Visibility among brussen

Master thesis

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itegrated product design

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Abbreviations

The following abbreviations are used specifically within the context of this research project to ensure clarity and consistency. These terms are contextualized based on this work and are not intended as universal definitions.

Definition

Visibility: the manifestation of presence, that feels instinctive and unforced, and therefore natural for brussen.

Empowerment: a process that enables children through opportunities that build self-belief, competence, and confidence, particularly in social play (Canning, 2020). Within this research project, empowerment is linked to both children and their play.

Play: play is defined as an open-ended and intrinsic activity characterized by self-motivation, creativity, and social interaction.

Brussen: Brussen are siblings of children with special needs or chronic illnesses, often young informal caregivers up to age 24.

Methodologies

The natural visibility of brussen can be qualitatively assessed by observing social interaction, specifically focusing on changes in; *body language, facial expressions, eye contact, talkativeness.*

Empowerment of brussen can be qualitatively assessed by observing the level of participation, specifically focusing on changes in; *participation, engagement in play, negotiating, making of choices and decisions (Canning, 2020).*

Play among brussen can be qualitatively assessed by observing their engagement in various activities, specifically focusing on indicators such as; *enjoyment*, *freedom*, *expressing of characteristics and preferences*, *development of play over time (Canning, 2020)*.

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Abstract

This research project created a tool designed to empower "brussen", the siblings of children with special needs, aged 7 to 12 to improve their visibility and recognition among their peers through play. Often overlooked within their families due to the primary focus on their siblings' needs, brussen face unique challenges regardless of the type of special need. They can find recognition and support in each other, but the term "brussen" is not widely known, complicating their ability to connect with peers. This project adopts a participatory design and research-through-design approach, engaging brussen in co-design sessions to ensure their perspectives shape the final outcome. The research highlights the importance of visibility among brussen, with empowerment and play emerging as key elements within the design process. The design activities themselves contribute to knowledge generation, which helps to better understand the complex context of brussen. The project developed a personalized "ByBrus backpack" with velcro buttons, allowing brussen to express their identities and control their visibility in a playful manner. This personalization provides a sense of ownership and autonomy, as the buttons symbolize the unique stories, emotions, and experiences of the brussen. Through this approach, brussen can show their unique experiences, ultimately enhancing their visibility. By addressing the need for social recognition and support, the ByBrus backpack aims to create a sense of community and mutual understanding among brussen, contributing to their overall well-being and resilience.



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All key take-aways from each chapter are summarized on the red pages at the end of each chapter. These pages provide a concise overview of the main insights and conclusions drawn from the chapter's content.

lcons

Icons are used to provide a quick overview of each organized session. These icons contain summarized explanations of the session. Detailed session protocols and full explanations can be found in the appendix.



The research goal of the session



- Goal presented to the participants
- 🖉 Locat
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Introduction

This chapter gives an overview of the research project, the client, and the stakeholders involved. It explains the problem being addressed, describes project activities, and the methods used in the project.

1.1 Stakeholders

Ontzorghuis

Ontzorghuis is a Dutch organization dedicated to supporting parents of children with intensive care needs (Ontzorghuis, n.d.). Founded by Marise Schot in 2018, it aims to provide resources, tools, and community support to help these families manage their care responsibilities. Ontzorghuis emphasizes a holistic approach, integrating elements of design, psychology, and community building to improve the well-being of both caregivers and care recipients. Marise Schot has worked as a social designer in healthcare since 2008 and has mentored several industrial design thesis projects. She is expanding Ontzorghuis's focus to also include the siblings of children with intensive care needs, in addition to supporting their parents. Through its academy, Ontzorghuis develops online training programs, shares insights from user research, and collaborates on projects like this thesis. These initiatives aim to enhance the well-being and resilience of families with intensive care needs.

Target group brussen

This project focuses on the group known as "brussen," which refers to siblings of children with special needs or chronic illnesses (Nederlands Jeugdinstituut, n.d.). The term "brussen" is derived from the Dutch words for brother ("broer") and sister ("zus"). This group comprises young informal caregivers, typically up to the age of 24, who grow up with a sibling requiring special care. The focus is particularly on brussen aged 7 to 12, a critical period for developing self-awareness and personal identity. During these years, children begin to understand their unique situations and build a sense of their own worth. Family attention is primarily directed towards their siblings' needs, creating a sense of invisibility for the brussen. The project aims to help overcome this sense of invisibility, by enhancing the visibility and empowerment, particularly among brussen themselves.

1.2 Project brief

Problem definition

According to Hanvey et al. (2022), the needs of brussen are often unnoticed due to the focus on their brother or sister's condition, leading to a sense of invisibility termed the "glass child" metaphor (TEDx Talks, 2010). This invisibility, both within and outside the household, can cause significant frustration and sadness for the siblings. However, when their needs are eventually acknowledged, it can result in powerful and memorable reactions (Hanvey et al., 2022). This concept of "invisibility" is a novel finding in sibling literature and underscores the importance of recognizing and addressing siblings' needs for effective support. Cordon (2010) suggests that brussen often experience isolation and sadness due to feeling misunderstood, particularly when lacking opportunities to connect with peers who understand their situation. Building secure peer relationships can provide a supportive environment where siblings can openly express their thoughts and emotions, potentially leading to lower levels of depression, anxiety, and stress (Foubister, 2017).

Research question

How can play empower brussen to enhance their visibility among one another?

Sub-research questions

This research question can be answered by gathering more knowledge about the two subdomains in this question: 'visibility', and 'empowerment through play'. These themes emerged from this research and are elaborated on in further chapters.

Visibility among brussen

- Where and when do brussen feel invisible to each other?
- How can social recognition from peers help fulfil the need for visibility?
- How can play enhance the visibility of brussen?

Empowerment through play

- What opportunities does play provide for brussen to enhance empowerment?
- Which themes in empowerment show the most potential in empowering brussen?



1.3 Project overview

Project relevance

European research focused on supporting adolescent young carers (brussen) in Europe stresses the need to tailor support to the specific needs of brussen, involving them in the process (Hoefman & Van Zoest 2019). To achieve this, the research advocates for a participatory design approach by encouraging direct participation by end users with co-design sessions. Industrial design can play a significant role in understanding emotional needs and wellbeing by using a participatory design approach. Additionally, the meta-analysis by Sharpe and Rossiter (2002) on siblings of children with chronic illnesses underscores the importance of recognizing the strengths and contributions of these siblings to promote their well-being. It is important to focus on the positives of being a brus, rather than portraying them as victims. By highlighting their strengths and resilience, it is easier to connect with and support them (Allstarz, 2024). Furthermore, industrial design is a discipline able to develop integral approaches and tools that move across education, welfare, and (youth) healthcare, which is now lacking for brussen (Hoefman & Van Zoest 2019).

Project approaches and methods

This project intertwines the phases of research and design simultaneously. Both phases use participatory design and research through design approaches. The project adopts the 5-Stage Design Thinking Process (Dam, 2024 and Brown, 2008), allowing empathizing, defining, ideating, prototyping, and testing to progress side by side in a non-linear way. This simultaneous progression leads to an early generation of a design concept, aligning well with the iterative nature of research through design. The design activities themselves contribute to knowledge generation, which helps to better understand the complex context by continually reframing it and creating responsive prototypes accordingly (Stappers & Giaccardi, 2017). The 5stages of the Design Thinking Process are indicated in the top right corner of each activity in this research project.



Figure 1, 5-Stage Design Thinking Process (Dam, 2024 and Brown, 2008)

1.3 Project overview

Type of research Research through design

Research Through Design (RTD) is a type of research that embeds the research process in a design project with the goal of generating knowledge (Prochner & Godin, 2022). This project contributes to gathering a better knowledge and understanding of the balance of natural visibility of brussen, resulting in the making of an embodied artefact. RtD methodology helps this project by having a more open-ended and exploratory approach compared to traditional research methods. The goal of this project is therefore broad, focusing on exploring, understanding, and innovating within the particular domain of co-design with brussen.

Perspective Participatory design

Within the research through design approach, this project adopts a Participatory Design perspective, grounded in the principles of collaboration, co-creation, and empowerment (What Is Participatory Design?, 2024). This approach is particularly relevant because it directly involves brussen in the design process, ensuring that their unique insights and needs shape the final outcome. By allowing brussen to provide feedback, suggest ideas, and participate in decision-making, the design becomes more tailored and effective in addressing their specific challenges. To achieve this, brussen are actively engaged in co-design and generative sessions. These sessions empower brussen by giving them a voice and ensuring that the design solutions are relevant and meaningful to their real-life experiences. This participatory approach is crucial for creating a design that truly resonates with brussen and addresses their needs comprehensively.

Data analysis Qualitative research

The data collected to address the research question will focus on a qualitative analysis to explore the specific needs and perspectives of brussen regarding their daily experiences, challenges, and interactions. This approach enables to gather indepth insights directly from the participants, which are crucial for developing a design that truly resonates with their experiences. By examining audio and video recordings, along with interview responses, patterns are identified in their answers, particularly regarding their practical and personal needs.

The analysis uncovers underlying values and themes that are important to the brussen. The insights gained from this analysis will be used in creating a design that is not only functional but also meaningful and supportive for the brussen. This detailed examination helps provide a deeper understanding of the participants' perspectives on their unique roles and challenges and how they relate to the design process, ensuring that the final outcome is both relevant and impactful.

1.4 Project activities



Context analysis This chapter provides an analysis of the context of

This chapter provides an analysis of the context of brussen. It examines the roles and responsibilities of brussen and what these mean for their unique needs and challenges they face. The chapter assesses existing support systems and tools, and highlights the gaps in current resources and recognition that provide opportunities for the scope of this project.

2.1 Siblings of special need children

Young informal caregivers

According to MantelzorgNL, young informal caregivers are children and adolescents up to age 24 who grow up with a family member who is ill or has a disability. It may be a parent, brother, sister, grandfather or grandmother.

Brussen

Brussen are a subgroup of young informal caregivers, specifically siblings of children with special needs or chronic illnesses. The term "brus" combines the Dutch words for brother ("broer") and sister ("zus") (Van Dijken, 2013). In this report, "brussen" refers to children up to age 24 who are growing up with a sibling with a disability, illness, or disorder. Approximately 150,000 brussen care for a long-term special needs sibling in the Netherlands, according to the most recent large-scale study representative of Dutch school-going youth (de Roos, 2020; de Roos et al., 2017). The study defines "long-term" as lasting longer than three months and involving a physical and/or mental illness or disability. This makes the group of brussen considerably large and significant, though there is still limited awareness of this group.



Figure 2, Picture of brus and sibling (Bakker et al., 2018)

Brussen are a group of young informal caregivers, who are siblings of a child with special needs or chronic illness.

There are approximately 150 000 brussen within the Netherlands (de Roos, 2020).

2.2 Understanding special needs

Types of special needs

Special needs can be described as physical or emotional difficulties or differences that require additional assistance or specialized services. According to Garcia (2023) there are four main categories of special needs:

Physical

Physical special needs encompass chronic or terminal physical illnesses such as multiple sclerosis, allergies, asthma, juvenile arthritis, leukemia, muscular dystrophy, and epilepsy.

Developmental

Developmental special needs involve disorders related to neurological development, including Down syndrome, autism spectrum disorder, attention-deficit/hyperactivity disorder (ADHD), auditory processing disorder, and visual processing disorder, and other disorders related to neurological development.

Behavioral/emotional

Behavioral and emotional special needs refer to mental health needs such as obsessive-compulsive disorder, dissociation, post-traumatic stress disorder, anxiety, depression, attention deficit (hyperactivity) disorder, and bipolar disorder.

Sensory

Sensory special needs are associated with sensory impairment, including blindness, deafness, limited hearing, and visual impairment.

What are brussen caring for

The report "Key Figures on Young Caregivers in the Netherlands (16-24 years)" identifies types of special needs among care recipients aged 16-24 in 2019, see figure x (De Boer, A., & De Roos, S., 2022). Young people provide assistance to a diverse group; half of them assist someone with a (temporary or permanent) physical limitation (see figure 1). Additionally, 18% offer help to individuals facing psychological or psychosocial issues. The proportion of young people aiding someone with an intellectual disability is relatively small (6%).



Figure 3, Types of disabilities among aid recipients aged 16-24, 2019 (in percent, n=382). Source SCP/CBS (IZG'19).

2.3 Support system

Looking at the support system of brussen, unique dynamics emerge that can lead to pain points. Understanding these challenges offers valuable insights in power and interest dynamics.

Family

The family, particularly the parents and the sibling with special needs, plays a critical role in the support system of brussen. Families are often the primary source of care and emotional support, not just for the sibling with special needs, but also for the brussen themselves (Sharpe & Rossiter, 2002).

Pain points

- Families may inadvertently focus more on the sibling with special needs, sometimes leading brussen to feel overlooked or less prioritized. Research indicates that siblings of children with disabilities often experience feelings of neglect as parental attention is mostly directed towards the child with special needs (Hanvey, Malovic, & Ntontis, 2022).
- There is often a lack of involvement of brussen because guardians don't want to burden them, which can leave them feeling excluded from important family discussions or decisions. Milevsky (2019) highlights that excluding siblings from these discussions can lead to feelings of isolation and neglect.

Professional caregivers

Professional caregivers such as doctors, nurses, and social workers are responsible for the well-being of the sibling with special needs, the parents/guardians, and the brussen (Kalsbeek et al., 2018).

Pain points

- It is not always made clear that professional caregivers are also approachable for brussen. Lobato & Kao (2005) emphasize the importance of integrating siblings into the caregiving process to ensure they feel supported.
- Communication is often not directly addressed to brussen, and the provided information is not tailored to their age, development, and available knowledge. Ensuring that parents are informed should include parallel communication strategies aimed at brussen (Kalsbeek et al., 2018).

Teachers and school

Teachers and educational institutions play a significant role in providing support and understanding to brussen. They influence how brussen manage their educational and social lives while balancing their family responsibilities (Lobato & Kao, 2005).

Pain points

• Teachers may not always be aware of the unique challenges brussen face, leading to insufficient support in the educational environment. McCullough & Simon (2011) discuss how awareness programs can help educators better support brussen.



2.3 Support system

- There is often a lack of initiatives to integrate awareness about brussen's circumstances within school programs, preventing the formation of a supportive peer network. Bee & Boyd (2004) indicate that integrating such awareness can significantly improve the social support systems for brussen.
- Educational plans and resources are rarely tailored to accommodate the intermittent availability and emotional states of brussen, potentially affecting their academic performance. Foubister (2017) underscores the importance of tailored educational plans to support students with unique family responsibilities.

Other brussen

According to Kalsbeek et al. (2018), brussen want to meet other brussen. Care organizations facilitate contact moments for brussen, allowing them to share experiences and insights, creating a sense of community and mutual understanding (McCullough & Simon, 2011).

Pain points

- There is often a lack of regularity and accessibility in the meetings, preventing brussen from forming lasting connections. Sharpe & Rossiter (2002) discuss the need for regular and accessible support meetings to maintain these connections.
- Meetings might not always address the diverse age ranges and developmental stages of brussen, making it difficult for all attendees to engage effectively. The

need for age-appropriate and developmental stageappropriate activities is crucial for effective engagement (Bakker et al., 2018).

- Information and activities provided during these meetings are not always tailored to the specific emotional or informational needs of brussen. Tailored approaches can significantly improve the efficacy of these support sessions (McCullough & Simon, 2011).
- Awareness and promotion of these meetings are limited, primarily online, leaving many brussen unaware of these support options (Bakker et al., 2018).

Friends

Friends provide emotional support and a sense of normalcy outside the family context (McCullough & Simon, 2011).

Pain points

- Friends may not fully understand the unique challenges brussen face, potentially leading to isolation or misunderstanding. McCullough & Simon (2011) highlight the importance of awareness among peers to prevent isolation.
- A communication gap frequently exists between what brussen are comfortable sharing and what their friends can appropriately handle or respond to. Milevsky (2019) emphasizes the need for better communication strategies to bridge this gap.



2.4 Unique challenges

Brussen can face a variety of unique challenges due to their family circumstances and their sometimes conflicting emotions. According to Sharpe and Rossiter (2002), who conducted a metaanalysis on siblings of children with a chronic illness, some of these challenges include:

Emotional impact

Brussen may experience a range of emotions, including guilt, resentment, fear, and sadness, related to their sibling's condition. They might struggle with feeling neglected or overshadowed by their sibling's needs. The emotional toll on brussen is significant, as they often juggle complex feelings of love and frustration towards their sibling and their situation (Fleary & Heffer, 2013).

Role reversal

Brussen may take on caregiving roles or responsibilities beyond their years, such as helping with their sibling's daily care or advocating for their needs within the family or at school (Dyke, Mulroy, & Leonard, 2009). This early assumption of adult responsibilities can affect their own development and social experiences (Lobato & Kao, 2005).

Social isolation

Brussen may feel isolated from their peers who may not understand their family situation or the challenges they face at home. They might also miss out on typical social activities or events due to their sibling's needs. The lack of peer understanding and support can exacerbate feelings of isolation and loneliness among brussen (McCullough & Simon, 2011).

Financial strain

Families with a child with disabilities or chronic illnesses may face increased financial burdens due to medical expenses, therapies, and specialized care, which can impact all family members, including brussen. The financial strain can lead to reduced resources and opportunities for brussen, affecting their overall well-being (Hanvey, Malovic, & Ntontis, 2022).

Educational challenges

Brussen may struggle academically due to disruptions at home or difficulty concentrating on schoolwork because of their concerns about their sibling's well-being. According to Foubister (2017), these disruptions can significantly impact their academic performance and overall educational experience.

2.4 Unique challenges

Future planning

Brussen may worry about their future responsibilities, such as long-term caregiving or financial support for their sibling, especially as their parents age or if their sibling's condition requires lifelong care. These concerns about the future can add considerable stress and anxiety (Milevsky, 2019).

Lack of attention

Brussen may feel overlooked by parents or other family members who are focused on meeting the needs of the sibling with a disability or chronic illness, leading to feelings of neglect or resentment. This sense of being overlooked can significantly impact their emotional well-being and self-esteem (Hanvey, Malovic, & Ntontis, 2022)

It's important for brussen to have access to support systems, such as peer support groups, counseling services, and resources specifically designed to address their unique needs, to help them navigate these challenges. The available tools for brussen are discussed in the next chapter.

Unique challenges are shared among brussen, They can find recognition in each other (Kalsbeek et al., 2018).

2.5 Available tools

To give a sense of what type of tools are available for brussen, several examples are given below.

Readings

Several books provide personal stories and reflective guidance for brussen. One well-known book is 'Het Brussenboek,' which offers support and empowerment to siblings of individuals with disabilities or chronic illnesses (Van Dijken, 2019).

Workshops and support

Organizations host workshops, discussion groups, and courses for siblings, allowing them to relax, engage in fun activities, share experiences, and learn about their sibling's disability or illness. Local municipalities and hospitals organize these events. For example, Vanzelfsprekend!? in 's-Hertogenbosch offers services for young caregivers, including a podcast, workshops, and social events (Vanzelfsprekend!?, 2023). The Emma Kinderziekenhuis 'Op Koers' initiative provides courses for brussen both online and in hospitals. Additionally, "Ervaringsmaatjes" is a national buddy project where young volunteers and interns, who have grown up in caregiving families, support young caregivers (Ervaringsmaatjes - MantelzorgNL, n.d.).

Social media

Social media offers an accessible platform for raising awareness and sharing personal experiences. SAME! is a national governmental platform for young people aged 12 to 18 with siblings requiring extra care, providing a space to share stories and experiences (SAME!, 2023). The Instagram account Mijn_Brus_Verhaal exemplifies an individual initiative, offering relatable stories, tips, and support (Sonneveld, @Mijn_Brus_Verhaal, n.d.).

Trips and activities

Several organizations focus on creating enjoyable experiences without always emphasizing the potentially challenging circumstances of brussen. Allstarz offers fun activities and camps six times a year for children and young people who have a sibling with a disability (Over Allstarz - Allstarz, 2022). FunCare4Kids organizes "Fundagen," special fun days for children living in families affected by chronic illness or disability, providing joy and respite while they connect with peers in similar situations (FunCare4Kids, 2024).

Serious game

'Broodles' is a psychological intervention serious game designed to help brussen to manage their thoughts and emotions on key issues (Sterkenburg, 2023). The game includes 8 levels, each taking about 20 minutes, complemented by worksheets for children and supportive tips for parents.

Despite these valuable resources, a significant challenge remains: if individuals are not familiar with the term "brussen," it can be difficult to find and access these tools. Awareness and understanding of the term "brussen" are crucial for utilizing these resources effectively. As Kalsbeek et al. (2018) highlight, the lack of widespread recognition of the term "brussen" can hinder the ability of siblings to access necessary support and resources.

Without awareness of the term brussen, it can be difficult to find and access support tools.

Chapter take-aways

Visibility among brussen

Brussen face the unique challenges of feeling overlooked by parents or other family members who are focused on the child with special needs. They can find recognition among other brussen who share similar experiences and understand each other's unique challenges. However, the lack of awareness of the term "brussen" makes it difficult for them to find each other and access support tools. Increasing visibility among brussen and awareness of the term "brussen" can lead to greater recognition, which could significantly improve their emotional well-being and resilience (Kalsbeek et al., 2018; McCullough & Simon, 2011).



Field research

This chapter is a compilation of interviews, online surveys, and generative data, aiming to provide a deeper understanding of the landscape of the context of brussen and how the chapter take away of visibility among each other resonates with them.



3.1 Understanding online connection

In the previous chapter, challenges in the visibility of brussen were identified. The supportive tools available for brussen aim to connect them, with most of these tools being available or starting online. To gain a better understanding of how brussen experience these online connections, an online survey was conducted. The survey (Appendix 2) was distributed across two social media platforms: the Facebook group BRUS and the Instagram account of mijn_brus_verhaal. This approach was designed to gain preliminary insights into how brussen connect with each other online. All 19 responses were from brussen aged 17 to 54. Key findings from the open-ended questions in the survey are summarized below.

How do you experience the process of coming into contact with other brussen?

Difficult and challenging were mentioned in 10 of the 15 responses.

"Difficult, as a child I had hardly any contact with other brussen. Now I often meet people and only find out after a while that we both have a brus. With social media,

it's a bit easier now, but it always remains somewhat challenging."

Mixed experiences with online and offline interactions

While online interactions provide a broader network, the quality and depth of these connections can vary. In-person interactions, while potentially more meaningful, are limited by fewer opportunities and geographical challenges.

"Difficult, it's hard to have both a personal connection and live close enough to have regular contact."

"It's often easier online because location doesn't matter, so you can have a much broader network."

Challenges with accessibility and awareness

Respondents noted difficulties in discovering support options and groups, with some only recently becoming aware of such resources. This lack of information contributes to the challenges in initiating contact.

"Difficult. I didn't even know there were options for a long time." "Challenging, because you don't know who they (brussen) all are. There's little to be found about it."

Value in shared experiences

Several brussen value the opportunity to connect with others who share similar experiences, emphasizing the enhanced understanding and empathy that comes from such interactions.

"It's nice to be able to talk to someone who has gone through the same thing. You understand each other so much better."

Q2 Would you like to have (more) contact with other brussen and why?

9 of the 15 answers were positive and open to come in contact with other brussen.

"Difficult, as a child I had hardly any contact with other brussen. Now I often meet people and only find out after a while that we both have a brus. With social media, it's a bit easier now, but it always remains somewhat challenging."

Support other brussen

Several brussen express a desire to support others based on their own experiences, indicating a sense of community and responsibility towards younger or less experienced brussen.

"Yes, especially to support and help others, as my experience is almost completely behind me."

"Yes. I am a bit older myself, and I think a lot of problems could have been avoided if there had been more attention and more exchange between brussen."

3.1 Understanding online connection

Value in shared experiences

Many brussen appreciate the potential for mutual understanding and emotional support that comes from interactions with peers who face similar challenges.

"Yes, it's nice to be able to share experiences with someone who really understands what it's like."

"Yes, I would like to come into contact with brussen of my generation to share experiences."

Revolve too much around care giving

A few respondents expressed concerns that these relationships might revolve too much around their caregiving roles rather than personal growth or mutual interests.

"No, I don't feel it adds anything to my own life. It would always revolve around my disabled brother, even in friendships."

Is it important for you that in potential contact with another brus, this person has a brother or sister with the same (type of) disease or disability as yours and why?

Responses are mixed, with some brussen emphasize the relevance of specific shared experiences, while others believe that the general experience of being a brus, regardless of the sibling's specific condition, provides enough common ground for support and understanding.

"Difficult, as a child I had hardly any contact with other brussen. Now I often meet people and only find out after a while that we both have a brus. With social media, it's a bit easier now, but it always remains somewhat challenging."

Specific conditions for deeper understanding

Some respondents believe that sharing similar specific conditions can facilitate deeper understanding and more relevant support.

"Yes. My sister is mostly invisibly ill, which is different from having a physically or intellectually disabled brother or sister." "For long-term contact, yes, because then I can discuss things that are specific to the conditions."

Recognition of universal experiences

Several brussen acknowledge the universal aspects of their experiences, suggesting that any brus can relate, regardless of the specifics of the sibling's condition.

"No, many brussen and, by extension, other young caregivers experience the same things and feel the same emotions." " No, not necessarily, the personal connection is more important." "No, I think the experience of a brus is comparable for many, regardless of what is going on with the brother or sister." "No, because I have noticed that there are often many similarities despite there being a different disease or disability."

Difficulties with awareness and finding online tools and support are shared among participants.

Brussen's experiences are universal; having a sibling with the same special need isn't required, but can enhance understanding.



3.2 Understanding real-life connection

Due to the difficulty brussen face in accessing supportive tools because of the lack of awareness of the term "brussen," places where brussen might encounter each other in person were observed. Most tools are available or start online. The diary aimed to reveal insights into how brussen behave around other brussen and their families during these real-life interactions. A researcher diary was used to document observations, ideas, and reflections.

VEINEdagen

The VeineDAGEN (Veinedagen, 2024) is an event aimed at children and adults with disabilities, their families, and care professionals. This event is a fun day trip for families with children with special needs and provides insights into the possibilities for people with disabilities, including aids, mobility, holidays, therapies, work, study, and social interactions. The event offered a place to observe brussen with their families and led to the following insights:

- There were only two stands out of the approximately 80 stands in total directed towards brussen. These were the lifestyle coach Nickee Hoedemaekers from Nice2Bme (Nice2Bme | Kind- En Gezinscoaching, n.d.), and the stand of the VU Amsterdam also featuring the serious game project of Broodels (Serious Game Voor Brussen, n.d.).
- The exhibitors at the stands primarily directed their conversations towards children with disabilities and their parents, often failing to include the other brussen in the conversations.
- There were no playgrounds designated for brussen; all the available play areas were designed primarily for wheelchair users or those with disabilities, leaving no space for brussen to wait and play while their families were engaged.



Brussen often seemed disengaged at the event, sometimes playing with items like a dog-shaped wheelchair cushion while their families interacted with exhibitors.



3.2 Understanding real-life connection

Hospital waiting room

While sitting in a children's hospital waiting room, two children were observed playing. The older child, presumably a brus, and the younger child, presumably with special needs as she was called for the appointment, were both playing at a Lego Duplo table. The brus actively helped his younger sister by reaching for blocks that were far away and assisting in making decisions for their building project. Although there were other children of the same age group as the brus in the waiting room, he focused more on playing with and helping his younger sister. The brus may not have realized that other brussen were in the waiting room, or perhaps he simply preferred playing with his sister and assisting her.

> A brus helps his younger sister with special needs build a Lego Duplo project, focusing on her despite other children being present.

Family day

During the family day for families of a child with special needs, organized by Ouders voor Ouders, brussen received a voucher for a free gift. At the brussen stand, where they could exchange the voucher, parents were introduced to the Ouders voor Ouders organization. This organization aims to support and empower parents of children with special needs by creating a network where they can receive support, be themselves, and recharge. However, the approach of engaging parents by giving brussen a gift felt awkward. The intention was to give recognition to the brussen with the gift, but this method unintentionally overshadowed them, as observed in the interactions. When parents engaged in conversation with the organization, the brussen often moved away and disengaged. An Ouders voor Ouders volunteer explained, "Parents are sometimes forgotten and sacrifice themselves but can find recognition among each other." It was surprising to observe that neither the parent nor the volunteer considered how these words might resonate with the teenage brus, who became even more disconnected and retreated to his smartphone.

Even in places where brussen encounter each other, there is a lack of a trigger to encourage engagement.

3.3 Co-design for visibility among brussen

With the insight that even when brussen encounter each other, there is a need for a trigger to facilitate engagement, a collaborative approach was taken to generate ideas for potential recognition possibilities among brussen. Through a co-design session, ideas were explored to enhance visibility among brussen. This session was held during an Allstarz brussen camping trip weekend, involving 15 participants aged 5 to 17, all of whom are siblings of children with special needs and familiar with each other. The main goal was to understand the environments where brussen feel invisible and how social recognition can improve their visibility. A detailed protocol of this session is available in Appendix 3.



- The co-design research goal is to gather insights to help answer this research sub questions:
 - In which places do brussen feel invisible to each other?
 - How can social recognition from peers help fulfil the need for visibility?
 - How can playful interactions in everyday locations enhance the visibility of brussen?

Think of ideas to help brussen recognize others as brussen and are able to meet each other.



T

Allstarz brussen camping trip weekend.

- 2**5** 15 p
 - 15 participants aged between 5-17.



Introduction: Presentation of the research findings
Warm-up: Quick wording brainstorm
Brainstorming: Using the Picture Brainstorm method to generate ideas for visibility-enhancing ideas.
Discussion: Group discussions to elaborate on ideas.
Wrap-up: Summarizing insights and validating findings with participants.

Audio recording and worksheets.

Not all brussen were used to brainstorming, leading them to interpret the picture sometimes too literally.

Figure 4, Co-design for visibility among brussen materials

3.4 Results and analysis

In this analysis, open coding was used to systematically categorize and interpret the quantitative data, helping to identify patterns and themes emerging directly from the data. The results are visually represented in two figures, illustrating the relationships between different data components and showing the progression from abstract suggestions to concrete values. This structured approach ensures that the analysis remains grounded in the actual data, providing relevant and reflective findings. By building each layer upon the previous one, it offers a comprehensive overview of the research outcomes.

Ideas and locations from the session

The core layer shows specific ideas and locations generated during brainstorming, reflecting the categories identified in the next layer.

Categories

This layer organizes the different types of ideas and locations.

Comments from the participants

This layer includes direct quotes or paraphrased remarks, adding context and depth to the values identified.

Underlying values

This layer captures the core values expressed by the participants.





3.4 Results and analysis - Underlying values

Comments "It's up to you Autonomy in visibility whether you want to share it or not." "I think it's **Ideas category** really important that you can choose Place away from home for yourself." "Monopoly is something that you mainly Ideas from the session Online Wearables "A sort of big chill play at home with your family, I think." lounge. Awesome. -"I think that when you're App Emoji Have you been to Ribbon, brooch, or pin Social media Avatar younger, games can help such a place Necklace Hat T-shirts initiate contact. When you're before? - No." Online older, you're more likely to Ring Colored shoelaces start a conversation instead." Festival "Whenever someone "A kind of Brussen football. You see a B Silent disco comes home with on a ball and know it's for the Brussen." Café Locations me to play, they're Hand grip or gesture Chill space Play and events always playing with **Brussen Monopoly** Easy engagement my brother." Lanyard Ball Water bottles through play Twister Sticker Power bank Building a chill room Keycard Cards "Most kids who play football, Tattoo outside the house: Flag or whatever they do with a "Those parents have Items ball, you can ask them to join the financial means to in, and you immediately get do that. But it might Statements some recognition." not have been the same otherwise." "Did you always want a tattoo? No, it came with age I think so because you "Something with a logo because it wouldn't "As you grow older, become more proud of it." stand out, and I wouldn't have to say anything." you feel more confident starting **Confidence when older** conversations." Awareness in recognition

Underlying values

Figure 6, Co-design analysis for ideas and underlying values



3.4 Results and analysis - Locations

Underlying values



3.5 Co-design insights and reflection

Insights from the session Location for visibility

Locations outside the home provide brussen with the freedom to choose how they want to present themselves. They can balance between blending in as a regular child or standing out by sharing their unique experiences as a brus. In daily settings, brussen often prefer the comfort of anonymity, as it allows them to avoid standing out.

Play for younger children

Play was highlighted in the session as a low-threshold tool for connecting with each other, particularly for younger brussen, as it offers an easy and natural way to engage with other children. As brussen grow older, their preference shifts towards more indepth conversations.

Personal attention and identity

The session emphasized recognizing the individual identity of each brus, not just their role as a sibling. It's essential for brussen to feel proud of themselves, focusing on their identity beyond their relationship with their sibling. A key insight from the camp showed that brussen appreciate moments where they are the center of attention, reflecting their often overshadowed needs due to the focus on the sibling with special needs.

"You can be proud of yourself as a sibling. But maybe that's really what it's all about. Not about having a brother or sister, but about being yourself."

Autonomy in visibility

The discussions highlighted the varying degrees of openness among brussen in sharing their roles and feelings. It is important to respect their choices in how they share their experiences. The willingness to share and be visible as a brus can vary daily, making it crucial for them to have autonomy over when and where they choose to be visible and stand out as a brus.

Reflection of the session

The co-design session provided valuable insights into brussen's visibility and experiences, confirming findings from the context analysis and field research. It emphasized the importance of enhancing social recognition among brussen by revealing their visibility issues. The session highlighted that playful interactions can naturally enhance visibility. The picture brainstorming method was challenging for some participants, as they took the pictures too literally, limiting their creativity. Fortunately, the word brainstorming activity allowed them to better express their ideas. Including multiple activities that stimulate different types of creative thinking proved helpful for future sessions.

Play could help brussen engage in a way that comes natural for children.

Brussen seek autonomy in their visibility and attention to their personal identity, both aligning with a theme of empowerment.



3.6 Definition of play in this project

Play is a concept hard to define, and experts on child development and play do not agree on a single definition. Within this project, play is defined as an open-ended and intrinsic activity characterized by self-motivation, creativity, and social interaction, with the goal of meeting the wishes and needs of brussen. The project aims to design a toy, a tool for play, to enhance the visibility of brussen and help them socially connect. As Gielen (2010) mentioned, anything can be a toy, but from a designer's perspective, a toy cannot be just anything: a designer needs to focus on a well-thought-out core use of the toy. Together with brussen, this core use of the project is discovered in a participatory way, involving them in generative and co-design sessions. The definition of play in this project is derived from core qualities of play that align with the project goals, such as intrinsic motivation, social interaction, and creativity.

Intrinsic motivation

Play is driven by internal desires and interests rather than external rewards or pressures. This intrinsic motivation is fundamental to play, as it allows children to engage deeply and meaningfully in activities that interest them, fostering a sense of autonomy and personal satisfaction (Hughes, 2001). In this context, when brussen often tend to stay in the background, enhancing their visibility should be a process that brussen can control and balance themselves. By focusing on activities that brussen find genuinely enjoyable and interesting, the toy should help them come forward naturally, allowing them to choose when and how to make themselves visible. This self-regulated approach is essential for ensuring that the increase in visibility feels comfortable for brussen.

Social interaction

Canning (2007) explains that play involves understanding and connecting with others on both cognitive and emotional levels. This empathetic engagement allows children to develop social bonds, practice cooperation, and navigate complex social interactions. Social interaction in play could help brussen address their experiences of feelings of isolation and invisibility. It could create opportunities for brussen to connect with each other and facilitate social interactions that help brussen feel seen, understood, and valued.

Creativity

Play provides a platform for creativity and the exercise of imagination. Through play, children can explore new ideas, experiment with different scenarios, and express themselves in unique ways (Sutton-Smith, 1997). Encouraging creativity in play allows brussen to personalize their play experiences, which can enhance their sense of ownership and pride in their activities. This could enhance self-awareness and confidence, helping them to dare to become more visible to each other.



3.7 six Types of play

Since play is difficult to define, six types of play can be used to assess and evaluate play within concepts within this project to meet the needs of brussen. These types of play combine various classifications based on the work of Dutch phenomenological psychologists Vermeer (1972) and Vedder (1977).

1. Movement play

Play that encourage gross motor skills through movement and physical activity. Examples include playing with rattle toys, tumbler toys, and balls which include coordination and physical development.

2. Sensopathic play

This type focuses on engaging the senses and includes activities that involve materials such as sand, water, and clay. It is important for the development of sensory processing skills.

3. Playful handling of objects

This type involves interacting with various objects to understand their properties and includes playing with blocks, ring towers, and dolls. This kind of play aids in cognitive development and fine motor skills as children learn to manipulate small items.

4. Construction play

Building and creating structures or other objects are key in this type of play. Activities such as drawing, cutting, pasting, and using construction toys like building blocks and carpentry tools help develop spatial awareness, problem-solving skills, and creativity.

5. Fantasy and role play

This involves imaginative scenarios where children engage in role-playing using costumes, play kitchens, and dollhouses. It encourages creativity, storytelling, and social skills as children act out various roles and scenarios.

6. Success and team play

Games and activities that involve other children or team efforts, like playing with dice games, football, and bowling, promote social interaction and teamwork. These activities help children learn about cooperation, competition, and the importance of following rules.



3.8 Brussen projects with play

After identifying play as a promising tool for natural engagement to brussen, I explored other research projects that incorporate play as a valuable and meaningful tool for brussen. Two of these research projects specifically targeting the siblings of children with special needs are 'Giving Siblings a Voice' and the serious game 'Broodels'.

Giving siblings a voice

In her Design for Interaction master's thesis at Delft University of Technology, Schumacher (2023) explored the dynamics within families having children with special needs, focusing on the siblings of these children, referred to as "brussen" in this research project. Her research identified key challenges and strengths that brussen experience, leading to the development of a storytelling tool designed to enhance the bond between siblings and their parents. This tool was primarily conceptualized to facilitate sharing and understanding within the family unit through playful interactions.

Schumacher's work provided an understanding of the emotional landscapes and the social dynamics brussen navigate. She identified that brussen often feel invisible within their families and communities because the focus is usually placed on their siblings with special needs. However, she also identified the potential and importance of the role of playful interactions in supporting brussen. Building on her ideas, the role of play for visibility among brussen is further explored in this project.



Figure 9, Insights of play for brussen (Schumacher, 2023, page 137)

Broodels serious game

Broodels is a psychological intervention serious game designed to help siblings of children with special needs manage their thoughts and emotions on key issues (Sterkenburg, 2023). There are still few evidence-based interventions and support systems for siblings of children with disabilities (brussen). Sterkenburg's 2023 study evaluates 'Broodels,' which targets young siblings and aims to improve their quality of life, adjustment to disabilities, and overall psychosocial health. While this research enhances the understanding of serious games for brussen, its effectiveness remains under review. If proven effective, Broodels could become a free, accessible intervention for siblings.

3.8 Brussen projects with play

Interview linda messemaker-vermaan

Due to ongoing evaluation of Broodles, I interviewed researcher Linda Messemaker-Veerman, a PhD candidate studying psychosocial well-being aspects including self-esteem and sibling relationships. In the interview we talked about how the design directions of visibility, play and empowerment resonate with the Broodles project, and with the experience of Linda.

Awareness and visibility of brussen

Linda highlights that many brussen are not aware of others in similar situations, which suggests a need for interventions that increase their visibility to each other.

"We are currently looking at what is available for brussen and have also conducted interviews with brussen to understand their need for support. We noticed that they say, 'Oh no, I actually don't know any other brussen,' even though you know they must know someone, but they are not aware of it."

sharing experiences with other brussen

Brussen enjoy engaging in fun activities with each other, suggesting that playful interactions can facilitate meaningful connections and shared experiences.

"In the interviews that I have previously conducted with brussen, we particularly emphasize that they enjoy doing fun activities, even with other brussen. I asked them, what would you like to do together with other brussen? And then they primarily want to do something fun, to talk and share experiences with each other, but it should also be mostly fun and not too serious."

Competence in discussing needs and experiences

Linda notes that brussen within the 7-12 age group can articulate their experiences and awareness of their unique situations, showing variability in how they perceive and discuss their challenges.

"Brussen are able to discuss their experiences and how aware they are of certain matters. You can see a difference; some kids focus only on the positives and find it hard or are reluctant to share the negatives, whereas others are quite aware of issues like getting less attention. This awareness usually starts to show from around the age of six."

Brussen are also just children who enjoy play and do not always reflect deeply on their situation.

7-12 is an age group when brussen start to articulate their experiences.



3.9 Age group

Brussen aged 7 to 12

Brussen are often more mature, overlooking their need to act like children (Milevsky, 2019). In adolescence, brussen are developing their own identity and are in a vulnerable transition period (Hoefman & Van Zoest, 2019). In preadolescence, children generally start to become more self-aware. By age 7 or 8, kids start to form a general sense of their own worth. They begin thinking about themselves in a more grown-up way around age 6 or 7, but it's a gradual process that continues until they're 11 or 12 (Piaget, 1969). This process of gaining more selfawareness involves the ability to identify and recognize emotions, self-perception, and recognizing strengths, needs, and values (CASEL, 2008).

This is why this project focuses on the specific age group of 7 to 12, where self-awareness generally starts to develop for children and can play a role in preparing them for the vulnerable transition to adolescence. This is also the moment when children start to recognize their personal needs.



Figure 10, Brussen within the 7-12 age target group (Kindred, 2021).
Chapter take-aways

No focus on specific special needs

Brussen do not prioritize interacting with those who have siblings with the same special needs. They find recognition in shared qualities and challenges, rather than specific conditions; it's about shared experiences. Consequently, this project does not focus on a specific special need of the sibling of the brus.

Age group

During preadolescence (ages 7 to 12), brussen begin to develop self-awareness, recognizing their own worth and personal needs (Milevsky, 2019; Piaget, 1969). This project focuses on this specific age group to support their development and prepare them for the vulnerable transition to adolescence (Hoefman & Van Zoest, 2019; CASEL, 2008).

Visibility Among Brussen

The lack of awareness of the term "brussen" makes it difficult for them to find each other online. Additionally, when brussen encounter each other in real life, there is often something missing to help them recognize and engage with one another.

Play as a Design Direction

Play was mentioned as a way to help young brussen engage with each other naturally, even without being aware of the term "brussen." The potential role of play in this project should be explored further and is adopted as a new design direction.

Empowerment as a Design Direction

Brussen want autonomy in their visibility and attention for their personal identity. Both insights align in the theme of empowerment. The developmental stage of the chosen age group fits well with this design direction, which should be explored further to understand its potential role in supporting brussen.



PROJECT VISION

THROUGH PLAY, EMPOWER BRUSSEN AGED 7 TO 12 TO ENHANCE THEIR VISIBILITY AMONG EACH OTHER.

Concept exploration This chapter begins with an overview of the initial

This chapter begins with an overview of the initial ideation phase, where various concepts were evaluated for their potential to empower brussen. Following this, the chapter delves into the findings

from a generative session, which led to the selection of the brus backpack concept as the project direction. The session provided valuable insights into how the backpack can empower brussen by enhancing their visibility and social connections. Participant feedback emphasized the importance of customization, personalization, and flexible design elements.



4.1 Ideation

With the design vision and goal in mind, an initial concept ideation was conducted to explore the potential of the core values.



mood lanterns

A set of public interactive mood lanterns that change color and intensity based on the emotions and energy levels of brussen. Brussen can control the lanterns using touch-sensitive panels or voice commands, creating personalized ambient lighting environments that reflect their inner feelings and moods.

Journal Kit

A journaling kit complete with writing prompts, art supplies, and mindfulness exercises tailored to the needs of brussen. The kit could provide a structured outlet for brussen to explore their thoughts, emotions, and experiences in a creative and therapeutic way.

Create recognition

Story stones

A set of storytelling stones engraved with symbols or images representing common themes ar experiences of brussen. These stones could be used in guided storytelling activities or as conversation starters to facilit*a* meaningful discussions and connections among brussen.



4.1 Ideation



Stuffed animal

A brus cuddly toy could be personalized, and making it could be a meeting point to meet other children. Items could represent challenges, emotions or characteristics of the brus and could serve as a conversation starter.

Create recognition



Hero backpack

Brus backpacks can be used to collect badges and buttons, for example, for attending appointments or treatments, or for personal development. The backpack can serve as a point of recognition for other brussen. Additionally, brussen can use it practically to carry items from home for themselves or for their sick sibling.

Geocaching

Brus geocaching game where brussen follow clues and search for hidden 'catches' that include games, treasures, or messages, specifically designed to connect and inspire brussen. This can be a fun and adventurous way to find each other and form new social connections.





Connection bracelets

Interactive brus connection bracelets that brussen can wear as a symbol of their solidarity with each other. These colorcoded stones can be exchanged between brussen as a sign of friendship and support, and can be used to recognize and connect with each other when they meet.



4.2 Opportunities for empowerment

Out of all the ideas generated in the ideation phase, the brus backpack and the brus geocache emerged as the most promising concepts. These ideas stand out because they offer significant opportunities for empowerment through play. Empowerment trough play in this research project is defined as a process that enables children through opportunities that build self-belief, competence, and confidence, particularly in social play (Canning, 2020). An ideation for opportunities for empowerment are visualized in figure 11 and figure 12.

Brus backpack

The brus backpack concept allows brussen to collect badges and buttons that represent their achievements, milestones, or personal development. According to Canning (2007), play provides children with the opportunity to develop their unique self, increase awareness of personal and social relationships, and most importantly, empower them to grow as individuals. The backpack serves not only as a practical tool but also as a symbol of identity and belonging. Brussen can recognize each other through these backpacks, creating a sense of community and reducing feelings of isolation. The ability to personalize the backpack with colors and designs further enhances their creative expression, which is a powerful form of selfempowerment.

Brus geocache

The brus geocache concept involves a treasure hunt where brussen follow clues to discover hidden caches containing minigames, treasures, and inspiring messages. This active participation encourages critical thinking, problem-solving, and teamwork, building a sense of competence and confidence. According to Grolnick, Deci, and Ryan (1997), autonomy in play, where children follow their interests and choose their activities, is one of the most empowering experiences. The geocache game's structure provides this autonomy, empowering brussen to build independence, self-esteem, and resilience. Personalized rewards, such as stickers of their avatars, reinforce their achievements and provide a tangible sense of ownership and pride in their journey.

Combining the two concepts

Combining the brus backpack and brus geocache concepts can further enhance empowerment by integrating the personal development elements of the brus backpack with the interactive and engaging activities of the brus geocache. To explore this potential, a co-design session will be held to evaluate the most important and valuable aspects of both concepts separately and together. Additionally, this session will explore other insights into the qualities and added values of certain characteristics, aiming to identify whether one concept is best for empowerment, if a combination of both provides the greatest benefit, or if there are other combinations that offer unique advantages. Beyond evaluating the concepts, the co-design session will also seek to gain deeper insights into empowerment for brussen, including their preferences and needs.



4.2 Opportunities for empowerment

Personalization through Badges and Buttons

Each badge or button could represent a personal achievement, milestone, or experience, allowing brussen to visually showcase their journey. This recognition can boost their self-esteem and sense of accomplishment.

Recognition and Identity

The backpack can serve as a symbol of identity and belonging among brussen. Seeing another child with the same backpack can create a sense of community and support, fostering connections and reducing feelings of isolation.

Hero backpack

Creative Expression

Allowing brussen to personalize their backpacks with colors, designs, and additional accessories lets them express their individuality, which can be a powerful form of self-empowerment.

Practical Utility

By using the backpack to carry items from home for themselves or their sick sibling, brussen are given a practical tool that supports their caregiving role, enhancing their sense of responsibility and capability.



4.2 Opportunities for empowerment

Interactive and Engaging Activities

The geocaching game includes following clues, searching for hidden 'catches,' and engaging in mini-games. This active participation encourages brussen to use critical thinking, problem-solving, and teamwork, thereby fostering a sense of competence and confidence.

Connection and Social Interaction

The game is designed to connect brussen, inspiring them to form new social connections. Shared experiences in finding caches and playing mini-games can build friendship and mutual support, stimulating emotional empowerment.

Personalized Rewards

At the end of the game, a sticker is printed from the personalized character that brussen have built during the mini-games. This tangible reward reinforces their achievements and provides a sense of ownership and pride in their unique journey.

Inspiring Messages and Treasures

The hidden catches include not just games, but also treasures and messages specifically designed to inspire and motivate brussen. Positive reinforcement and motivational messages can significantly boost their morale and self-worth.

Geocaching

Character Building

Earning items for a character through mini-games allows brussen to see a visual representation of their progress and achievements. This characterbuilding aspect can serve as a metaphor for their personal identity, growth, and development.

Figure 12, Opportunities for empowerment brus geocache concept

4.3 Generative session for empowerment

This chapter details a generative session exploring how the brus backpack and brus geocache concepts could empower brussen. Two scenarios were presented: one for the brus backpack and one for the brus geocache. Participants used post-its for feedback, with colors representing different responses: Red for negative feedback or concerns, Yellow for neutral comments or questions, and Green for positive feedback, suggestions, or likes. After discussing these scenarios, participants envisioned a combination of both concepts. The session, conducted in collaboration with Allstarz supervisors, involved two participants aged 20, who are brussen themselves and familiar with each other. A detailed protocol of this session is available in Appendix 5.



The co-design goal is to gather insights to help answer this research sub questions:

- What opportunities does play provide for brussen to enhance empowerment?
- Which themes in empowerment show the most potential in empowering brussen to be integrated into play activities?

Online, collaboration with Allstarz supervisors, familiar to
work with the target group.



 \bigotimes

2 participants both aged 20.

Introduction: Presentation of the research findings
 Brainstorming: Participants introduced to concepts via scenarios of brus backpack and brus geocache.
 Collaborative thinking on implementing these concepts.
 Discussion: Participants asked about combining both concepts and preserving key values.
 Wrap-up: Group discussion to elaborate on the feedback.

Audio recording.

After starting the session and noticing that discussions progressed faster than pasting the post-its, participants suggested continuing without writing them out.

Figure 13, Scenario example pages and posits from the generative session

4.4 Results and analysis

To analyse the data from the co-design session on empowerment scenarios, an affinity diagram method was used. This method organizes qualitative data into meaningful categories and identifies key themes related to empowerment.

Data collection

During the co-design session, participants discussed various aspects of three concepts presented in scenarios. These discussions were recorded and transcribed to capture all relevant feedback and comments.

Selective coding

Selective coding was applied to the transcriptions to identify quotes and segments related to the four key themes of children's empowerment highlighted by Natalie Canning (2007): Autonomy and Control, Participation and Voice, Social and Emotional Development, and Creative Expression. This whole research project frequently references Natalie Canning's work, a prominent researcher in child empowerment. Each data segment was labelled with the corresponding theme described below.

Autonomy and control

A fundamental aspect of empowerment in play is allowing children to have autonomy and control over their activities. This involves providing opportunities for children to make their own choices and decisions during play, helping them develop a sense of independence and self-efficacy.

Participation and voice

The paper emphasizes the importance of giving children a voice in their play by listening to their ideas and incorporating their preferences. When children feel their opinions matter, their engagement and investment in play increase, enhancing empowerment.

Social and emotional development

Empowerment through play supports children's social and emotional development by allowing them to explore emotions, develop empathy, and build social skills. Peer interactions during play teach children to negotiate, cooperate, and resolve conflicts.

Creative expression

Play serves as a vital outlet for creative expression. Empowering children through play encourages creativity and imagination, aiding cognitive development and allowing children to express themselves freely and develop unique identities.

Creating the affinity diagram

An affinity diagram was created to visually organize the coded data. Quotes and comments from the transcriptions were written on color-coded post-its, each representing a different conclusion:

- Blue: Insights on the brus backpack
- Purple: Insights on the brus geocache
- Orange: Insights on the combination of both concepts
- White: Quotes from the co-design session



4.4 Results and analysis

Grouping and categorization

The color-coded post-its were grouped based on their related themes and sub-themes. Similar ideas were clustered together to form broader categories under each theme. For example:

- Autonomy and Control: How children can personalize their backpacks or control geocaching gameplay.
- Participation and Voice: How children's opinions and preferences are incorporated into the backpack design or geocache activities.
- Social and Emotional Development: How these activities help children understand their emotions and develop social skills.
- Creative Expression: How children can express themselves through customization and imaginative play.

The categorized affinity diagram can be found in Appendix 6.

Analysis and interpretation

The final step involved analysing the grouped data to draw conclusions about the effectiveness and empowerment potential of each concept (backpack and geocache) and their combination. This included interpreting how each theme was addressed by the different concepts and determining which concept offered the most potential for an empowering experience for brussen.



Figure 14, Affinity diagram to analyse the co-design session



4.5 Session insights and reflection

Insights within the categories of empowerment

The analysis of the co-design session results, organized using an affinity diagram and selective coding, shows that the brus backpack concept shows most potential for empowering children across four themes: autonomy and control, participation and voice, social and emotional development, and creative expression, as explained below.

Autonomy and control

Participants highlighted the importance of being able to personalize the backpack based on their daily moods, experiences and preferences. The ability to choose whether to use the backpack as a standard school item or as a tool for social interaction empowers children to manage their social engagements actively. This flexibility supports their independence and helps them develop a sense of self-efficacy.

Participation and voice

Participants appreciated the opportunity to influence the design and functionality of the backpack. By incorporating elements such as customizable buttons and colors, children can express their preferences in what kind of connection they are in need of and open to. The participants feedback underscores the value of involving children in the design process, which enhances their engagement and investment in the product.

Social and emotional development

The backpack serves as a metaphor for personal journeys, helping children reflect on and share their experiences. This symbolic aspect enhances empathy and social connections, as children can relate to each other's stories through the backpack's design. Customizing the backpack based on personal experiences can help children reflect, understand, and manage their emotions better, promoting emotional growth and social interaction.

Creative expression

A basic, universally attractive design provides a way for children to personalize and decorate. Participants emphasized the importance of a versatile design that allows for ongoing customization, enabling children to express their individuality and creativity freely. This flexibility ensures that the backpack remains engaging and meaningful to each child.

4.5 Session insights and reflection

Additional Insights from the Session

The generative session provided valuable insights outside the categories of empowerment. One significant insight was the importance of customization and personalization in making the brus backpack more appealing and effective. Participants expressed a strong desire to personalize their backpacks with different colors, patches, and accessories. This level of customization allows children to express their individuality and enhances their attachment to the backpack. As one participant mentioned, "You need to be able to personalize it, either by making it completely your own or by having enough options so there's always something you like."

The concept of flexibility and adaptability was also emphasized. Participants discussed the need for the backpack to allow for frequent changes in personalization, reflecting how children's feelings and circumstances can change daily. There might be days when they want to display all their badges related to their situation as a "brus," and other days when they want to remove all such indicators. One participant highlighted the importance of this feature, saying, "I think the idea of a button is really nice... I can also understand if you've had a bad morning and just want people to leave you alone... that you have that choice." Additionally, the ability to change how the backpack is personalized means it can grow with the child. As one participant noted, "Having the choice to change how you personalize your backpack means it can grow with you, as you start to like different things or are open to new connections." Another key insight was the potential for the backpack to facilitate social recognition and interaction. Participants suggested that the backpack could include visible indicators, such as specific patches or colours, that signal specific shared experiences or interests. This would make it easier for children to recognise and interact with brussen who have similar backgrounds or experiences. For example, one idea was to use colour-coded straps or buttons to indicate different types of connections or needs.

Spreading awareness about the term "brussen" was another important topic. Participants suggested that the backpack could serve as an educational tool to inform others about the concept of "brussen" and to spread awareness. This could involve adding informational tags or QR codes linked to resources explaining the term. Additionally, participants mentioned the importance of having a universal design element so that all backpacks are recognisable as belonging to "brussen." This would help in spreading awareness and creating a sense of community among children. As one participant noted, "Something with a logo because it wouldn't stand out, and I wouldn't have to say anything."

4.5 Session insights and reflection

Reflection on the session

Reflecting on the limitations, the online nature of the session made it harder for participants to creatively express themselves through drawing or quick writing. This may have hindered participants' ability to fully engage with the brainstorming process. After starting the session and noticing that discussions progressed faster than writing the post-its, participants suggested continuing without writing them out. This adjustment was necessary but may have limited the depth of recorded ideas.

Additionally, although the scenarios were designed to be as open as possible to stimulate input from the participants, they may have constrained participants' thinking to specific contexts.

The session was joined by two supervisors of a brussen camp who are brussen themselves. While they are experienced in working with the target group, they are not part of it themselves. Their involvement may have been beneficial for discussing issues and potentials more easily, but further validation within the actual target group is still necessary.

Linking insights to design vision

The insights from the generative session support the design vision of empowering brussen by emphasizing customization and personalization of the brus backpack. This approach enhances autonomy and creative expression, allowing children to actively manage their visibility, social interactions, and display their unique identities. The inclusion of flexible and adaptable design elements ensures that the backpack can grow with the child and remain suitable for the large age group of 7 to 12, maintaining relevance as their preferences and connections evolve with age. Additionally, the backpack's potential to facilitate social recognition and interaction through visible indicators and universal design elements helps brussen identify and connect with each other, thereby enhancing their visibility and sense of community.

Chapter take-aways

concept direction

The brus backpack has been chosen as the primary concept due to its strong alignment with the project's design vision and core values, as revealed by the generative session insights. It supports customization, personalization, and flexible design, enhancing children's autonomy and creative expression. Additionally, the backpack could improve visibility among brussen and stimulate social recognition and interaction.

Visibility

The generative session highlighted the potential of the backpack to facilitate social recognition and interaction. Visible indicators, such as specific patches or colours, can help children identify and connect with other brussen, enhancing their sense of community.

awareness potential

Spreading awareness about the term "brussen" was seen as crucial. The backpack can serve as an educational tool, with informational tags or QR codes to explain the concept, helping to increase recognition and support among peers.

Flexibility and Adaptability

Participants of the generative session emphasized the need for the backpack to adapt to changing moods and circumstances. This flexibility ensures that the backpack can grow with the child, remaining relevant and useful as they mature and their preferences evolve.

Empowerment in personalisation

The findings support the design vision of using play to empower brussen. Integrating playful elements into the backpack design helps children express themselves and manage their self-awareness. The generative session highlighted the importance of allowing children to customize and personalize their brus backpacks, promoting autonomy and creative expression, and enabling them to actively manage their visibility and social interactions.

Concept direction

This chapter focuses on developing the brus backpack concept with personalized buttons to enhance social recognition and connection among brussen. It details co-design sessions where brussen provided feedback on personalization features like symbols and colors. These sessions highlighted the importance of elements that promote visibility and easy social engagement. The insights gained help align the design with brussen's needs, ensuring the backpack is functional and emotionally supportive, enhancing empowerment and social connection.

5.1 Co-design for buttons

To determine if the concept of the brus backpack resonates with the target group of brussen, a co-design session was organized to co-create buttons. This session aimed to engage brussen in the design process of the buttons for the brus backpack and evaluate if these buttons could stimulate social recognition. Held during a family day event, the session was designed to be short and straightforward to facilitate easy data collection. Participants were asked to draw a button and explain their design. A picture was taken of their answers and the resulting button, which participants could keep for the rest of the day. At the end of the day, brussen were asked open-ended interview questions to determine if they noticed any differences when wearing the button during the event. The session, conducted in collaboration with Ouders voor Ouders at a Brussen Festival. involved 34 participants aged 5 to 13. A detailed protocol of this session is available in Appendix 7.

The co-design goal is to gather insights to help answer this research sub questions:

• How can social recognition from peers help fulfill the need for visibility?



How could you show what kind of brus you are with this button?

Conducted in collaboration with Ouders voor Ouders at a day for the whole family of brussen.



34 participants both aged 5-13.

Introduction: Presentation of the brus backpack concept. **Drawing activity:** Participants were asked to draw and design a personal button.

Discussion: Participants asked to explain what they drew and why.

Wrap-up: A picture was taken of their answers and the resulting button, which participants could keep for the rest of the day.

Interviews: At the end of the day, open-ended interview questions were asked to determine if participants noticed any differences when wearing the button during the event.



Photographs of the buttons and the participants' responses were collected, along with field notes from the interviews.



Drawing selection could have influenced different potential outcomes.

High participant numbers led to incomplete data and lack of engagement with the questionnaire.

Morning participants were unavailable for interviews later in the day.



5.2 Co-design insights and reflection

The co-design session provided valuable insights into the preferences and behaviors of brussen regarding visibility and social recognition through the use of personalized buttons. The following insights and conclusions are drawn from the session.

Potential for interaction and connection

Some participants, despite noticing other buttons, felt intimidated to initiate conversations. For instance, a participant noted, "I did see others, but I found it intimidating to bring it up." This indicates a need for additional interaction possibilities to encourage social engagement. For example a other participant mentioned, "Yes, I talked to another girl about them. She also had one, and she had a lightning, and I had a cloud, so she said that we could fit together." This suggests that buttons with complementary designs can serve as conversation starters and facilitate connections between brussen. A new co-design session could help ideate on the design of additional interaction possibilities.

Attachment methods

A participant expressed concern about potential damage to clothing: "I was afraid it would make a hole in my shirt." This feedback highlights the importance of using attachment methods that do not give the feeling of damaging the material. A different attachment method and a universal item like the backpack designed for placing the button could help reduce the fear of damaging personal items.



Figure 15, Pictures from the button co-design session



5.2 Co-design insights and reflection

Social dynamics

The comparison of buttons among brussen can affect children's self-esteem. It is crucial to design buttons that emphasize uniqueness and personal meaning, rather than promoting comparison. One participant mentioned not wearing their button because they "liked the one my sister had better and didn't like mine." This underscores the need for designs that suit individual tastes and reduce comparisons. Ensuring a variety of attractive designs or offering limited personalization options can help address this issue.

Reflection on the session

The selected drawings were intended to make it less daunting for the brussen to start on a blank sheet of paper, which can be challenging for children. These drawings were chosen because they could serve as metaphors while still allowing room for interpretation and additions by the brussen. However, a different set of drawings might have influenced them to draw something different. For future sessions, it would be beneficial to reflect on this beforehand and select drawings or figures from literature with deeper meanings or intentions.



Figure 16, Buttons made in the button co-design session

Not all brussen who created a button completed the questionnaire. Due to the high number of participants, attention was divided ineffectively. Brussen who chose a button and colors just because they liked them were given the option to write that down. Most did not feel the need and left without completing the questionnaire.

The family day lasted the entire day, so brussen who made their buttons in the morning had left by the time interviews could be conducted about their experiences.

Linking insights to design vision

The co-design session provided valuable insights into the preferences and behaviors of brussen regarding visibility and social recognition through personalized buttons. Participants indicated a need for interaction possibilities, as complementary designs encouraged connections, but some felt intimidated to initiate conversations. Concerns about damaging clothing highlighted the importance of non-invasive attachment methods, such as magnetic or clip-based options. Additionally, the issue of button comparison affecting self-esteem underscored the necessity for designs that emphasize uniqueness and personal meaning. Ensuring a variety of attractive designs and limited personalization options can suit individual tastes and reduce negative comparisons. A new co-design session could help to explore and ideate on additional interaction possibilities.

5.3 Design decisions & insights summary

Backpack

- Allows frequent and easy changes in personalization with interchangeable elements for daily mood changes.
- Adaptable design that grows with the child.
- Facilitates awareness, recognition, and engagement among "brussen" through its universally identifiable features as a brus backpack.
- Serves as a practical tool for carrying items from home for themselves or their sick sibling, enhancing their sense of responsibility and capability in their caregiving role.
- Symbolizes personal journeys and responsibilities, encapsulated
- by the Dutch expression "een rugzakje hebben" (carrying a backpack, symbolizing personal burdens).



Buttons

- Encourages social engagement through complementary designs and interactive features.
- Avoids attachment to personal items to prevent damage, using a universal item like a designed backpack for buttons.
- Emphasizes uniqueness with designs focused on personal meaning, reducing negative comparisons and supporting self-esteem.
- Uses personalized yet universal buttons for social recognition and as signals for shared experiences.

5.4 Interactive features exploration

Reflecting on the need to facilitate easy social engagement, a design ideation focused on additional interactive features was conducted. A customer journey map, based on previous design insights and decisions, identified pain points and opportunities for iteration on the ByBrus backpack concept. Each phase in the journey offers valuable insights and opportunities for further development.

Recognition

One key insight is the potential issue for siblings unfamiliar with the term "brussen." To address this, a scannable brus icon could be introduced on the backpack, linking directly to a brus Instagram page with a pinned explanation of the term "brussen" and the concept behind the backpack. This approach would not only educate new users but also integrate them into the community seamlessly, enhancing visibility and recognizability.

Buy to Join

Events specifically for brussen are often difficult to find due to their local nature, and they frequently face low participation rates. When attempting to organize co-design sessions, many events were cancelled due to a lack of attendees. Introducing buttons designed for specific events could help raise awareness and attract more participants. These event-specific buttons could act as both souvenirs and a means to promote future gatherings, thereby creating a stronger sense of community and increasing engagement.

Get Buttons

Instead of relying solely on website ordering, using social media, particularly Instagram, can be more effective. Brussen could design their own buttons and share their stories online. By doing so, they can order new relatable buttons directly from Instagram posts, integrating the process of button acquisition with community storytelling.

Personalization

Personalizing the backpack should be effortless and engaging. To improve user experience, the system for attaching and detaching buttons should be user-friendly, ensuring that personalization remains appealing even as brussen grow older. The process should be simple to encourage frequent updates, reflecting the brussen's mood or experiences.

Sharing

A major challenge lies in lowering the threshold for brussen to start conversations about their buttons and backpacks. Interactive buttons that can be scanned to reveal stories or achievements could facilitate these interactions. Creating structured activities, such as allowing brussen to earn new buttons by scanning other brussen's buttons and making connections, can further enhance engagement and social interaction among brussen.

5.4 Interactive features exploration

Recognition	Buy to join	Get buttons	Personalization	Sharing	
Customer Activities					
 Seeing another child with a ByBrus backpack at an event. Noticing the unique badges and buttons on the backpack. 	 Visiting a stand at an event where ByBrus backpacks are sold. Interacting with the sales person, choosing a backpack and available buttons. 	 Browsing Instagram for posts related to ByBrus backpacks. Discovering new button designs and stories shared and designed by other brussen. Ordering new buttons directly from Instagram posts. 	 Choosing different accessories or buttons to attach each day. Reflecting personal mood or daily experiences through these choices. 	 Talking to other brussen about their backpack and the meaning of their buttons. Sharing stories and experiences linked to the badges and buttons. 	
Customer Thoughts and Emotions					
 Curiosity, excitement, a sense of belonging. 	 Excitement, anticipation, a slight anxiety about fitting in. 	Inspiration, connection, creativity.	• Joy, creativity, empowerment.	 Pride, sense of community, emotional support. 	
Customer Thoughts and Experience					
"That backpack looks special. It must have something to do with brussen."	This backpack looks cool."	"These stories are so relatable. I want that button too."	"Today, I feel like showing my happy mood."	"I can connect with others who understand my journey."	
 Initial recognition creates a sense of community, but interaction can be challenging without clear cues or knowledge of the term brussen. Pain Points and Opportunitie 	 Positive buying experience and happy to start personalising the backpack. Finding out some buttons are scannable and invite to join an Instagram community. 	• Engaging with Instagram allows for creativity and community connection, but navigation and discovery can be improved.	 Daily personalization possibilities enhances continuous engagement and emotional connection. 	 Sharing experiences could lead to community bonds and personal empowerment. 	
 Pain Points: Initial hesitation in approaching someone, fear of being judged or intervene. Opportunities: Enhance visibility and recognizability with unique, scannable buttons linking to an online community. 	 Pain Points: Prices should be low so the options are available for everyone. Opportunities: Provide guided choices, offer special event buttons and customization options. 	 Pain Points: Children might not have a phone or can purchase on Instagram themselves. Opportunities: Improve awareness of the buttons and in collaboration with events also improve the visibility of events. 	 Pain Points: Limited accessories or difficulty in changing them frequently. Opportunities: Offer a wide variety of easily attachable/detachable accessories. 	 Pain Points: Initial shyness in sharing personal stories. Opportunities: Create activities to help brussen share their stories and make it easier to engage. 	

5.4 Interactive features exploration



connection tags

Integrate an NFC tag that can be scanned with a phone to guide users to a platform that spreads awareness about brussen or allows them to collect points for interacting with others. These points could be redeemed for new button designs or other rewards.





Audio-Enabled Buttons

Equip buttons with a small speaker or Bluetooth connection that plays a greeting or fun sound when another brussen's button is detected nearby.





5.5 Co-design for interaction

In addition to the journey map and ideation on additional interactive features, a co-design session was held to generate ideas and insights for interaction possibilities with the buttons on the ByBrus backpack. The session involved two brussen, aged 7 and 8. Participants brainstormed ideas, created lowfidelity prototypes, and presented their designs for feedback. The session's primary goal was to understand how brussen could use these buttons to connect with others and how the buttons could be more engaging. Conducted in collaboration with Nice2Bme brussen coaching, this session provided valuable insights into the preferences and experiences of brussen. A detailed protocol of this session is available in Appendix 9.

The co-design research goal is to gather insights to help answer this research sub questions:

- How can social recognition from peers help fulfil the need for visibility?
- How can playful interactions in everyday locations enhance the visibility of brussen?
- How can co-design workshops involving brussen enhance empowerment through play?

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Generate ideas for interaction possibilities with the buttons on the ByBrus backpack so it is easier to engage with each other.

Nice2Bme brussen coach.



2 participants aged 7 and 8, and a brus coach.

Introduction: Explanation of the ByBrus backpack concept. **Brainstorming:** Generate ideas for button interactions using example buttons, a ByBrus backpack template and markers. **Prototyping:** Create low-fidelity prototypes of buttons with craft supplies.

Presentation and Feedback: Present prototypes and discuss feedback.

Wrap-up: Summarize the session and discuss overall advise for the ByBrus backpack concept.



Audio recording, pictures of the session and the results.

Initially, three brussen were expected to join, but with only two participants, the co-design session became slightly less effective due to reduced group dynamics.



Figure 17, Co-design for interaction prototyping activity



5.6 Session insights and reflection

Use of metaphors

In the co-design session for the buttons on family day, limited drawing options might have influenced outcomes. To address this, the warm-up activity used buttons from Verwonderland's symbol set (Basis Beeldtaal Symbolenset, n.d.), wooden symbols designed to help children visually express themes. The coach introduced these symbols to inspire the design of buttons and badges. The session began with the brussen selecting buttons that resonated with them, explaining their choices and writing down their thoughts. They easily understood the symbols and added metaphors and stories effortlessly. For example, one brus chose a cactus button, saying, "My sister sometimes hurts other children, like a cactus, but if you are careful, cactuses can be nice." Another brus noted that cactuses can grow flowers with care. The coach added, "Maybe you are like the flower, showing how nice a cactus can be."

Sensorics engagement also for the sibling

The first items the brussen grabbed were fluorescent lights and soft, tactile objects. They explained that the lights stood out to them, while the tactile items were chosen because their sibling with special needs would also like them. The boys wanted their siblings to like the backpack, so they chose materials and colors they would appreciate. One brus mentioned, "A big fluff, that's nice to touch. My sister loves feeling things and often squeezes, so that's why I wanted a fluffy ball." Another said, "You use a lot of glitter. Would you personally like glitter? No, but my sister does. I don't necessarily dislike glitter, but it's not my favorite thing either."



Figure 18, Co-design for interaction brainstorming activity results



5.6 Session insights and reflection

Reflection on the Session

The co-design session aimed to enhance social engagement by exploring additional interactive features for the ByBrus backpack. Although initially expecting three participants, only two brussen attended, slightly reducing the session's effectiveness due to diminished group dynamics. However, the session still provided valuable insights. Despite the reduced number of participants, the brussen coach's active involvement helped maintain the session's collaborative spirit. The coach's facilitation ensured that the session remained a true co-design effort rather than just a generative session. The brussen were encouraged to discuss their choices, write down their thoughts, and share personal stories, leading to rich, qualitative data.

The warm-up activity utilized Verwonderland's symbol set (Basis Beeldtaal Symbolenset, n.d.), consisting of wooden symbols designed to help children express themes visually. This approach effectively facilitated conversation and expression among the brussen, allowing them to relate personal experiences to the symbols easily. This method overcame the limitation of a constrained drawing selection that could have influenced potential outcomes in the button drawing co-design session at the family day.

Linking Insights to Design Vision

The session demonstrated that symbols are highly effective in facilitating expression and connection among brussen. Incorporating universally recognizable symbols into the backpack design can enhance social recognition and help brussen identify with each other more easily. Interactive elements, such as exchangeable patches and buttons, can maintain engagement and keep the backpack meaningful over time. These features could include sensorics or other technical additions to create a dynamic and responsive design.

Metaphors resonate differently with each brus, making their stories relatable and personal. Sharing these explanations on a broader level, rather than solely through personal connections, can enhance the collective understanding and empathy among brussen. This could be facilitated through features like scannable QR codes or NFC tags linking to shared stories or experiences.

Chapter take-aways

Engagement Through Interactive Features

Incorporating interactive features could enhance social engagement among brussen. This insight emphasizes the necessity for design elements that encourage brussen to interact and connect more easily.

Effectiveness of Symbols

Utilizing Verwonderland's symbol set proved highly effective in facilitating conversations and allowing brussen to express their experiences visually. This approach helped overcome limitations associated with a constrained drawing selection and demonstrated the potential of symbols in inspiring meaningful design elements.

Personal Stories and Metaphors

Brussen's use of metaphors and personal stories, such as comparing their experiences to a cactus, revealed the depth of their emotional and social insights. This highlights the importance of incorporating elements that allow brussen to share their narratives and connect with others on a deeper level.

Minimizing Damage Concerns

Feedback about potential damage to personal items underscored the importance of designing attachment methods specifically intended for the backpack. This insight will guide the development of user-friendly and non-damaging attachment solutions for the buttons and badges.

Encouraging Broader Engagement

Introducing elements like scannable icons linking to an Instagram page can help educate new users and integrate them into the brus community. This approach can enhance visibility and recognizability, making it easier for brussen to connect and engage with one another.

community Event-Specific Designs

Designing buttons for specific events can raise awareness and attract more participants, creating a stronger sense of community and increasing engagement. These buttons can serve as souvenirs and promotional tools for future gatherings.

Design embodiment

This chapter explores the design embodiment of the ByBrus backpack concept, focusing on the development and refinement of symbolic and interactive buttons. The embodiment is examined in a co-design sessions with brussen, that provided a final feedback and insights. This chapter emphasizes the iterative process of prototyping and testing, highlighting the role of feedback in shaping the final design to better meet the needs and preferences of brussen.



6.1 Symbolic buttons

The first realized buttons for the ByBrus backpack are created inspired by Verwonderland's symbol set (Basis Beeldtaal Symbolenset, n.d.) mentioned earlier in the report and are intended to spark conversations among brussen. Each symbol is meant to be open to interpretation, allowing for multiple meanings and metaphorical understandings, intended to encourage brussen to share their personal interpretations and stories. The embroidery process involves the use of a Brother embroidery machine. The embroidery is done on a special type of fabric that dissolves in water. After the embroidery is complete, the fabric is placed in water, causing it to dissolve completely and leaving only the embroidery. The standalone embroidery is then sewn onto a Velcro cutout piece.





6.2 Interactive buttons

To evaluate whether an additional interaction layer would enhance engagement of the ByBrus backpack concept, an NFC (Near-field communication) chip was integrated into some of the buttons. These buttons were specifically chosen to tell the stories of brussen from the co-design sessions. For instance, the cactus story from Chapter 5.5 is one such example. The story goes: "My sister sometimes hurts other children, like a cactus, but if you are careful, cactuses can be nice." Another brus noted that cactuses can grow flowers with care. The coach added, "Maybe you are like the flower, showing how nice a cactus can be." In the realization, the flower button is separated from the cactus button, allowing the brus to choose whether to combine them. On a bad day, they might not want to show the story of their sister and can decide to leave the flower button off. When you scan the button with your phone, it directs you to an Instagram page that narrates this story. The NFC chip is discreetly embedded, so only a brus who is aware of this feature will know about it. This creates a cool secret among brussen or a fun feature to share with friends. The potential benefits of this addition, and whether a connected platform could further enhance the concept, will be considered in an upcoming session.

The one they both,

flower!

the other day just the

NFC







6.3 Backpack design

The backpack is made from a material that easily adheres to Velcro. Brushed nylon is used for its ability to self-heal quickly and efficiently, making it ideal for repeated use. This material is characterized by its long fibers and woven construction, contributing to its durability and resilience. The long stitches further enhance its strength and longevity, ensuring the backpack can withstand the daily wear and tear of the Velcro buttons. The color of the backpack is green; however, this was not a deliberate choice but rather because it was the only available material sample at the moment. An preferable color choice would have been a dark, gender-neutral shade like navy, which would also enhance the visibility of the buttons and make the colors pop. The entire backpack is made from the same material, allowing for personalization options everywhere. It features a front pocket designed to store all the buttons. This pocket is made from a standard fabric that does not adhere to Velcro, ensuring the buttons stay securely inside. The front pocket is flat, providing a large canvas for personalization, maximizing the space available for brussen to customize their backpack according to their preferences.



Figure 21, Pictures from the prototyping process



6.4 Co-design for embodiment

A co-design session was conducted to evaluate how an embodied version of the ByBrus backpack and buttons would be received by brussen. The session aimed to iterate on the embodiment and generate ideas and insights for possible improvements. Five brussen, aged 9 to 10, participated in the session. They interacted with the embodied ByBrus backpack, brainstormed iteration ideas, created drawings for these improvements, and presented their designs for feedback. The primary goal was to understand if the ByBrus backpack could achieve the intended goal of empowerment through play. Conducted in collaboration with Ons Welzijn's brussen coaching group, this session provided valuable insights into the preferences and experiences of brussen. A detailed protocol of this session is available in Appendix 10.

The goal of this co-design session is to evaluate the reception of
the embodied ByBrus backpack by brussen, iterate on its design, and generate ideas and insights for potential improvements, ultimately determining if the backpack can effectively serve as a tool for empowerment through play.

Can you help me to improve the ByBrus backpack? How could you show what kind of brus you are with this button?

Ons Welzijn, Pieter Brueghelhuis Veghel brussen coach group.



5 participants aged 9 and 10, and a brus coach.

Introduction: Explanation of the ByBrus backpack concept. **Interaction:** Allowing the brussen to engage with the ByBrus backpack prototype.

Brainstorming: Generate and draw ideas for improvements for the backpack, and buttons.

Presentation and Feedback: Present ideas and discuss feedback.

Wrap-up: Summarize the session and discuss overall advise for the ByBrus backpack concept.



Audio recording, video recording of the interaction phase of the session, pictures of the session and the results.



Limited possibilities for first impression interactions.



Figure 22, Co-design for iteration with the brus backpack prototype



6.5 Co-design insights and reflection

Buttons should also express negative feelings

The brussen expressed a clear need for buttons to represent a range of emotions, including negative ones. For instance, one participant mentioned, "I am going to make a crying emoji. - Oh, tell me why? - Then my sister will do something that I don't like at all, and then she gets angry, and that makes me very sad. - And how would an emoji help when you feel so sad? - I actually don't always dare to say it.". This highlights the importance of having the means to express sadness and frustration, emotions that are just as valid and significant as positive ones. Additionally, the idea of drawing a "vomiting smiley" because "sometimes you just have a day that feels like bleh" underscores the necessity of representing the full spectrum of emotions. Furthermore, a participant was initially hesitant to draw something more negative: "Oh, I know something, but it is not very nice. - What then? - A middle finger? - Well, that is allowed too. - I am definitely going to draw that. You don't do it yourself, but it stands as a symbol. Everyone will understand immediately what you mean. - That can be allowed sometimes. It doesn't always have to be nice, right?" After this three of the brussen also drew a middle finger symbol on their worksheet.



Figure 24, Co-design for embodiment brainstorming results

Another participant demonstrated the difficulty of expressing certain negative feelings verbally: "I don't know how to draw if, if, if I want to say that I want to get away for a moment. I don't know how to draw that. - How do you feel then? Maybe you want to fly away, Maybe you want to look for the door, Maybe you want to run away? Do you just want to be alone? Hide, become invisible? What fits your feeling? - Yes, I feel like running. - I am going to draw a world globe because then you really want to fly somewhere else. Because I want to get away from the world. Like it seems like you are flying. Then, uh, you just fly, - I draw wings because you want to get off the world. - Look, then, uh, I have an idea. I have an idea for a butterfly. If you have wings, uh, if you want to fly. - No, not a butterfly, Redbull gives you wings!" This quote illustrates how diverse visual symbols could convey complex feelings of wanting to escape or hide shared among all the participants, which might be difficult to articulate to the family verbally.

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6.6 Co-design insights and reflection

A communication medium to the family

The backpack could have potential as a medium for communication to the family of the brus. This was implicitly supported through various comments about expressing feelings and needs that might be difficult to verbalize directly. For example, the use of symbols like a stop sign and the request for a hugging symbol suggest that these visual cues can help communicate personal boundaries and emotional needs within the family context. One participant explained the stop sign concept: "Stop sign to just say they should stop. - I know something super funny, if your brother comes running and wants to hit you. Then you have such a stop sign. You do this STOP! An other example is the idea for a hugging symbol was expressed as: "knuffel" written down. "Can that be in letters or can it also be a hug? And is it a human hug, or a hug from animals or something? - Human hug because my sister never wants to give me a hug, and I like the feeling of a hug." These examples show how the ByBrus backpack can serve as a medium for expressing and managing frustrations and conflicts in a non-verbal way.



Figure 25, Co-design for embodiment brainstorming results



Figure 26, Co-design for embodiment brainstorming results

Symbols as a reflection of coping mechanisms

Symbols were frequently used to reflect individual coping mechanisms and personal interests, providing insight into how each participant deals with stress and emotions. One participant shared, "A horse! That is important to me, it just calms my anger down." This indicates that for this individual, the horse symbolizes a personal and effective way to manage feelings of anger. Another participant mentioned the importance of sports as a coping mechanism: "I don't know why, but it is a football icon, but I don't know how. - Yes, that suits you well. And I think that is true for many siblings. Yes. Because sports can really be an outlet too. - Yes, just run with your team for a while. Lose some energy." This illustrates how symbols can represent outlets and coping mechanisms for emotional release and stress relief for many children.



6.6 Session insights and reflection

Reflection on the session

The initial plan for the session was to subtly introduce the backpack to one of the brussen and ask them to wear it without the others noticing, to observe their natural responses and interactions with it. Unfortunately, this plan could not go through because of the presence of an additional guest at the session. This guest started the session, taking away the spontaneous moment hoped to be captured.

Despite this setback, the session provided valuable insights. The participants engaged in constructive play, testing the limits of the buttons and the backpack. They experimented with how the buttons could be used together to tell a story, hinting at the potential for facilitating role-play scenarios. This interaction highlighted how children might use the backpack not just as a communication tool but also as a toy.

Linking insights to design vision

The session shows hints of how the backpack can facilitate play. The vision of using play to create empowerment and thereby enhance visibility is until now tested with brussen in segments, but a total evaluation focusing on observing all aspects - play, empowerment, and enhancing visibility - could provide a more comprehensive proof of concept. The findings from this session reinforce the design vision that emphasizes customization and personalization as empowerment methods, and play as central elements.

Chapter take-aways

Diversity of button design

The co-design session revealed the potential for developing a broader range of buttons beyond just symbolic and interactive ones. Future explorations should consider buttons that express negative feelings, communicate more effectively with family members, and reflect personal coping mechanisms. This expanded variety can address a wider spectrum of emotional and communicative needs among brussen.

Play

The chapter highlighted the backpack's potential to support role-play and constructive play. During the co-design session, brussen used the backpack as a tool for both communication and play, demonstrating its versatility. Future research should explore how play dynamics change in different settings or when multiple backpacks are involved, to better understand the potential impact of the backpack.

Practical considerations

Testing showed that the attaching and detaching of buttons worked well, allowing brussen to engage enthusiastically without restraint. This positive feedback suggests that the current design with Velcro is user-friendly. However, there is still room to explore different colours and shapes to further enhance the aesthetic appeal and functionality of the backpack.

Conclusion

This chapter discusses the conclusion and key findings of the research project, along with the limitations encountered and recommendations for future work. It concludes with a personal reflection by the designer, offering summarised insights into the design process and the project's overall results.

Conclusion

This research project has demonstrated the importance of creating tools that enhance visibility among brussen, siblings of children with special needs. Throughout the research, valuable insights were gathered for designers and organizations working on supportive tools for brussen and their families. These insights led to the development of the ByBrus backpack concept, which aims, through play, to empower brussen aged 7 to 12 to enhance their visibility among each other. The insights in these themes are explained in the next chapter 7.2 Project insights.

By adopting a participatory design and research-throughdesign approach, the project engaged brussen in co-design sessions, allowing their unique perspectives and needs to shape the final outcome. This methodology ensured that the design process was iterative and responsive, incorporating feedback and ideas from brussen at each design phase. The emphasis on empowerment through play emerged as a crucial factor in designing interventions that resonate with brussen and enhance their visibility by enabling them to express themselves and connect more easily with peers.

The project scope focused on the concept design of a single ByBrus backpack. This decision aligns with the defined scope and characteristics of a graduation project and marks a natural conclusion point, opening up numerous possibilities for future exploration. These possibilities include developing different button designs, backpack variations, and understanding how play dynamics change with multiple backpacks among brussen and other children who may not be familiar with the term "brussen."

BYBPUS BY AND FOR BRUSSEN

7.1 Project insights

This project demonstrates the relationship between how play can empower brussen and enhance their visibility. Play offers a lowthreshold engagement to gain empowerment for brussen, which boosts their confidence and ability to express themselves. This increased empowerment leads to greater visibility, as brussen feel more comfortable and supported in sharing their unique experiences and connecting with each other. The main project insights on these themes are explained below.

Visibility

Brussen can feel overlooked within their family due to the focus on their siblings with special needs. They face similar challenges regardless of the type of special need of their sibling. They can find recognition and support in each other (Kalsbeek et al., 2018), but the term "brussen" is not widely known, complicating their ability to connect with peers. This research emphasized the importance of increasing visibility among brussen. Locations outside the home offer brussen the freedom to choose how they present themselves, balancing between blending in and sharing their unique experiences. The ByBrus backpack, featuring customizable buttons, acts as a visible symbol of identity and connection. This design allows brussen to recognize each other and engage more easily, creating a sense of community and mutual understanding.

Empowerment

Central to the backpack's design is the theme of empowerment, allowing brussen to express their individuality through various buttons. The autonomy in visibility provided by the backpack enables brussen to decide when and how to show themselves. This flexibility empowers brussen to adapt their visibility based on their comfort and situation, reinforcing their decision-making abilities. Additionally, the backpack serves as a metaphor for carrying a weight and includes practical utility features to support brussen in their caregiving roles, enhancing their sense of responsibility and capability.

Play

Play was identified as a natural and effective method to engage brussen, providing a low-threshold means for creative expression and social interaction. Types of play such as construction and role play were particularly promising, offering opportunities for brussen to connect with peers and share experiences in an enjoyable and meaningful way. The playful features of the ByBrus backpack not only entertain but also promote social connections and emotional development. Through these interactions, brussen feel more comfortable sharing their unique experiences, with the goal of enhancing their visibility among each other.



Figure 27, Main themes of the key findings

7.2 Limitations

Concept selection

Halfway through the project, I realized that the organizations did not understand the explanation of a co-design session without a clear concept. Their responses often included questions like, "What are you making?" A few organizations even cancelled their participation despite my efforts to explain the project over the phone. It was already hard to find organizations that would be open to collaborate with me, so their cancelling because they didn't understand felt like a missed opportunity. I concluded that having a concrete concept would help me better communicate with the organizations. Consequently, after these experiences, I decided it was essential to select a concept. The concept selection was based on a generative session with two supervisors from the Brussen camp. Although they themselves are brussen and frequently work with different brussen within the target age group, they are not part of the target group themselves. It would have been beneficial to have one more generative session with the actual target group before making a final decision on the ByBrus backpack concept.

Once the ByBrus backpack was chosen, I noticed a significant change in the responses from organizations. I successfully scheduled four additional co-design sessions, and the organizations' reactions were much more positive and enthusiastic. In hindsight, choosing a concept was a good decision. However, I remain curious about whether a generative session with the target group would have provided different ideas and potentially changed the project's outcome. Ultimately, it is crucial to acknowledge that while the ByBrus backpack is a good concept, the knowledge of brussen and their preferred forms of self-expression is the most valuable aspect. This experience underscores the importance of including a organisation early on in the project so there is an opportunity to communicate ideas to gain support and participation, or have a clear and concrete concept when approaching organizations throughout the a project. This reflection is not only valuable for this project but also serves as a recommendation for other designers and researchers who wish to work on similar subjects.

7.3 Recommendations

Uniform backpack design

The primary focus of the project was on the buttons, rather than the backpack design. For the ByBrus backpack to maintain its value in creating awareness, it must remain a uniform, easily recognizable factor. Consistency is crucial; varying shapes and colors would limit recognizability and undermine its purpose of visibility. Such variability could cause confusion and raise questions about whether it should even be a backpack or just the brus buttons attached to any item. Future work should test this aspect with brussen to evaluate the effectiveness of a standardized backpack versus the flexibility of using brus buttons on any item. Testing would provide valuable insights into balancing uniformity and personal expression while ensuring the primary goal of visibility and awareness is achieved.

Exploration of Button Varieties

To further enrich the ByBrus backpack concept, there is significant opportunity to diversify the buttons. This can involve more shapes, sensory features, and interactive elements. The current embroidery buttons provide a solid foundation, but exploring different materials could enhance sensory engagement and user experience. Co-design sessions have revealed potential for more tactile and sensory buttons, using materials like soft fabrics, shining materials, or textured surfaces. Experimenting with these can make the buttons more engaging for brussen. Additionally, integrating interactive elements such as thermochromic fabrics, LEDs, and audio features can add another layer of engagement. For example, buttons that change color with temperature or light, or play sounds, can create dynamic experiences.

Awareness strategy

For the brus concept to achieve widespread adoption, a business strategy focused on visibility and community engagement is essential. Organizations and events can play a role in promoting the ByBrus backpack and its unique buttons. Designing event-specific buttons not only raises awareness but also serves as souvenirs, enhancing the sense of community among brussen. Such buttons can highlight and support various events, increasing both the visibility of the brus concept and the events themselves.

Further research of the target group scope

The initial goals of the project are to raise awareness for the term "brussen" and to make brussen more visible to each other so they can socially connect with one another. In this research project criteria for participant selection were established, focusing on brussen who were already familiar with each other and aware of the term "brussen". This choice was intentional, as engaging with brussen unfamiliar with the term would have presented significant challenges. These characteristics were chosen to ensure the participants could provide relevant and insightful feedback related to the research questions centered around social recognition and visibility among brussen. Future research could explore interactions with brussen who are not yet familiar with the term, providing additional layers of understanding and further validating the design's effectiveness in diverse contexts.

Furthermore, the ByBrus backpack currently is designed for brussen aged 7 to 12. However, there is an opportunity to expand the target age group to include both younger and older brussen, making the backpack a longer-lasting and more versatile product. For younger brussen, modifications could include more tactile buttons. For older,

7.4 Recommendations

adolescent brussen, the design could be adapted to be more mature and functional, with features like an online platform and personalization options for NFC chips. These ideas emerged from co-design sessions but require further research. Expanding the target age group can increase the product's marketability and ensure that brussen continue to benefit from the community and visibility provided by the ByBrus backpack throughout different stages of their lives.

Business and awareness Strategies

The project so far has not incorporated a comprehensive business strategy. A detailed business approach is important for future consideration. The ByBrus backpack could be positioned as a consumer product, but there are alternative strategies that might also be effective. Possibilities in partnerships and collaborations could be investigated. Collaborating with organizations that share the values and mission of the ByBrus backpack can provide significant support. Potential partners could include non-profits, healthcare and wellbeing organizations, educational institutions, and corporate sponsors. These collaborations can assist in funding, promoting, and distributing the ByBrus backpacks and buttons, ensuring broader reach and impact. Effective sales and distribution channels must be identified and established. This could involve setting up an online store, partnering with retail outlets, and offering direct sales at events. Organizations and events can play a role in promoting the Brus backpack and buttons. An oppurtunity for this could for example be the design of an event-specific buttons which not only raises awareness but also serves as souvenirs, enhancing the sense of community among brussen. Such buttons can highlight and support various events, increasing both the visibility of the Brus concept and the events themselves.

Although developing a marketing plan is crucial for future efforts to enhance the visibility of brussen, it falls outside the scope of this graduation project. The current focus should remain within the theoretical framework and research questions defined at the start. Future actions could include leveraging both online and offline strategies to maximize visibility and engagement. For example, utilizing social media platforms to share stories and updates about the ByBrus backpack can build a strong community around the concept. Engaging content such as videos, stories, and interactive posts can enhance awareness and create a sense of connection among brussen.

Organizations

As mentioned before, it was challenging to come in contact with the target group. Therefore, for future research, working with organizations that have established partnerships with other (event) organizations would be a smart approach. One such example is Steunpunt Mantelzorg Zuid. At the Brussen Festival, where the button co-design session took place, they had a stand and initiated a conversation with me. They explained that when brussen register with them, they receive a gift box containing information and small gifts, such as a chocolate bar and a backpack. They expressed interest in the ByBrus backpack idea and provided their contact information. Collaborating with an organization like Steunpunt Mantelzorg Zuid would be beneficial because they can participate in events organized by other entities, have a broad social reach, and can assist with developing a business strategy. Such partnerships would facilitate better access to the target group and enhance the overall impact of the research.

7.5 Reflection

The project

Throughout this project, there has been a strong emphasis on in-depth user research, an area that was relatively new to me. I was fortunate to have coaches in Design for Interaction departments who provided invaluable guidance and support. Their supervision has been crucial in my learning process. In Integrated Product Design (IPD), there is often a stronger focus on the outcome and embodiment of a project. This project, however, allowed me to engage deeply in user research and apply conscious reasoning to the choice of terminologies and approaches. My biggest challenge was my tendency to move too quickly through the project. The patience and expertise of my supervisory team have been extremely helpful, always ensuring that I reflected on my decision-making. Their support has enabled me to explore new methodologies and approaches with confidence. I appreciate the balance between allowing me the freedom to explore and providing the necessary guidance to keep the project focused and relevant. The coach meetings were particularly helpful in improving my ability to communicate my thoughts and reflections, and I noticed my communication skills within this topic improved with each meeting.

The project context, involving a vulnerable and challenging target group, underscored the importance of ethical considerations and careful planning in design research. Considerable time was required to identify and arrange suitable meeting places for interaction with the target group, as well as to navigate the lengthy HREC application process due to the vulnerability of the participants. Despite these challenges, I am proud that I was able to plan five sessions and meet with 60 brussen, all of whom have made a significant impact on my project and on me personally.

Personal growth

This project has provided significant opportunities for personal and professional growth. A major part of my personal ambitions involves understanding and designing for empowerment, especially within the context of play. I have gained valuable insights into what empowerment means and how it can be facilitated through design. Designing for children, particularly in contexts that go beyond toys or play, has expanded my understanding of user-centered design. I am learning how to create designs that not only engage but also empower children, helping their development and self-confidence. This project helped me achieve my ambition of becoming a designer who creates meaningful and impactful experiences for children.

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