and the interview were the most valuable. As expected, this helped to really engage with the CID children and to understand their individual needs. However, as the results may show, this has also led to mostly programmatic input. This might be due to the fact that it was difficult for the addressed people to explain the problems they face in an architectural way and relating to spaces. While interpreting the answers and stories, the only way they could be interpreted was in relation to the programme list of a retreat centre. Furthermore, since at the daycare facility, most time was spent with the children, unable to answer any questions, it was more difficult than expected to find affected parents or siblings to talk to. However, a lot of essential information was gathered during this time. Talking to different staff members during the fieldwork gave concise information concerning the health and care needs of CID children.

All in all the rest of the used methods, like the literature review and the analysis of the case studies, provided the expected knowledge. Through the combination of these methods it was therefore possible to close the stated research gap.

To extend the research in this field, future research could be conducted on the economic aspect of recess centres for families with CID children and the impact it has on the guidelines that were developed in this report. Although this was not addressed in this thesis, the economical aspect is not completely neglectable, since, as previously explained, those families are often economically strained due to the high care needs of their child.

However, through the creation of a recess centre that is equipped with all the necessary amenities and staff, as well as designed in an inclusive way, the families save some additional costs. This makes travelling more affordable for many and allows for the necessary regeneration for the caregivers, the connection with other families, the needed care for the CID children and the creation of core memories for the whole family.

Overall this report proves that the stated hypothesis can be confirmed. In the right setting, families with CID children benefit from staying at a recess centre which will result in an improved QoL and health.

The results found through the research gave new insights on what this ideal architectural environment would look like for families that have a CID child. This knowledge can now be extended to other parts of

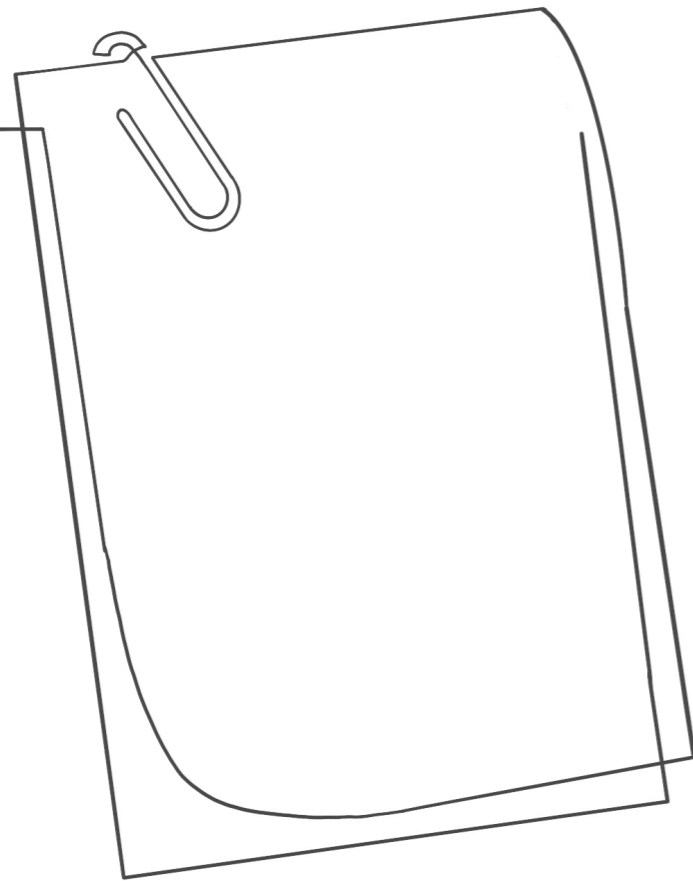
housing design. With the right adaptation the guidelines are not only valid for vacation parks. Finding the overlap in family friendly and inclusive design broadens the field of inclusive and universal design and will hopefully be helpful in the movement towards more inclusive and healthy design and architecture tendencies.



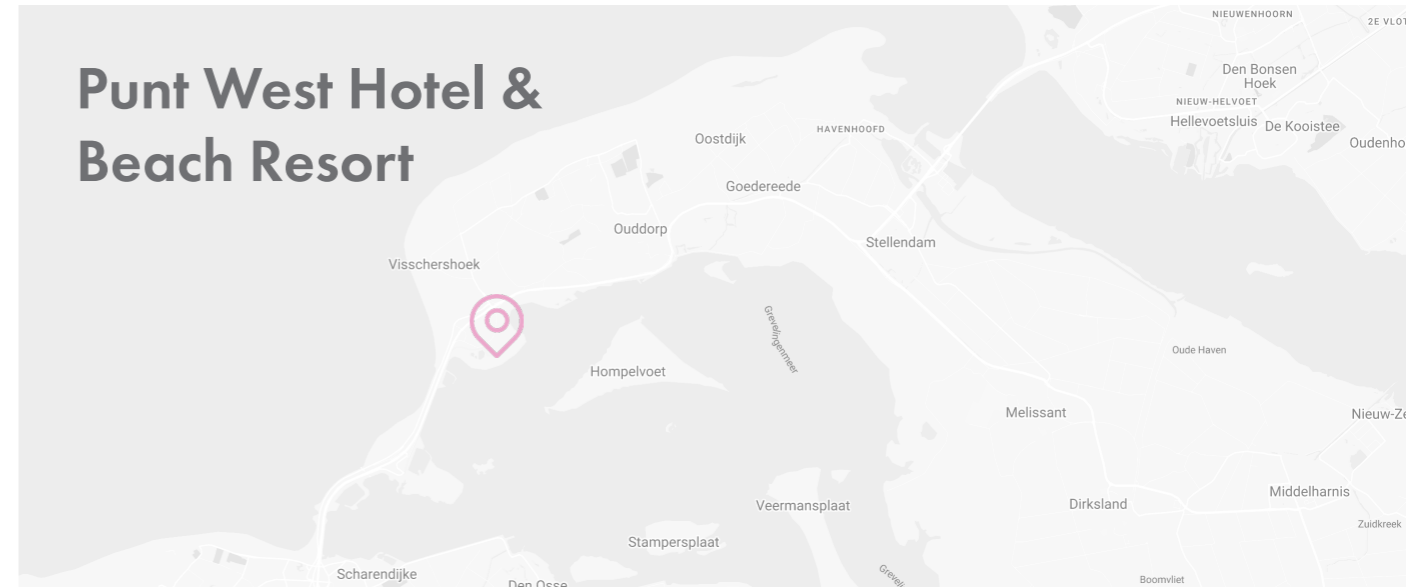
Figure 35
CID child feeling strong

VIII. appendix

a. case study analysis



Punt West Hotel & Beach Resort



Goeree-Overflakkee (NL), 2015-16

Zeelenberg Achitectuur

72 villa's & 20 suites

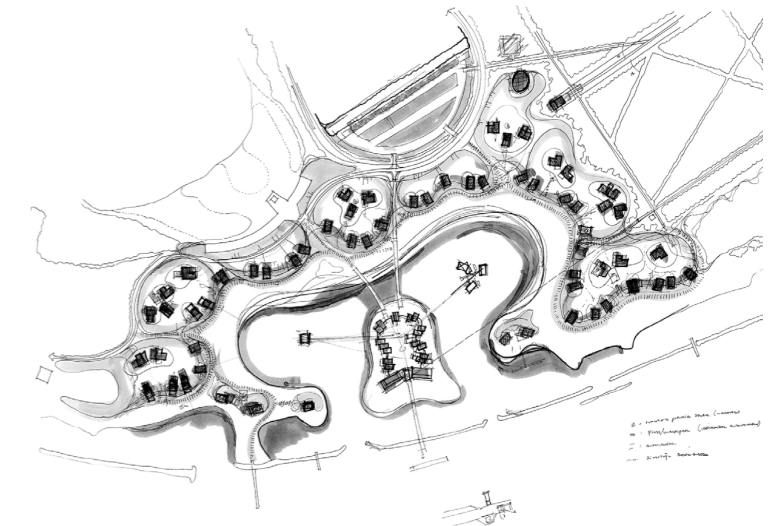
area of ~140'000 m²

max. of 2 storeys

cluster arrangement with central beachclub

activities: watersports, brasserie, masage service, bicycle renting, cycling and hiking routes

- designed to bring back the historical dune landscape
- planned as low density and using natural material to fit into the landscape



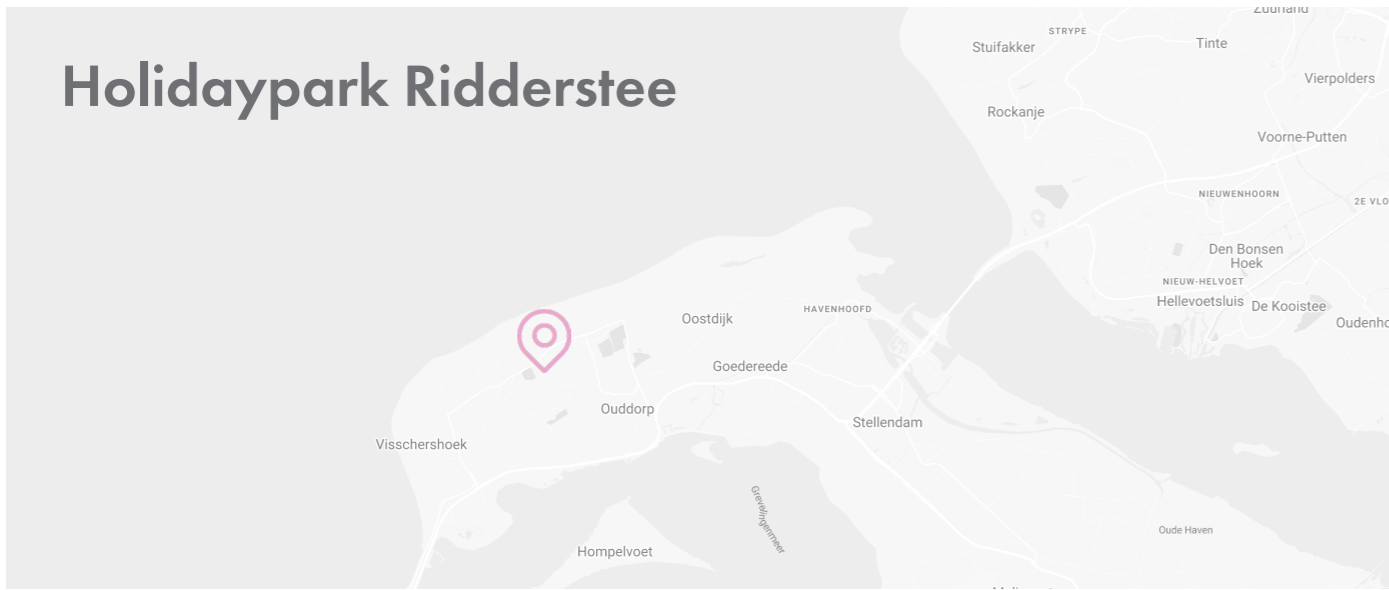
sources (for figures and information):

<https://www.zeelenbergarchitectuur.nl/en/projecten/punt-west-hotel-beach-resort/#>

<https://www.oasisresorts.nl/punt-west/strandvillas>



Holidaypark Ridderstee



Ouddorp Duin (NL), 2018-21

LSWA

104 holiday homes

area of ~143'000 m²

max. of 2 storeys

organic, scattered arrangement

activities: theatre, playground, bistro, bicycle renting, natural swimming pond

- designed to recreate dune landscapes and including water features
- the units have a closed, private side to protect from wind and weather and an open, transparent side to enjoy the sun
- every unit has a terrace with a membrane cover which creates a connection between in- and outside



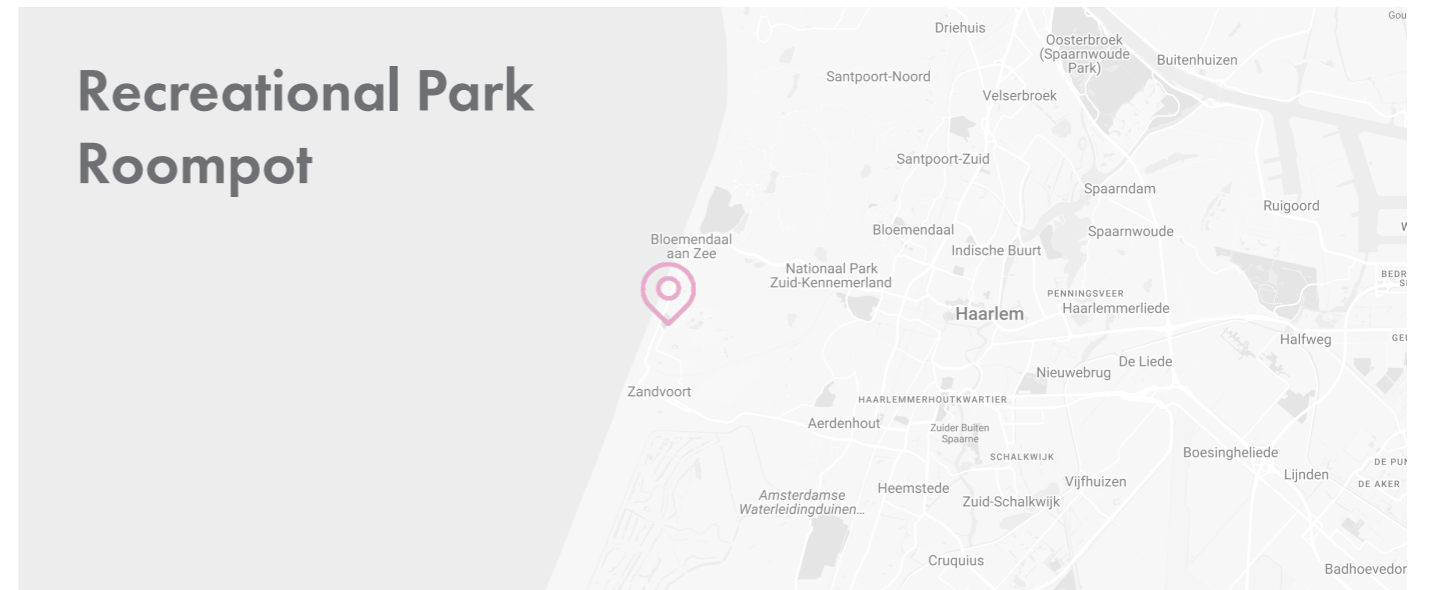
sources (for figures and information):

<https://www.lswa.nl/projecten/alle-projecten/71/vakantiepark-ridderstee>

<https://www.ridderstee.nl/vakantiehuis-6-personen-aan-zee>



Recreational Park Roompot



Zandvoort (NL), 2019

2by4-architects

100 cottages

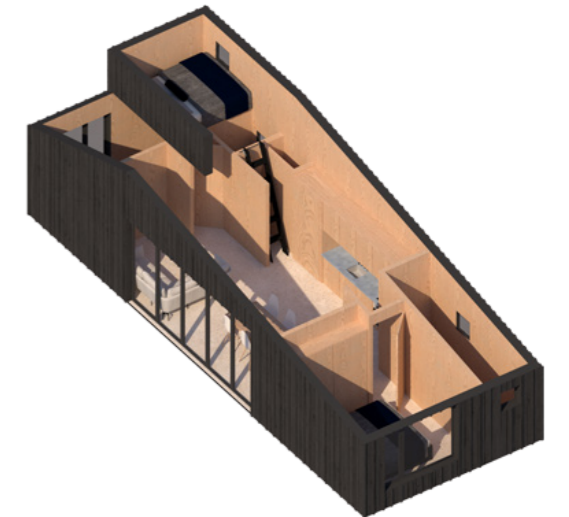
area of ~32'000 m²

max. of 2 storeys

organic, scattered arrangement

activities: kidsclub, playgrounds, mini market, bistro, bicycle renting, laundry room

- adapted to a diverse group of visitors, therefore 5 types of cottages
- designed dune parc with different levels, the cottages on the plateaus all have different orientation to create multiple atmospheres



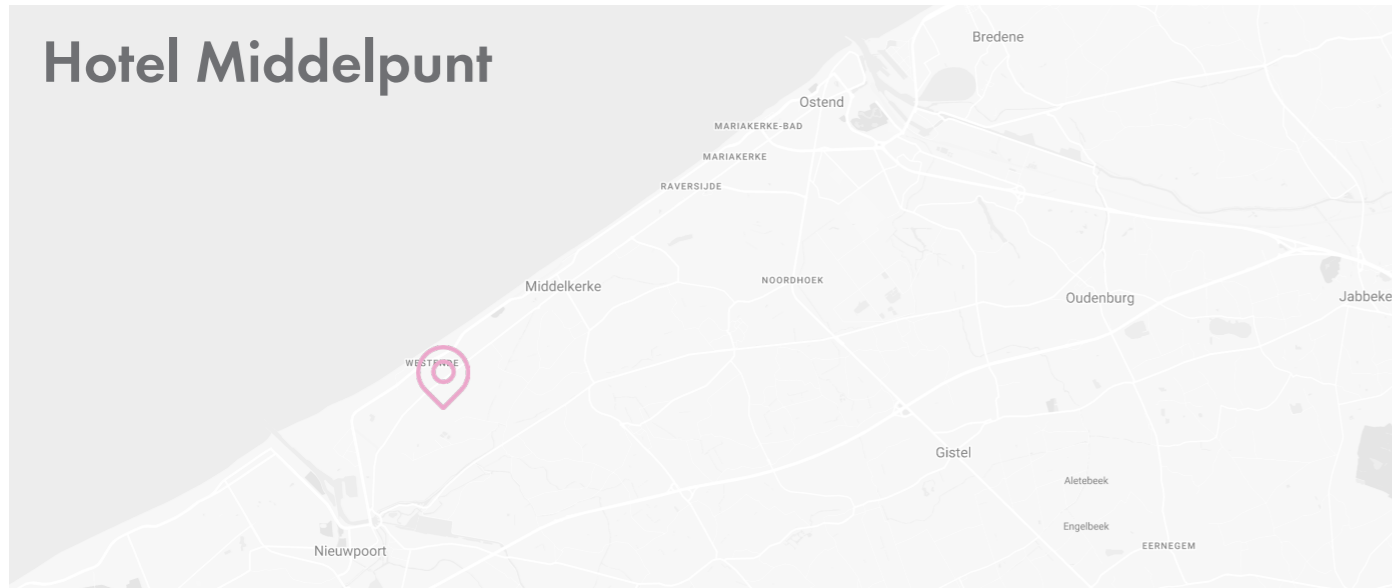
sources (for figures and information):

<https://www.2by4.nl/portfolio-items/curios-zandvoort-cabins/?portfolio-Cats=30%2C31%2C29>

<https://architectenweb.nl/nieuws/artikel.aspx?ID=46462>

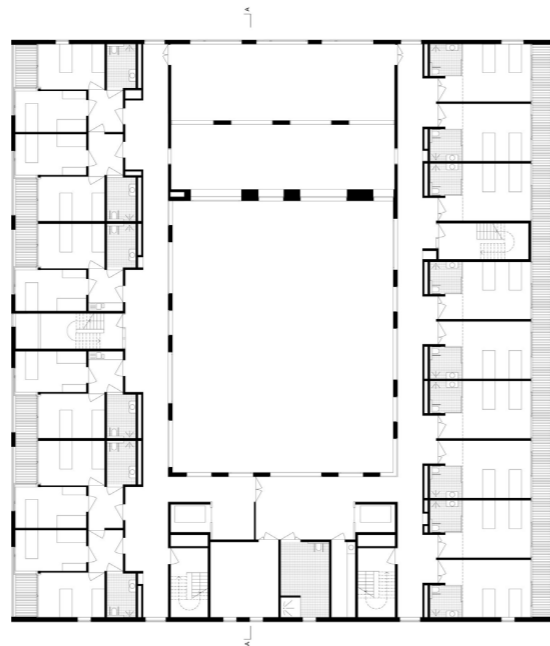


Hotel Middelpunt



Middelkerke (BE), 2013
 Architectuuratelier Dertien 12
 44 rooms
 area of ~5'700 m²
 max. of 3 storeys
 1 building with inner courtyard
 care hotel on the coast with stimulating meeting places,
 completely wheelchair accessible, flexible care service,
 customised wellness offer

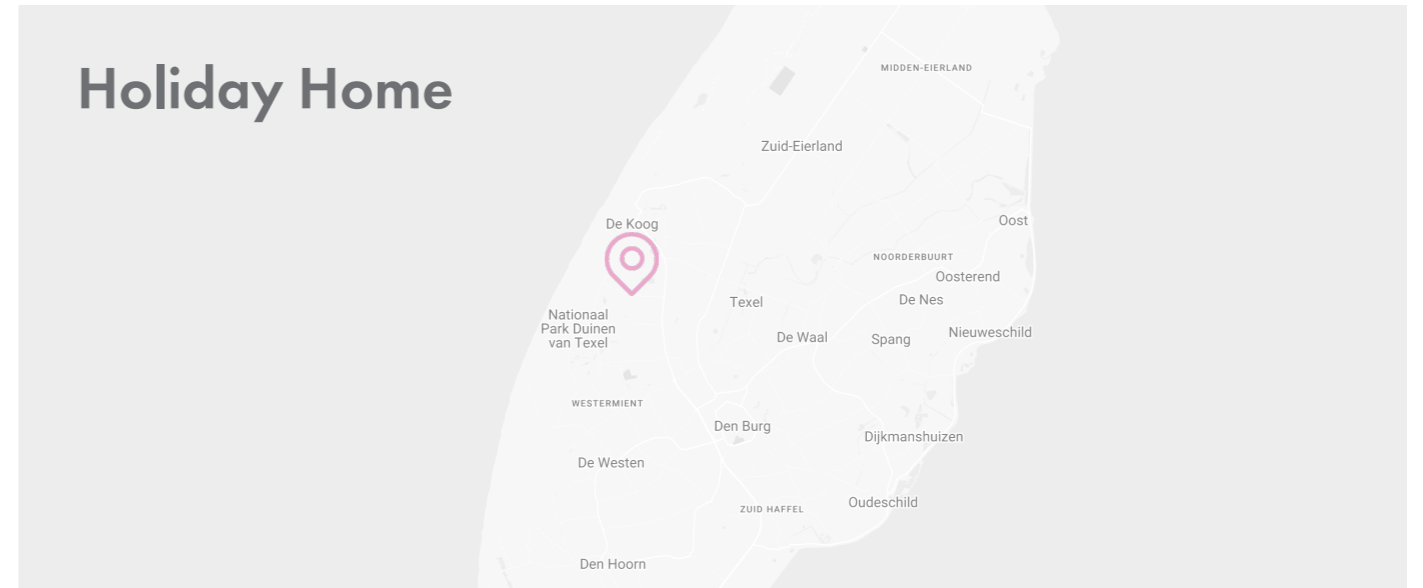
- creating an uplifting place by eliminating the visual presence of "care"
- a transparent plinth to enjoy the view on the coast
- spacious double rooms and modular family rooms
- goal: create a care free holiday, because "everyone is entitled to it"



sources (for figures and information):
<https://middelpunt.be/en>
<https://dertien12.be/projecten/middelpunt>

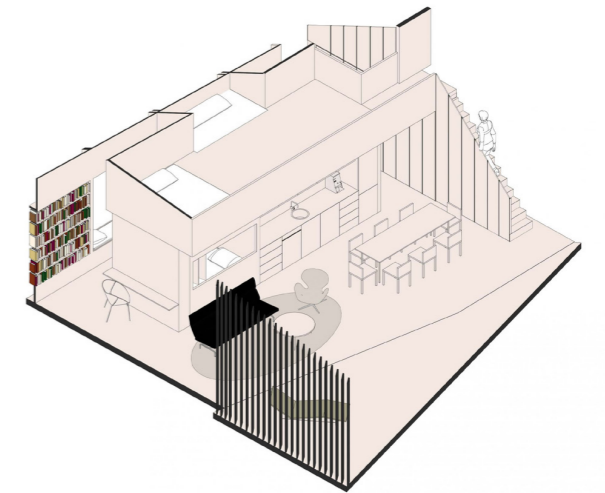


Holiday Home

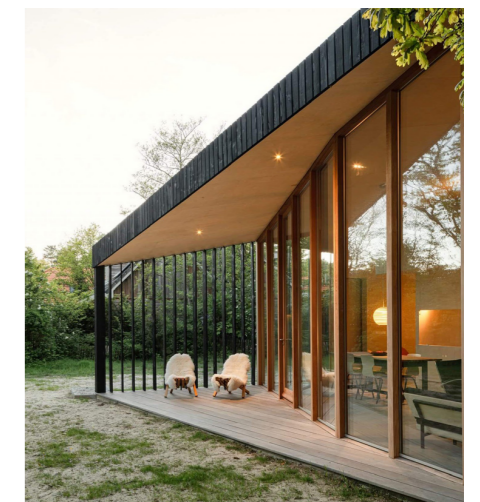
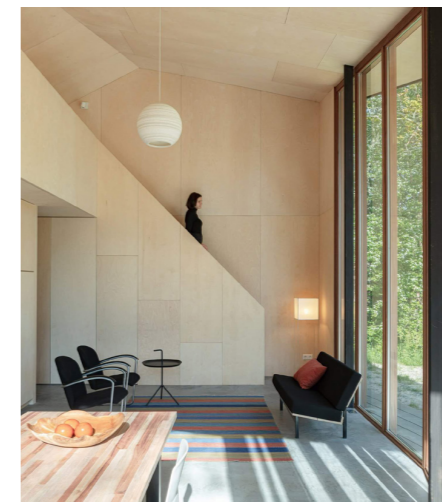


Texel (NL), 2021
 Orange Architects
 private house
 area of ~600 m² (neighbourhood area: ~23'000 m²)
 2 storey
 building in grid organised neighbourhood

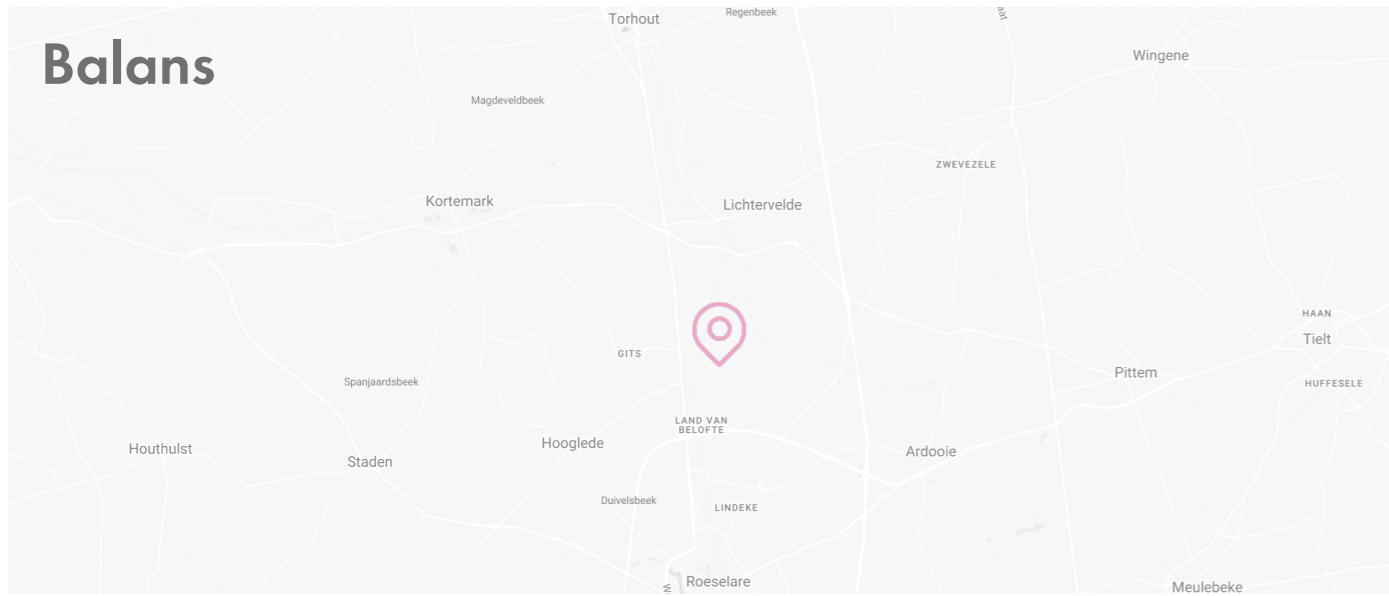
- large windows to extend the living room onto the terrace
- use of natural material: wood
- black wooden cladding with adjustable lamellas according to weather conditions



sources (for figures and information):
<https://orangearchitects.nl/projects/holiday-home/>



Balans



Gits (BE)

Architectuuratelier Dertien 12

7 rooms

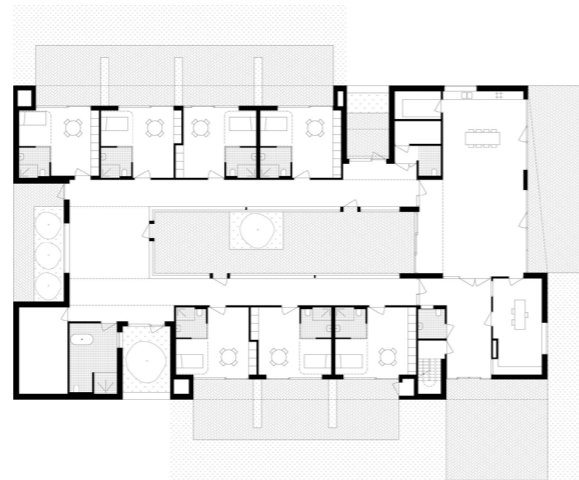
of ~2'300 m²

max. of 2 storeys

1 building with inner courtyard

living group for adults with disabilities and multiple problems with an included time-out space

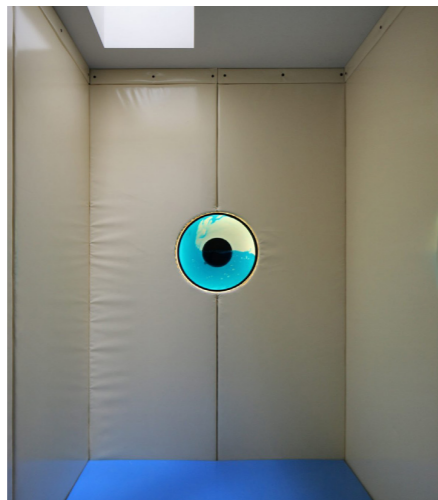
- create a homely feeling while using spatial qualities of a home, individual rooms & common open areas
- challenge: integrate necessary control in a natural way but without creating a limiting feeling
- structured low-stimulus environment with a limited material palette



sources (for figures and information):

<https://dertien12.be/projecten/balans>

<https://zorg.dominiek-savio.be/volwassenen/wonen/woongroepen/balans>



b. interview transcript

Interviewer: Jil Weber (JW)

Interviewee: Nathalie Arend (NA)

Date and time: January 12th 2023

Location: phone call (Delft, Netherlands and Luxembourg)

(*all names were changed to protect the privacy of the family*)

JW: I would like to start by asking you about additional items that you have to take with you on vacation due to your daughter's illness/disability that would not be necessary with a healthy child?

NA: A bed. Our daughter falls out of normal beds. She is now getting too big for typical travel beds and needs the option of a fall out protection on the sides. Meanwhile, there are such beds for rent, it still remains incredibly expensive and also unwieldy and bulky. But it actually starts before that, on the journey to the location. Where do I freshen up my daughter? Most of the time I have to use the floor to change her diapers.

JW: And what does the situation look like when it comes to eating?

NA: Yes, exactly, that's where it continues. She needs a kind of high chair, but one that is adapted to her height. A chair that gives her more support and on which she can't rock so much. Since my daughter is not in a wheelchair, I often take a buggy with me. This is then not always perfectly adapted to the table height.

JW: Are there any architectural requirements for accommodation that influence the choice of where you stay? For example, the size of a bathroom?

NA: In the bathroom, I need the possibility to bathe my daughter while sitting. Ideal is a bathtub or a place to sit in the shower. Personally, though, we don't need special fixtures or anything like that. And I'm usually out and about with the stroller, so I need a little more space to get through. For example, elevator doors, hallways, and so on. Everything should be planned a little bigger in the best way. But also the signage could be better. Sometimes it's hard to find out where and what is adapted for wheelchairs and even if it's written somewhere you still sometimes get there and it's not really like that. What is also very important to me is the sound transmission. My daughter screams a lot and we once had a hotel room that had high sound insulation between the rooms, which was brilliant. When she screams, it always bothers me a lot and in this room she could scream and the neighbors didn't hear anything.

JW: What do you prefer for accommodation? Rather a hotel complex or a vacation home/apartment?

NA: Well, I would rather go to a hotel once in a while, so that I don't have to do anything myself and don't have to cook, for example. But because of our daughter, we almost can't do that anymore. I can hardly take her to a restaurant anymore either.

That's why we rented a vacation home last year and took a student with us to support us. Otherwise, my husband and I would not have been able to enjoy any of the vacation at all.

However, I would like to add that if a Babysitter is accompanying us into a hotel, we pay 4000 € additionally. In general, it will be very expensive. I usually look for apartments or larger rooms in hotels, because our daughter needs her own room to sleep in. She can't sleep with her siblings! For example, she also needs to be able to sleep in complete darkness. And we need a baby monitor with a camera function. I always take this with me myself, but I need cable access to the internet, because this does not work on wifi.

JW: What do you think is needed in terms of activities or care for your two daughters (healthy and disabled)?

NA: For my healthy daughter there is always enough that is offered! For Julie, on the other hand, I have only found one hotel so far that would cater to children with disabilities to a certain extent. The big problem here is the lack of properly trained staff. You would need 1-to-1 care for these children. Our daughter could not play with other children, since she has slightly autistic traits. Therefore she would need someone to take her for a walk alone, for example, so that we as parents could also get some time off. It is really this that I miss the most and that is why we decided to bring a student as a babysitter. In general, the most important thing for me is that my daughter is taken care of adequately. In a hotel, I would rather have a short-term individual care than a longer one, where I can't be sure that she feels comfortable. And that's exactly what I was able to experience again last summer, thanks to our babysitter. I was able to go to the beach with my husband three times. This was the first time in five years that we were able to do that. Otherwise, one of us always stayed in the hotel room with our daughter.

JW: Would you consider "dropping off" your daughter for a few days at a camp for children with special needs, or a short stay at an appropriate organization, to travel without her?

NA: She is only five and, I think, too young for that now. But I could see myself testing it out for 2-3 days at least once if there was a suitable offer. The appropriate care and the range of activities must be right, and a great variety would also be very important to me. But yes, in the right setting, I would certainly give it a try, because she also draws no added value from the vacations. Maybe she does a little from hiking vacations in the mountains, but that's it.

JW: And what about swimming and the water?

NA: She likes that a lot too. I would even say she blossoms there, but again we would have to be two adults to take care of her.

JW: Is there anything else you would like to add that you think I have forgotten?

NA: Well the most important thing for me would be just the right care, where my daughter would be welcomed with open arms, and then they would take her for a walk.

And a buffet in the hotel restaurant would be a must. Our daughter usually only eats sandwiches on vacation, as I can never know if she will eat the dish I would order her or not. With a buffet I could offer her various things in small quantities.

JW: Thank you very much for taking the time to answer all my questions and for your openness on this intimate topic.

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b. figures list

Figure 1: *Vacation memories*. (n.d.). Storyset. <https://storyset.com/illustration/moment-to-remember/amico>, adapted by Weber, 2023

Figure 2: *Work life balance*. (n.d.). Storyset. <https://storyset.com/illustration/work-life-balance/amico>, adapted by Weber, 2022

Figure 3: *Methods scheme*. (Weber, 2022)

Figure 4: *What is it going to look like?* (Weber, 2022)

Figure 5: *Research plan scheme*. (Weber, 2022)

Figure 6: *Theoretical framework scheme*. (Weber, 2022)

Figure 7: *Salutogenesis* (Weber, 2023)

Figure 8: *7 principles of universal design*. (Weber, 2023)

Figure 9: *Family with CID child* (n.d.). Storyset. <https://storyset.com/illustration/international-day-of-families/amico>, adapted by Weber, 2023

Figure 10: *Corridor widths and reachable heights*. (Weber, 2023)

Figure 11: *Playground situation*. (Weber, 2023)

Figure 12: *Sketch of a snoezel room*. (Weber, 2023)

Figure 13: *Observations from fieldwork*. (Weber, 2022)

Figure 14: *Floorplan sketch Tricentenaire*. (Weber, 2022)

Figure 15: *Accommodations at Camp Jened*. (n.d.). Retrieved from <https://averyreview.com/media/pages/issues/45/notes-on-crip-camp/b8419d5c53-1663135716/galan-04.jpg>

Figure 16: *Children at Camp Jened*. (n.d.). Retrieved from <https://www.fordfoundation.org/media/5497/crip-camp-01.jpg?&width=&height=&rnd=132997834230000000&mode=crop&quality=60&cropmode=>

Figure 17: *Hotel Middelpunt*. (2017, September). Archdaily. <https://www.archdaily.com/546622/carehotel-middelpunt-architectuuratelier-derien12>

Figure 18: *Recreational Park Roompot*. (n.d.). 2by4 Architects. <https://www.2by4.nl/portfolio-items/curios-zandvoort-cabins/?portfolioCats=30%2C31%2C29>

Figure 19: *Holidaypark Ridderstee*. (n.d.). LSWA. <https://www.lswa.nl/projecten/alle-projecten/71/vakantiepark-ridderstee>

Figure 20: *Punt West Hotel and Beach Resort*. (n.d.). Retrieved from <https://www.oasisresorts.com/punt-west/watervilla-super-vip-4-pers>

Figure 21: *Bathroom at Recreational Park Roompot*. (n.d.). Retrieved from <https://www.roompot.com/destinations/the-netherlands/north-holland/roompot-zandvoort/accommodations/lodge/kennemer-lodge-special-4/563071/>

Figure 22: *Floorplan at Recreational Park Roompot*. (n.d.). Retrieved from <https://www.roompot.com/destinations/the-netherlands/north-holland/roompot-zandvoort/accommodations/lodge/kennemer-lodge-special-4/563071/>

Figure 23: *Interior at Hotel Middelpunt*. (n.d.-e). Retrieved from <https://www.archdaily.com/546622/>

carehotel-middelpunt-architectuuratelier-derien12/540f98f0c07a807b9b00007f-carehotel-middelpunt-architectuuratelier-derien12-photo?next_project=no, and from <https://middelpunt.be/en/kamers/hoge-zorgkamer-mindervaliden-vakantie>

Figure 24: *Reference project check list*. (Weber, 2022)

Figure 25: *Patient lifter*. (Weber, 2022)

Figure 26: *Shower trolley in adapted bathroom*. (Weber, 2022)

Figure 27: *Mother reading Illustration*. (n.d.). Storyset. <https://storyset.com/illustration/woman-reading/amico>

Figure 28: *Nature intergation in architecture*. (2015). Dezeen. <https://www.dezeen.com/2015/07/23/naman-spa-mia-design-studio-latticed-walls-hanging-gardens-pools-vietnam/>

Figure 29: *Site criteria* (Weber, 2022)

Figure 30: *impressions of the site* (n.d.). retrieved from: <https://www.google.com/maps/@52.487575,5.4140317,3a,75y,270.01h,65.22t/data=!3m8!1e1!3m6!1sAF1Qip-MycUkh4FNcrF3M7qA6s7NG3sBDlc4BdXaeT6Fk!2e10!3e11!6shttps:%2F%2Fh5.googleusercontent.com%2Fp%2FAF1QipMycUkh-4FNcrF3M7qA6s7NG3sBDlc4BdXaeT6Fk%3Dw203-h100-k-no-pi0-ya89.93355-ro0-fo100!7i8192!8i4096>

Figure 31: *surrounding cities* (studio's student group, 2022)

Figure 32: *Figure groud plan* (studio's student group, 2022)

Figure 33: *Contextual situation of the site* (Weber, 2022)

Figure 34: *Design guidelines* (Weber, 2023)

Figure 35: *CID child feeling strong*. (2016). Isha. <https://isha.sadhguru.org/in/en/wisdom/article/do-children-with-disabilities-suffer>

Illustrations on title page and frontpages of chaperts: Weber, 2023