

# Meaningful encounters

Explorative studies about designers  
learning from children with autism

Proefschrift

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# Summary

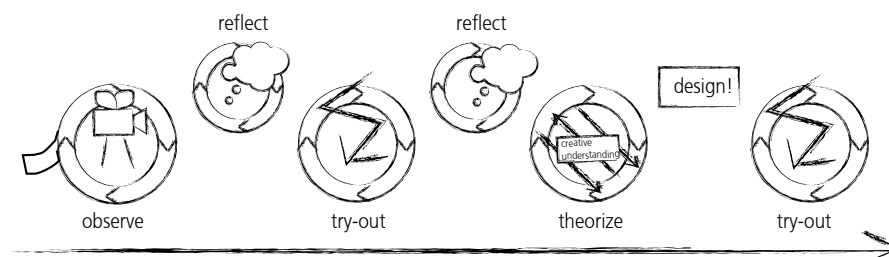
## Meaningful encounters

Just like any other person, children with autism need products and services that fit their needs and experiences. Imagine you are briefed to design a product or service for non-verbal children with autism, while you have no experience whatsoever with this user group. You might search on the internet for more information, watch the Hollywood production *Rain Man*, or look for books that explain these children's behaviour. However, the way that children with autism truly think and act is left up to your imagination until then. Direct contact or an encounter is the only means to come closer to the needs and experiences of these children.

This dissertation investigates how designers can learn from encounters with these children and their caregivers to inform and inspire new product development. During encounters, designers can experience how children react to them, but also to other people and objects. They obtain information about the user and his/her surrounding, empathy for this user, and inspiration for idea generation.

Although this sounds promising, designers will face some challenges when encountering these children for design. Often, they are not that experienced in making contact with these children, who have substantial difficulties with social interaction and communication. Moreover, they cannot use existing user research methods such as interviews, generative sessions, or focus groups, because these methods rely on verbal communication. In order to bridge this gap, we developed a framework that delivers starting points for the development of new tools and techniques to support these encounters.

The framework describes the learning process of designers by means of activities such as 'observe', 'reflect', 'theorize', and 'try-out'. In the studies, teams of M.Sc. design students (referred to as designers) encountered children that varied in age, gender, diagnosis, intelligence, and speaking abilities. In each study, the teams followed a similar design process that included the activities from the framework (see figure below).

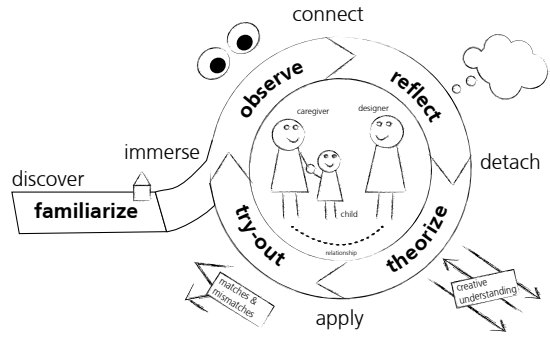


We used qualitative research methods to keep track of the designers’ thoughts, feelings, and experiences throughout their design process in order to investigate their learning process in detail. Designers annotated their experiences and thoughts in a reflective notebook. They made video diaries before and after an encounter, and participated in class meetings. The information collected from these rich self-reports and discussions served as research data.

Each study investigated a part of the framework by means of questionnaires, structured interviews, and/or observations. Study I mapped the experiences of designers in the activity of observation. Study II used a newly developed observation tool to support designers in this observation. Study III used a set of toys as tools to support designers in the activity of try-out. Study IV investigated the effects of uninformed designers entering an existing design team that had had encounters with the children. Finally, study V described the designers’ thoughts and opinions about different sources of information when designing for children with autism.

The studies brought three main findings, and provided nuances of the framework. They indicated the necessity for designers to (1) familiarize themselves with the new context before entering the learning cycle, (2) observe the children without any instructions to record these observations in order to immerse, and (3) consciously search for moments in which the children give a different meaning to objects and/or interactions than they do themselves. The latter emphasizes the importance of admitting mistakes in interactions, to assist the goal of learning.

The developed framework is presented below. It contains five main activities (familiarisation, observation, reflection, theorisation, and try-out) and transitions (discover, immerse, connect, detach, and apply). It describes, but also prescribes how designers can learn from encounters. In parallel to developing the framework, the findings were translated into a set of guidelines for practice. These guidelines aim to support designers in learning about the needs and experiences of users, so they are informed and inspired in new product development. The goal of this research is that product designers are better able to create a better world for children with autism to live in by creating products and services that fit their everyday lives.



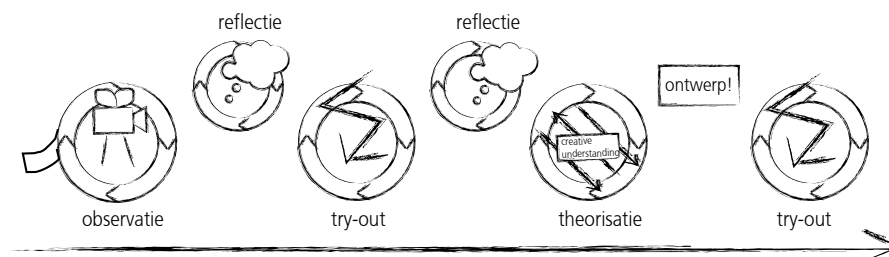
# Samenvatting

## Betekenisvolle ontmoetingen

Kinderen met autisme hebben net als ieder ander producten en diensten nodig die passen bij hun specifieke behoeften en ervaringen. Maar wat doe je als je de opdracht krijgt om een product of dienst voor deze kinderen te ontwerpen en je helemaal geen ervaring hebt op dit gebied. Wellicht begin je dan met het afstruinen van het internet naar meer informatie, het bekijken van de film 'Rain Man' of het lezen van een boek dat het gedrag van deze kinderen verklaart. Je ontdekt dan dat de wijze waarop kinderen met autisme werkelijk denken en handelen is overgelaten aan je verbeelding. Het blijkt dat direct contact met de kinderen of een ontmoeting zijn verzorgers of behandelaars de enige manier is om dichterbij de behoeften en ervaringen van deze kinderen te komen.

Dit proefschrift onderzoekt hoe ontwerpers kunnen leren van de hiervoor bedoelde ontmoetingen met deze kinderen en hun verzorgers om zo zichzelf te informeren en te inspireren en zo nieuwe producten te ontwikkelen. Tijdens die ontmoetingen kunnen ontwerpers ervaren hoe kinderen reageren op henzelf, maar ook op andere mensen en objecten in hun omgeving. De onderzoekers verkrijgen informatie over de gebruiker en zijn omgeving, empathie voor de gebruiker van het product en inspiratie voor idee-generatie.

Hoewel dit veelbelovend klinkt, zullen ontwerpers een aantal uitdagingen moeten trotseren wanneer zij met deze kinderen in contact willen komen. Ontwerpers zijn namelijk vaak onervaren in omgang met deze kinderen die moeite hebben met sociale interactie en communicatie. Bovendien kunnen ontwerpers de gebruikelijke onderzoeksmethoden, zoals interviews, generatieve sessies of focus groups niet toepassen, omdat deze methoden gebruik maken van verbale communicatie. Om toch effectief contact te kunnen maken met de kinderen is als oplossing een raamwerk ontwikkeld. Dit raamwerk levert startpunten op voor de ontwikkeling van nieuwe tools en technieken om ontwerpers te ondersteunen in dergelijke ontmoetingen. Het raamwerk beschrijft het leerproces van ontwerpers door middel van activiteiten zoals 'observatie', 'reflectie', 'theorisatie' en 'try-out'. In de studies, ontmoetten verscheidene teams van ontwerpstudenten M.Sc. kinderen met autisme. De kinderen varieerden in leeftijd, geslacht, diagnose, intelligentie en spreekvaardigheid. In elke studie volgden de teams een vergelijkbaar ontwerpproces dat de activiteiten van het raamwerk bevat (zie onderstaand figuur).

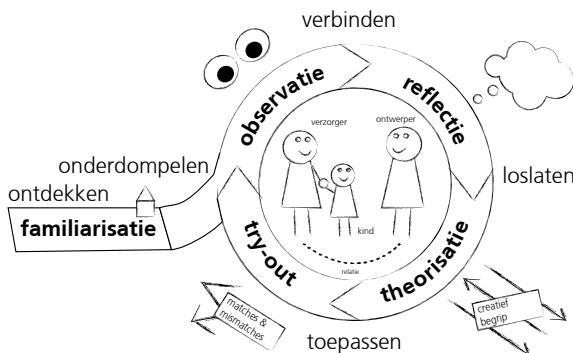


Er is daarbij gebruik gemaakt van kwalitatieve onderzoeksmethoden om de gedachten, gevoelens en ervaringen van ontwerpers vast te leggen. Zo werd het leerproces van de ontwerpers in detail onderzocht. Ontwerpers schreven hun gedachten en ervaringen in een notitieboek. Ze maakten videodagboeken voor en na elke ontmoeting en participeerden in groepsbijeenkomsten. De gegevens van deze rijke zelfverslagen en discussies dienden als data ten behoeve van het onderzoek.

Elke studie richtte zich op een deel van het raamwerk door middel van questionnaires, gestructureerde interviews en/of observaties. Studie I bracht de ervaringen van ontwerpers in kaart tijdens 'observatie'. Studie II gebruikte een nieuw ontwikkelde observatietool om ontwerpers te ondersteunen in deze observatie. Studie III gebruikte een set van speeltjes als tools om ontwerpers in 'try-out' te ondersteunen. Studie IV onderzocht de effecten van ongeïnformeerde ontwerpers die zich bij een bestaand ontwerpteam voegen dat al ontmoetingen had gehad met de kinderen. Tenslotte, beschrijft studie V de gedachten en meningen van ontwerpers over verschillende informatiebronnen voor het ontwerpen voor kinderen met autisme.

De studies leidden tot nuances in het raamwerk en resulteerden in drie hoofdbevindingen. De studies toonden de noodzaak voor ontwerpers aan om (1) zich vertrouwd te voelen in de nieuwe omgeving, (2) de kinderen te observeren zonder concreet doel en (3) en bewust te zoeken naar momenten waarin de kinderen een andere betekenis geven aan objecten en/of interacties dan zij zelf doen.

Het ontwikkelde raamwerk is hieronder gepresenteerd. Het bevat vijf hoofdactiviteiten (familiarisatie, observatie, reflectie, theorisatie en try-out) en overgangen (ontdekken, onderdompelen, verbinden, loslaten en toepassen). Het beschrijft, maar ook schrijft voor, hoe ontwerpers kunnen leren van ontmoetingen. Naast het ontwikkelen van het raamwerk, zijn de bevindingen vertaald naar richtlijnen voor de praktijk. Deze richtlijnen hebben tot doel om ontwerpers te ondersteunen in het leren over de behoeften en ervaringen van gebruikers; dus ontwerpers te informeren en te inspireren voor nieuwe productontwikkeling. Het doel van dit onderzoek is het in staat stellen van ontwerpers om een betere wereld te creëren voor kinderen met autisme door middel van het ontwerpen van producten en diensten die passen bij het leven en de belevingswereld van het kind met autisme.



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# Introduction

*During this research project, I have met many children with autism in the last five years. Still, I remember clearly my very first meeting with a boy with autism as a designer. It was at a medical day care centre. The caregiver told me to sit down on the sofa in the corner of the room. I observed five children and one caregiver in their daily activities. The children sat down in a circle and the caregiver was teaching them about emotions. At a certain moment, a boy from the group approached me and climbed onto my lap. It did not feel as though he considered me as a person. He treated me more like the couch, an object to sit on. After a while, he started to touch my head and hair, pushed his nose on my nose and looked into my eyes. It was a special experience, although I felt uncomfortable about the whole situation. I had no idea why he was doing that and how I should react. I just let him do his thing. He seemed to like it. After a little while, the caregiver 'rescued me' by taking him back to the circle of children...*

This dissertation is about designers learning from encounters with non-verbal or hardly speaking children with autism, just like the author's encounter with the boy on the sofa. In this dissertation, an encounter is defined as a meeting between a designer, child, and caregiver, in which the people participate either as actor or observer (see 3.2). During an encounter, designers can experience how children react to them, but also see how they react to other people and objects. These experiences can inform and inspire designers in new product development. Designers can create a better world for children with autism to live in by creating products and services that fit their everyday lives.

Although this sounds promising, new product development for children with autism hardly takes place, as for any other user group with cognitive impairments. Designers will face some challenges when encountering these people for design. Often, designers are not that experienced in having contact with these children, who have substantial difficulties with thought processes and communication. Moreover, they cannot use existing methods, tools, and/or techniques for user research, because these tools and techniques rely on verbal communication.

To bridge this gap, this dissertation describes a framework for how designers can learn from encounters with children with autism, and various tools and techniques based on this framework. In the included studies, the framework and developed tools and techniques are evaluated in a qualitative and explorative manner.

## **1.1 People with cognitive impairments in product design**

Designers create and develop products for others. In empathic design, there is a broad consensus that designers should draw upon the experiences of the people they design for (Koskinen et al., 2003; Kouprie and Sleeswijk Visser, 2009; Leonard and Rayport, 1997). In this way, designers can avoid making mistakes, learn about their users, and gain inspiration for new product ideas. In learning about the experiences of others, designers face a continuous challenge. Every person has a unique set of experiences, which can only be viewed through the eyes of that person (Wright et al., 2003). Designers need to learn about the experiences of different people in their target group and design one product that fits them all. This challenge may be even larger when designing for people with cognitive impairments, because the differences are larger than with standard target groups. Each person with a particular type of impairment, such as autism spectrum disorder, has a unique profile of skills and needs (Bird and Buckley, 1999). The field of inclusive design has explored the cognitive limitations of specific target groups (Clarkson et al., 2003). It tries to include people such as elderly with cognitive decline, by considering the needs of the widest group of possible users. Children with autism as a user group present the design community with a totally new challenge. These children's understanding of the world is so unique that designers need to put effort into learning about them, and are likely to never fully understand them. However, the effort of designers can potentially result in products and services that are attuned to these children's skills, needs, and experiences and improve their quality of life by enhancing independence, social inclusion and community participation.

### **Product design for children with autism is scarce**

Between 2007 and 2012, the author interviewed people in daily practice in the Netherlands to obtain insight into new product development for individuals with cognitive impairments, and for children with autism in particular. She discovered that very little is designed and even less is commercialized for these children. Along with markets for many other types of impairments, the market for people with autism is positioned outside the world of mass production. It is too specialized and narrow to follow a standard new product development process. Still, the author managed to find some examples, which were all funded by subsidies. For example, the foundation Waag Society is developing 'Bodyguard' together with the foundation Dr. Leo Kannerhuis. Bodyguard is a system to signal and reduce stress in working people with autism (Waag Society, 2012). Another example from the Dr. Leo Kannerhuis is the game 'Hows', to enhance the independence of people with autism (Dr. Leo Kannerhuis, 2012). In arts and non-profit organisations such as universities and higher education, product concepts are developed such as LINKX in chapter 2 and Snapje (Karthaus, 2009). However, these concepts are not commercialized, because without investors or funding they remain castles in the air.

### **Adhoc design by caregivers**

The section above explains why caregivers often lack affordable products for the children they care for. The author observed during the studies that caregivers buy products that were originally developed for another user group, or create solutions themselves without involving professional designers. The products that caregivers bought were actually developed for different user groups, but appeared to be useful and pleasant for the children they care for. For example, many children with autism are still attracted to baby toys because of their sensorial properties. In the Netherlands, Barry Emons B.V. sells a broad variety of such products for people with impairments. They also decorate spaces for care institutions, but designers are not employed there. Similarly, a number of web stores exist for people with special needs (e.g., [www.thesensoryshop.nl](http://www.thesensoryshop.nl)). In addition to buying products, caregivers develop their own materials that fit the children. For example, all schools for special education in the studies possessed a laminating and binding device to develop educational material for the children (see figure 1).



**Figure 1:** Laminating and binding device in the common room for staff (left), material made by a teacher to educate the concept 'below' with photos (right).

### **Now is the time for change!**

Usually, designers are trained for and involved in new product development for mass production. They create products in design studios or research and development departments of large companies. They follow a new product development process that includes three main phases: pre-development or fuzzy front end, development, and commercialization (Veldhuizen, 2008). Designers collaborate with various disciplines such as marketing, sales, engineering, usability, and manufacturing.

Nowadays, the landscape of product development is changing. Firstly, cheap and powerful prototyping tools have become available for everyone. Fab Labs, small-scaled workshops that offer personal digital fabrication, have opened all over the world (Gershenfeld, 2007). They include tools such as laser cutters, rapid 3D printers, and printed circuit board milling. With these tools, designers can design custom-made solutions for small user groups and produce them in small series (de Couvreur and Goossens, 2011). Secondly, developments in software have brought opportunities for people with cognitive impairments and their caregivers. They provide caregivers the possibility to keep track of progress and offer people interactions that fit their impairment such as; predictable behaviour, possibilities for repetition, and consistent feedback (Dawe, 2007). The introduction of smart phones (e.g., android, iphone) has provided platforms to reach and connect caregivers from all over the world. In the last three years, applications have been springing from the ground. For example, the iTunes app store contains 898 applications for and about autism (last accessed on June 4, 2012).

For a long time, design was about scaling up products to a maximum amount of people to minimize the price. New technologies such as prototyping tools and software developments have brought business opportunities for smaller user groups, but also challenges for design. Many designers are not used to learning about and designing for small user groups such as children with autism. To bridge this gap, this dissertation describes a framework for how designers can learn from encounters with children with autism, and various tools and techniques based on this framework. The studies took place in an educational setting due to the lack of a business case at the time.

### **Designing ‘the chitchatters for people with dementia’**

In the next page, the author describes one of her design projects. Conducting this project served as way to explore how she could design for another user group with cognitive impairments, namely dementia, and to derive first constructs to be used in the framework later on. Together with another designer (Schreurs), she designed a leisure activity for people with dementia. In contrast to children with autism who can be obsessed with objects, people with dementia show a decline in personal interest. In development of these products, the designers followed a user-centred design process in which they employed participant observation, interviews with caregivers and users, and probes with relatives. They discussed early ideas with caregivers, and evaluated prototypes with the users and caregivers (see van Rijn et al., 2010). Conducting this project helped in generalizing the findings for people with cognitive impairments.

---

Funding body:	Province of Noord-Brabant
Designers:	Helma van Rijn, M.Sc. & Mariet Schreurs, M.Sc.
Assignment:	Design a leisure product for people with dementia
Period:	August – November 2008
Website:	<a href="http://www.klessebessers.nl">http://www.klessebessers.nl</a>

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People with dementia have difficulties in recognizing and communicating with others, which has a damaging impact on social interaction and maintenance of social networks. They often feel isolated, which makes them rather passive, lonely, or bored. They tend to take less initiative in interacting, or don't interact at all. People with dementia show a decline in personal interests, while at the same time caregivers find it hard to motivate them to participate in recreational activities. The province of Noord-Brabant in the Netherlands acknowledged this problem and set out a design competition. For our entry, we designed 'the Chitchatters' ('de Klessebessers' in Dutch); a group activity for people with dementia to help them actively recall and discuss memories together. The game consists of four everyday objects put in a circle of people (see figure 2). These objects are a television, radio, telephone, and a treasure box. Each object triggers memories from the people's youth in its own specific way. The television shows movie clips, the radio plays music, the telephone 'tells' poems and sings children's songs, and the box reveals a tactile object. One by one, a specific object that is assigned by the activity leader attracts the attention of the group using a lamp that switches on. A person from the circle can activate the object, e.g., by pushing the television button or picking up the receiver of the telephone. The people have been familiar with these interactions for decades. They can show others their competencies by operating the objects and providing songs or movies for the others. This entry won first prize, which was funding for product development. As a result, two sets are now in use at elderly homes in the Netherlands.

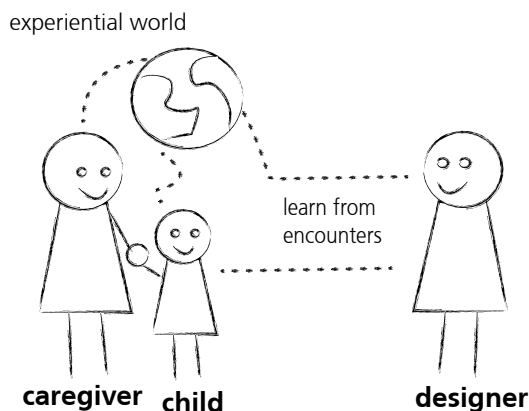


**Figure 2:** The Chitchatters exhibited at the Dutch Design Week in Eindhoven, the Netherlands.

## 1.2. Focus on learning from encounters in design

The target group of the studies are children diagnosed with autism spectrum disorder. Autism is a neurobiological developmental disorder that affects around 1% of all people. Officially, the term is Autism Spectrum Disorder, because of its many variations in manifestation, and even within one person the diagnosis can change over time. They may display a triad of impairments: impairment in social interaction, communication, and imagination (Wing, 1997). In the continuation of this dissertation, the term autism spectrum disorder is abbreviated to autism. Designing for children with autism would be simply impossible without any background information. Before design activities start, designers should learn about the needs and experiences of such a user group, especially if they have little or no prior knowledge. They can learn about these children in several ways. In this dissertation, designers learn about them by means of encountering them during the design process. Early in the project it was concluded that the conventional user-designer interaction (e.g., Preece et al., 2002) could not describe or explain the research situation, because children with autism are dependent on their caregivers.

This dissertation focuses on encounters between designers, children with autism and caregivers in the user's context (see figure 3). The scheme is a simplification to explain the main roles of the people involved in the encounter, and present a working definition for these roles. The remainder of this dissertation uses these terms to refer to these people and roles. In the end of the dissertation, these encounters with children with autism are generalized to user groups with cognitive impairments.



**Figure 3:** Focus of this dissertation: direct contact between designers, users, and caregivers.

- **Child:** the person who is the designer's topic of interest and contributes by reacting to the designer's presence and newly brought objects, or by ignoring them. For the designer, this child is the primary user for the future product. In this dissertation 'child' refers to 'child with autism'.

- **Caregiver:** the person who takes care of the user during the encounter and is responsible for the child at that moment. He or she contributes to the designer's growing understanding by providing explanations about the child's behaviour, and interpretations of the child's experiences. Examples of caregivers are parents, teachers, volunteers, therapists, and psychologists. For the designer, the caregiver is secondary user.

- **Designer:** the person who participates in direct contact and needs the insights for idea generation and concept development in the current design process.

In these encounters, designers learn from direct contact. This involves both observation and interaction. In observation, designers observe children and caregivers in their daily life, without trying to influence their behaviour in any way. In interaction, the people undertake an action to evoke a reaction from the other person, or react with their own actions to the action of the other person. Observation and interaction can occur sequentially during an encounter.

The encounters preferably take place in the children's daily environment. First, this context provides rich information about the daily life of children with autism. 'Real' needs and experiences take place in a 'real' environment. Second, these children feel most comfortable in, depend on, and are attached to their personal environment, and thus show typical behaviour. Third, caregivers might not have the time and energy to bring children to other places. The children's context includes the physical location, objects, and social -, cultural -, and political factors. The physical location can be a child's home, school, or a therapy setting. It contains the space itself with everyday objects, such as favourite toys, medication, or special learning aids. These objects can provide cues to designers about the children's habits and routines in daily life. The context also includes people, such as their caregivers, who help them cope in daily life.

In this dissertation, children and caregivers play a role in learning through encounters, but are not involved in co-design activities. Designers learn about how these children live their everyday life with their caregivers, and develop new products and services that aim to improve their quality of life.

## **Problem definition**

Designers are faced with several challenges in these encounters with children with autism and their caregivers. Although many see value in user research, they often have little budget to spend time with users (e.g., Sleeswijk Visser, 2009). Moreover, standard tools and techniques for user research do not apply to children with autism, because most of them rely on verbal communication. And lastly, these children are difficult to engage in social interactions. For example, they can react in unexpected ways to new events or situations, have low empathic skills (Baron-Cohen, 2009), and a lack of joint attention (Mundy and Neal, 2001). Designers need to find other ways to interact with and learn about these children.

## **The research question**

In order to tackle these challenges, this dissertation aims to answer the following main question:

*How can designers learn from (and about) children with autism, through encounters with them?*

As interim answer to structure the research, this dissertation presents a framework on how designers can learn from encounters with children with autism and their caregivers for design (see chapter 5). Here, the research question is further developed (see page 78). In the studies, various tools and techniques are developed from this framework and evaluated by using them in encounters (see chapter 6). In the discussion, the answer to the main question can be found (see chapter 7).

## **1.3. Relevance of this research**

This dissertation combines design research and the social sciences to support designers in learning about and designing for non-verbal children with autism.

In design research, tools and techniques have been developed to incorporate users' experiences into the design process (e.g., Gaver et al., 1999; Mattelmäki, 2006; Sleeswijk Visser et al., 2005). These tools and techniques rely heavily on verbal communication and therefore cannot be used with this non-verbal user group. In the past, participatory design or co-design projects have been undertaken with verbal users with autism (e.g., Francis et al., 2009; Millen et al., 2011). As this dissertation concerns children with autism who have little or no verbal skills, these projects are not the answer.

In social sciences, the autism spectrum disorder has been widely studied and is still being researched. The number of references on the internet exceeds 24 million and is growing every day (Roeyers, 2008). Although researchers generally focus on the impairment itself, some create stimulus material that fits with the children, and hence carry design knowledge (e.g., Noens et al., 2006). In developing stimuli, they make choices about aspects such as the material, shape, and functionality, but these processes are not published.



In design research, researchers develop and evaluate technologies for children with autism. Examples are robotics (e.g., Barakova and Lourens, 2010; Robins et al., 2005), wearable technologies (e.g., Goodwin, 2008), and interactive products (e.g., Keay-Bright, 2009; Pares et al., 2005; Piper et al., 2006). These researchers learned about the user group and made design choices. But just as in social science, researchers do not report how they learned about the needs and experiences of users before developing these technologies. Rather, their studies focus on the developed technology.

Finally, occupational therapists create ad-hoc designs without involving professional designers. Their tailor-made solutions can inform and inspire designers, but these are not often reported.

Artefacts are developed in social sciences, design research, and occupational therapy. However, none bring insight into the process of learning about and designing for these children. This dissertation aims to bridge this gap and thereby enable designers to design for these user groups.

For society, and especially for these people and their caregivers, it is relevant that (some) designers are capable of designing for user groups with cognitive impairments. In chapter 8, practical insights are presented in a set of guidelines for practitioners in the field of healthcare and design. These guidelines can support designers in utilizing encounters with users during the design process. They can support caregivers in effectively collaborating with designers, because this dissertation brings insight into the needs and working methods of designers.

## **1.4. Design-inclusive research approach**

This dissertation takes a design-inclusive research approach, meaning both research and design activities are used to answer the main research question above (Horvath, 2007). This research question is framed as a ‘how-question’ and thereby contains a research and design goal. The research goal is to develop knowledge about how designers learn from encounters with children with autism and their caregivers, for the purpose of designing. This knowledge will contribute to the design goal; the development of tools and techniques for designers. Again, developing these methods, tools, and techniques (and especially evaluating them in the studies) brings knowledge and feeds the research goal. To avoid confusions with the design activities of the students who develop product concepts for the children, we label the design activity of the research as developing instead of designing.

In the studies, the author developed tools and techniques, which were used by M.Sc. design students in a design process for children with autism. By means of several qualitative research methods such as reflective notebooks, interviews, and observations, she followed these students in their design process. In this way it was possible to evaluate the use and value of these tools and techniques in the process. The methods sections in the studies are often described from a first person perspective, especially when describing design activities. In this way, the author clarifies whether information derives from a research or design perspective, and how it will be used.

## 1.5. Reading guide

In order to explore how designers can learn from and about children with autism, through encounters with them, this research followed several steps reflected into the chapters of this dissertation. The outline of this dissertation is based on the visual on the right (see figure 4). The first seven chapters focus at the scientific audience. Chapter 8 translates and presents the findings that are relevant to practice.

Chapter 1 introduced the context, goal, and focus of this dissertation.

Chapter 2 describes the designers' activities in the fuzzy front end when designing for children with autism.

Chapter 3 describes theories and models on learning from encounters, which can be applied in the design process.

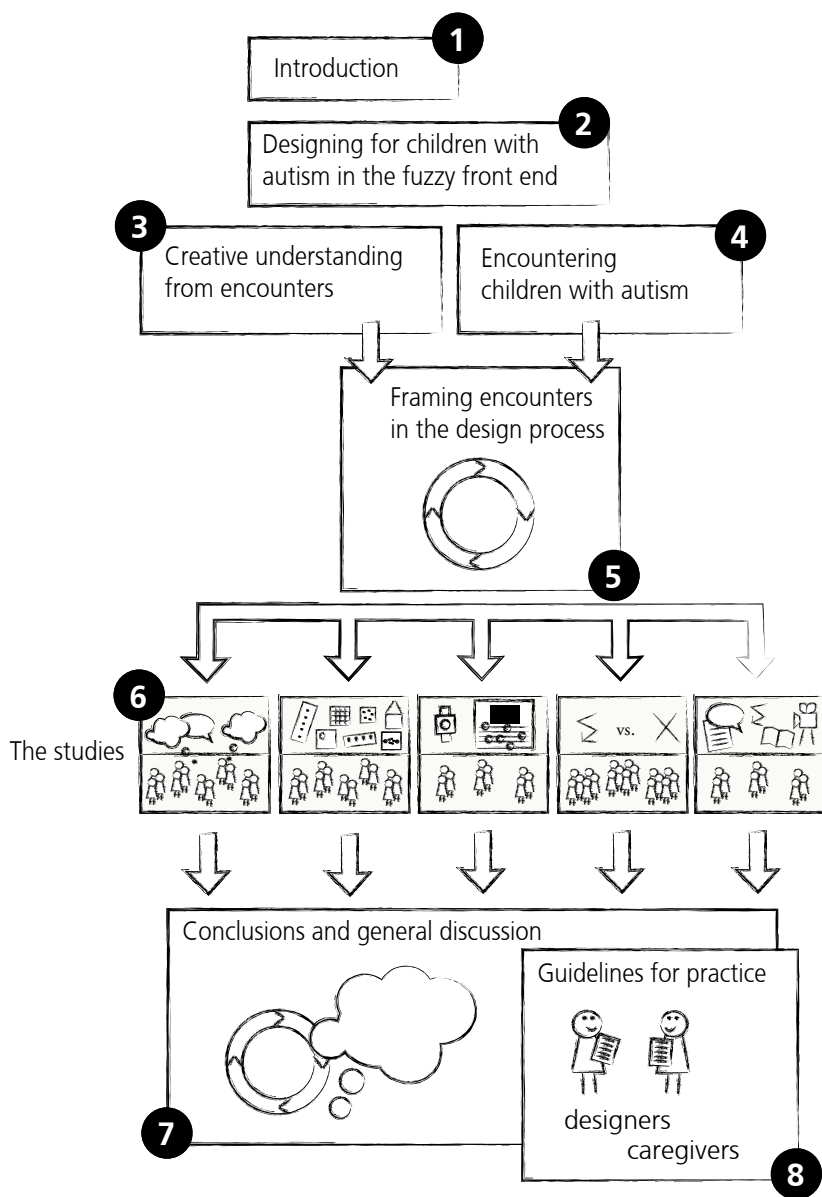
Chapter 4 describes the background of autism spectrum disorder and its implications for learning from encounters with these children.

Chapter 5 presents a framework for learning from encounters based on the theory and experience described earlier. This framework serves to structure the findings from the studies.

Chapter 6 presents five studies, in which M.Sc. design students use encounters, sometimes supported by specially developed tools and techniques, to learn about the children's experiences for designing. We explored how designers use these encounters in their design process by means of qualitative research methods such as observations, interviews, reflective notebooks, and video diaries.

Chapter 7 presents the answer to the main question and discusses the findings from the studies. We conclude with reflections on the research aim, approach, limitations to this research and recommendations for further research.

Chapter 8 presents guidelines, tips, and tricks for both designers and caregivers to effectively collaborate, and support designers best in learning from encounters with users with cognitive impairments.



**Figure 4:** Dissertation outline

2



# Designing for children with autism in the fuzzy front end

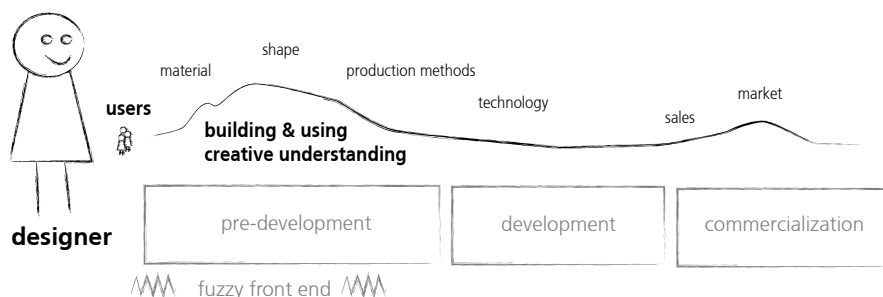
*This chapter brings insight about how designers work when designing for children with autism. It introduces the term creative understanding and describes the activities of designers in the fuzzy front end. These activities are illustrated with the example of a design project, in which a language-learning toy was developed for children with autism. We conclude with an overview of tools and techniques that support designers in learning about the experiences of users and the importance of encounters for building creative understanding.*

## 2.1. Introduction

New product development for children with autism in professional practice is scarce, because the market is too specialized and narrow to support this. In reality, caregivers develop solutions themselves to help the children they care for cope with everyday situations. They come up with tailor-made solutions that suit their context, without any formal design training. New prototyping tools and developments in software brings possibilities to include professional designers in product development for small user groups such as children with autism. In contrast to caregivers, designers are more likely to design products that make use of current technological possibilities and fit the children's experiences. Designers have knowledge about the design process and more creative skills. Detachment from the design situation in question is needed for incubation in creative processes and generalization of individual skills, needs and experiences to a larger user group. Designers can detach themselves more easily than caregivers, because they are not permanently involved in the children's lives, while caregivers are. Although designers can detach more easily, generalizing remains a challenge, because each child has a unique profile of skills and needs (Bird and Buckley, 1999).

## 2.2. Designers' activities in the fuzzy front end

Designers play an important role in the early phases of new product development, referred to as 'the fuzzy front end'. The 'fuzzy front end' includes activities such as gathering information, idea generation and conceptualization (Veldhuizen, 2008). During these activities, designers develop new ideas based on input such as user' needs, technological developments, or trends in society. In order to come up with new product concepts, they need information about various aspects such as existing products, users, markets, materials, technologies, and production methods (see figure 1). Designers intuitively select from these aspects. They scan fast and select information that is meaningful (Pasma, 2003). The sheer quantity and diversity of information makes it impossible to make structured overviews or simultaneously take all concerns for a product into account. Therefore, designers are used to making quick, intuitive, and temporary choices (Sleeswijk Visser, 2009). To come up with new ideas, designers use a variety



**Figure 1:** The needs and activities of designers in the fuzzy front end.

of creative techniques and visualize their concepts in sketches and prototypes. They continuously discuss, store and demonstrate their early ideas, to confront themselves or others who are involved in the design process. Sketches and rough prototypes are a means of exploring their abstract ideas, and imagining possible situations to which the product could respond (Buxton, 2007). During these activities, designers go through a complex, intuitive and reflective process with iterations (Schon, 1983). In other words, they step back and forth between steps and repeatedly perform the same sequences of operations. About every design decision (e.g., shape, material, functionality), designers first diverge by thinking of alternative solutions for the decision they need to make, and subsequently converge by selection the best solution (Roozenburg and Eekels, 1995).

### **2.3. Designers need creative understanding**

When designers are briefed to design for children with autism, they need insight into the experiences of these children in order to design. They probably start browsing the Internet for more information. They might read literature such as the novel 'the curious incident of the dog in the night-time' (Haddon, 2004), watch the Hollywood production 'Rainman' (Levinson, 1988), or try to meet children in person. This dissertation refers to the sought after insight into the experiences of users as the designer's need for 'creative understanding'. Creative understanding is defined as the combination of a cognitive and affective understanding of the other, and the ability to translate this understanding into product concepts and services (Wright and McCarthy, 2005). Creative understanding is both informative and actionable, because it includes information about the user and his/her surrounding, empathy for this user, and inspiration for idea generation. Designers build creative understanding from 'rich experience information' (Postma et al., 2009). In this process, designers seek relevant information that builds on their prior knowledge and inspires them in designing products that fit the users. The level of creative understanding that is reached depends on the quality of the collected rich experience information, and the empathy, creativity, and willingness of the individual designer.

#### **Rich experience information**

One important source needed for the process of building creative understanding is rich experience information. Use of this process is intended to direct designers towards better-informed design. It helps them to evaluate ideas and explore implications of these ideas for the use situation, and serves as means to mediate the thought and communication processes that takes place whilst designing (Sleeswijk Visser, 2009). Designers learn from users' experiences in the past and the present to envision possible users' experiences for the future (Sanders, 2001). Bate and Robert (2007) describe this with the following phrase: hindsight gives insight and insight gives foresight. In this research, we follow the notion that experiences are holistic, situated and constructed (e.g., Dewey, 1934). This means experiences have many dimensions adding up to a

whole, depend on particular circumstances, are ephemeral, and belong to the person who has the experience (Sleeswijk Visser, 2009). They are personal, subjective, and derive from first hand occurrences. This dissertation refers to 'everyday experiences'; people's current and prior experiences in their daily life with objects and people in their surroundings. Designers can never directly access the experiences of users, because experiences are exclusively personal. They also cannot be an objective or detached researcher as well, because learning about experiences relies upon interpretation and synthesis. This leaves us to question, what they can do?

In general, storytelling is a natural and frequently used way to share experiences in design, as in everyday life. In a sense, words are the messengers of experience, because they are capable of transporting 'experience', into stories and anecdotes (Bate and Robert, 2007). Experience itself is abstract and ungraspable matter in the past, while stories are in the present and can be analyzed. The power of using stories in design is that they can compile various aspects of experiences into one tidy package (Nielsen and Madsen, 2006). Moreover, designers are people, and people are good at listening to and interpreting anecdotes and stories from real people (Pruitt and Adlin, 2006).

### **The challenges of researching the experiences of children with autism**

Researching people's everyday experiences is quite complex. In general, people are not necessarily aware of all facets of their experiences, nor skilled in reflecting upon these experiences and sharing them with others. In the case of children with autism this is more extreme. Designers are faced with some particular challenges when learning about and designing for children with autism. Firstly, the experiences of children with autism are likely to be very different to those of designers. Designers (and people in general) only have direct access to their own experiences, and use these experiences as a starting point for learning about others. They can more easily identify with experiences of people that are similar to their own. Secondly, these children have difficulties in making sense of experiences and in sharing them verbally with others. Designers are accustomed to apply storytelling as a technique in learning about the experiences of users (e.g., Wright and McCarthy, 2005). When verbal communication with these children proves impossible, designers need other ways to learn about their experiences. Even in cases where verbal communication is possible, we return to the challenge that people can never access or observe the experiences of others directly. They can only interpret the experiences of others indirectly, by means of observing and listening to the stories told by people to describe their experiences, when they look back and try to describe or recall them. In this sense, shared experience is a reconstruction or reconstitution of something a person has lived through: an elapsed, recalled memory. In other words, designers can only build a creative understanding from rich experience information if the children and/or caregivers have effectively shared their experiences with them. For example, designers can observe the children's behaviour or listen to the stories of caregivers about the children.



### **The empathic ability of designers**

Creative understanding includes empathy for users. Kouprie and Sleeswijk Visser (2009) described empathy as the intuitive ability to identify with other people's thoughts and feelings. It is the ability to sense and understand someone else's feelings as if they were one's own. Empathy is an individual capability, varying in strength from one person to the other. Designers have their own unique experiences and empathic ability which define their 'empathic horizon' (McDonagh-Philip and Denton, 1999). The term empathic horizon indicates that designers have a personal range of vision (and thereby personal limitation) in empathizing beyond certain characteristics, such as nationality, background, age, gender, culture, experience, and education. Someone's empathic horizon is never static. Designers can expand their empathic horizon or empathic skills by learning about others, and through their own life experiences.

Most psychological literature distinguishes two components of empathy: affective and cognitive. The affective component is seen as an immediate and automatic emotional response of the empathizer to the affective state of the other person. This emotional response can have several forms, of which the most common is emotional contagion such as automatically responding with a smile when you see somebody smile at you (Gladstein, 1983). The cognitive component is seen as the understanding of the other person's feelings (Baron-Cohen and Wheelwright, 2004). The empathizer sees or hears about the situation of the other and imagines the other's situation from that person's perspective. This component is therefore concerned with intellectually taking the perspective of another person (Mead, 1934). Although these two components of empathy are discussed separately in theory, researchers have argued that they cannot be separated in reality because they are strongly interrelated (e.g., Damasio, 1994). Designers need both an emotional response (affective) to a user's emotional state and a reflection on that by taking the user's perspective (cognitive) in order to obtain empathy. Achieving the right balance between affective resonance and cognitive reasoning is a basic skill of empathy (Kouprie and Sleeswijk Visser, 2009).

In the empathic process, people can never learn about the experiences of others and completely forget about their own experiences at the same time (Wright and McCarthy, 2005). It is a process of engaging the other by opening up yourself, in which designers use their own emotions as a sounding board for understanding those of others (Battarbee, 2004). Designers and users must come to understand the experiences of one another if they are to develop real shared understanding of possible futures (Wright and McCarthy, 2005). Everyone, including designers, retains a degree of outsidership which they cannot see themselves (Bakhtin, 1986). This remoteness helps designers to see the situation in another light, helps them let go of the current situation and solutions, and allows them to envision alternative experiences of users. Children with autism lack the feeling of empathy with others (Baron-Cohen, 1993). In this dissertation, designers must empathize with a user group that most likely cannot empathize with them.

Kouprie and Sleeswijk (2009) proposed a framework for design practice that integrates the factors of ability, affective resonance and cognitive reasoning. This framework provides a fundamental understanding of the designers' mental process while achieving empathy with the users they are designing for. The four phases in this

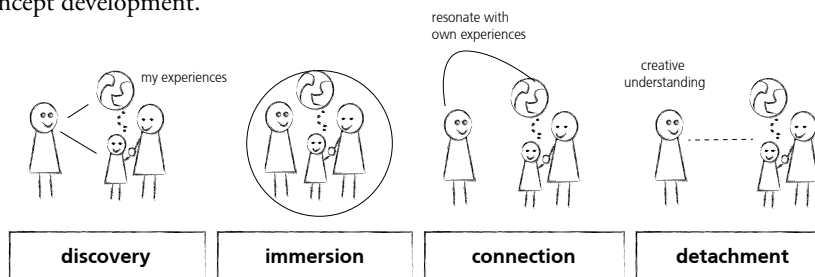
framework are: discovery, immersion, connection, and detachment (see figure 2). In each phase designers adopt a different role, which changes the relationship between themselves and users. One limitation of the framework, however, is that it assumes the users' experiences are relatively close to the designers' experiences. In that case, designers are able to compare their own experiences to the users' experiences in that same situation.

The discovery phase is necessary to stimulate the designers' curiosity, willingness, and motivation, which determine to a large degree the achieved level of empathy. The process starts with an initial contact between designers and children with autism. In this phase, designers observe the children. When designers arrange this contact early in their design process, they can learn and adjust their expectations about the user group. Nervousness about the encounter itself can make designers hesitant, and cause them to postpone arranging an encounter. But even a short encounter can take this uncertainty away and replace it with curiosity and willingness to stimulate empathic learning.

The immersion phase is important for the designers' empathic learning process. Designers wander around in the children's environment and immerse themselves, without making judgements and implementations. They become open-minded and observe and experience the users' world for a while without being solution-focused. Various aspects of the user's world surprise the designers. This phase takes time, and is necessary to increase knowledge about user experience.

In the connection phase, designers feel emotional resonance with the users' experiences, by drawing upon their own experiences. Designers connect to users on an emotional level by reflecting upon their own feelings and extrapolating those to the users' experience. At this phase, both affective and cognitive components are important: the affective to feel, and the cognitive to make sense of feelings. This phase emphasizes bringing out the designers' own experiences, in order to understand what users feel and what this could mean to them. The experiences of children with autism are often very different from those of designers. For resonance, designers might need to search for completely different, yet somehow comparable experiences.

In the detachment phase, designers detach from their emotional connection and take a step back to make sense of the users' experiences. By objectively theorizing on moments of resonance, designers can interpret and utilize new insights for ideation. By leaving the user's world, a designer can use his or her increased understanding in new concept development.



**Figure 2:** Four phases of empathy. Adapted from Kouprie and Sleeswijk (2009)

### **The creative ability of designers**

Designers build creative understanding about users in order to feed idea generation and concept development. While building an empathic understanding about users asks for an empathic process, translating this understanding into product concepts asks for creative processes. Sleeswijk Visser (2009) defined creativity as the ability to transcend traditional ideas, rules, patterns, relationships, and to create meaningful new ideas, forms, methods, interpretations. The ability to be creative depends on the designers' background and training. Moments of intense creativity are characterized by the enthusiastic activity of designers (Amabile, 1996) and a state of flow (Csikszentmihalyi, 1998). This state of flow is an optimal experience in which designers are totally engaged in their activity, and has implications for their level of control, attention, curiosity and intrinsic interest. Sleeswijk Visser (2009) listed four elements that determine the inspirational setting for designing: freedom and constraints, imagination, discovery, and rich sources of information. This suggests that to support the designers in using their creative understanding, we should enable them to collect and/or use rich experience information. Moreover, we should take into account their amount of control, attention, and possibilities for imagination, curiosity and interest in learning.

The creative process can be divided into four phases: (1) preparation, (2) incubation, (3) illumination and (4) verification (Wallas, 1926). In the preparation phase the designer gathers information and creates a context for the design brief. The designer collects, studies, orders and sifts the information in order to make sense of it, which establishes directions for product ideas. When no more progress is being made, the problem is set aside. This is the incubation phase, which leaves an interlude for the designer to be surprised by new insights, and be receptive to new ideas. For example, breaking the rhythm by going away from the desk is a way 'to get inspired' (Keller, 2005). When designers move off the beaten path, they become more open for discoveries (Kelley and Littman, 2001). Then, in the illumination phase, the designer begins to see possible solutions. After some period of time (the incubation phase), often with no clear cause, the solution appears. Several stimuli can help the designer to suddenly see possible solutions to the design problem. This is the phase of illumination. As often as not, it is not the elements that were carefully gathered in the preparation phase, but rather, an extraneous element previously considered irrelevant that provides the stimulus. The sensation of inspiration is most related to this third illumination phase, where the sudden insight; the 'a-ha' moment, takes place and new ideas are formed. This suggests that efforts to inspire designers are linked to the two previous phases; preparation and incubation. Inspiration then provides the fuel of the creative process (Sleeswijk Visser, 2009). While learning, designers make (new) connections and relations. This process in itself can provide inspiration to designers. In verification, the final phase, designers carry out activities to demonstrate whether or not what in illumination satisfies the needs and criteria defined in the preparation stage.

### **The willingness of designers, caregivers and children**

Building creative understanding requires direct and personal engagement between the involved parties. This engagement serves as motivation for learning, and is not only dependent on the willingness of designers, but also on that of children and caregivers. For example, a designer feels sympathy for the user group, a strong commitment to the project, or he really wants to see something changed. This can influence him to put in more effort. Thereby, the willingness of designers influences the level of creative understanding that is reached in a positive manner (Kouprie and Sleeswijk Visser, 2009).

## **2.4. Example of a design project for children with autism**

In the LINKX project, the author built a creative understanding about non-verbal children with autism, and designed a language learning toy for them (van Rijn and Stappers, 2007). The project presented a challenge, because no tools or techniques are available to learn about the experiences of children with autism for the purposes of design. This section explains the design outcome first. Next, it illustrates her activities ‘as designer’ in learning about and designing for children with autism from the first person perspective. Most importantly for this dissertation, she felt the need to participate directly in the community and collect rich experience information herself. The LINKX project was the cause to begin this PhD-project, and served as basis for the framework in chapter 5. The project produced findings on different levels such as insights about the application of the toy itself (van Rijn, 2007), how to learn about these children (van Rijn and Stappers, 2007), how to collaborate with caregivers (van Rijn and Stappers 2008b), and design guidelines for children with autism (van Rijn and Stappers, 2008a).

.....

Client:	LinguaBytes
Designer:	Helma van Rijn (M.Sc.)
Assignment:	Design a language-learning toy for children with autism
Period:	March 2006 – January 2007

.....

### **LINKX for non-verbal children with autism**

LINKX is an interactive toy to help non-verbal children with autism learn their first 100 words; simple words such as ‘door’, ‘table’, and ‘cupboard’ (van Rijn, 2007). Young children with autism often develop language and speech slowly, or not at all. When they acquire language, they use it instrumentally instead of socially. Disorders that prevent development of language and communication can have severe psychological consequences, especially for social and emotional development and the ability to do things independently. Stimulation of language and communication should therefore be done as early as possible.

The LINKX toy consists of interactive labels and blocks (see figure 3). These labels are called ‘speech-o-grams’. They can be attached to objects in the child’s surrounding and contain an audio file of a spoken word. Before play starts, a caregiver prepares the toy by speaking words into speech-o-grams. For example, a parent records the word ‘cabinet’ in a speech-o-gram and attaches this speech-o-gram to the cabinet. Next, children can start to play by linking blocks to speech-o-grams or to other blocks. Each time a block connects, the word moves from the speech-o-gram to the block, which is visualized with travelling light. When the word reaches the block, the block plays the audio file of the corresponding word. For example, when a child links a block with the speech-o-gram attached to the cabinet, the word ‘cabinet’ moves into this block. After that, this block plays the recorded word ‘cabinet’. Each speech-o-gram has its own colour, which travels with the word, to help children predict the result of making a new link. In this way, children can explore names of objects in their everyday environment using playful and predictable interaction. This concept design has not been commercially developed.

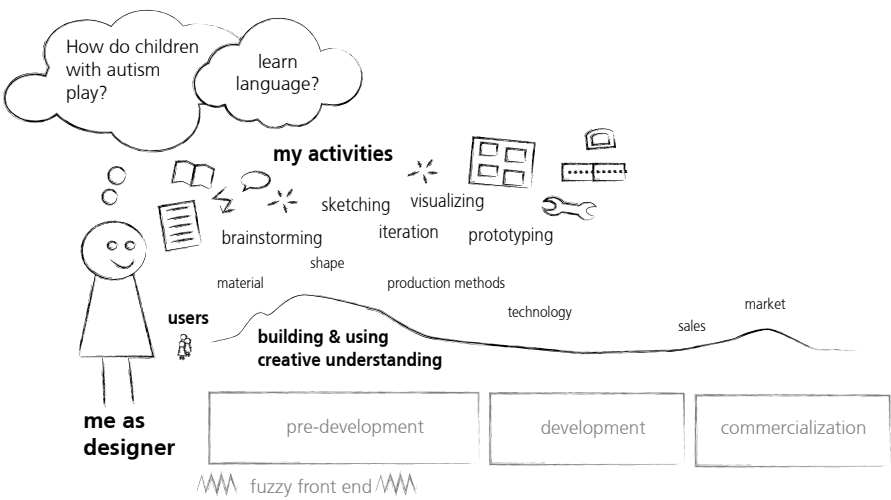


**Figure 3:** A presentation of LINKX. By playing with blocks, children cause the blocks to play back the recorded word they received from objects in their everyday environment. For example, by connecting a block to the speech-o-gram attached to the cabinet, the block says ‘cabinet’.

### **My activities as a designer**

The LINKX project was my first experience with children with autism as a design student. I had never designed a product for a user group with impairments. My interest in special user groups, and the psychology courses I was taking during that time, motivated me to begin the project. First, I started to read about autism in literature and on The Internet. It wasn’t long before I felt the need to see these children for myself. I was curious about how they behave, what they can and cannot do concerning language, and how they play. Luckily, I knew someone who worked at a medical day care centre. She allowed me to visit her class of four children with autism for a day, to

see what they do and how they behave. I still remember that I felt a bit awkward in the beginning. When I entered the classroom the children did not look at me. The caregiver told me I could just sit down on the couch and observe what they did. I brought my notebook and wrote some things down. But actually, I did not know the correct way to act or what to do as an observing design student. On a certain moment, one boy approached me and climbed on my lap, and treated me like an object to sit on and investigate. This dissertation began with a description of that encounter. That morning, I also joined them when they went to the playground. That was a more comfortable moment, because the caregivers were supervising the children while they played more or less by themselves. I could talk with the caregivers about the children and move around amongst the children and help out where necessary. Figure 4 illustrates all my activities as designer during the project.



**Figure 4:** An overview of the author's needs

### *Sending letters for participation*

When the children went home, the caregivers had more time to answer the questions I had about the children I had observed. More importantly, one caregiver introduced me to the director of the medical day care centre. Face to face I explained my design assignment, and that I wanted to learn about the needs and experiences of these children. I explained that I wished to do this by means of involving children, caregivers, speech therapists, and parents in my design process. The director and caregivers understood that this was necessary, and gave permission for me to visit and observe the class of four children with autism and two caregivers any time I wanted. To make video recordings and photographs, I had to first arrange consent from the parents. So, I sent the parents a letter in which I asked for their participation. The director made sure these letters

reached the parents. Three parents reacted positively. They were glad someone was taking effort to assist their children in learning language, and were happy to participate. From that moment onwards, the boys Daniel, Robby, Jonas, and their caregivers were the participants in this project. These caregivers were their parents, speech therapists, and employees of the medical day care. The children and caregivers have been given fictional names for privacy reasons.

### *Observing the children*

I observed the children in language learning activities such as lessons and speech therapy. I remember being impressed by the patience of caregivers and therapists, who persisted with performing the same exercises over and over, often without instant success. Moreover, I felt sympathy for the children, who had difficulties in understanding what to do. Rewards such as a compliment or a sticker, for actions like saying the right word at the right moment, taught the children behaviour by heart. They were programmed to react in a certain way. I also observed the children playing with objects. I was amazed by their difficulties in deciding what to do, and with moving from one activity to another. It is often the case that children do not like to stop doing something they enjoy, but this was different. For example, one boy started to scream very loudly and refused to join the circle. After a while, he had to calm down in another room. I also remember the unique way that Daniel played with wooden blocks. Mostly you would expect a child to build something, like a tower. But Daniel enjoyed touching the blocks, looking at them from different perspectives, tapping them on the floor to explore the sounds they produced, and holding them against his face and ears. Moreover, instead of building, he made patterns on the floor with them. Only afterwards when looking at the observation video, I realized he had constructed the number 'two'.

### *Home visits*

I wanted to learn more about the children's lives by visiting them at home and talking to their parents. In preparation, I sent parents a little booklet with questions about their child's life such as: what is the favourite toy of your child, what is his favourite spot and how would you teach him the imaginary word 'kroekel' (see figure 5). A week later, I discussed these answers with them and asked about sensory experiences their child enjoys, how they like to play, and what kind of materials they like. I remember Daniel's mother wrote down that her son's first word was 'eight'. That is completely different than the usual 'mama'. This example illustrated to me Daniel's preoccupation with numbers and letters, but also made me realize how hard it must be for a parent to raise such a child. Although I started these visits with the expectation of learning about the children, I could not neglect the parents. They were secondary users of my future products, and experts on their child's experiences. These conversations with parents were sometimes difficult for me, because I was no expert on autism myself. I did not know what was right or wrong to do, for example how to deal with the child when he screams. But the parents enjoyed sharing their experiences and concerns with

me, since I was ‘an outsider’ without expertise on autism. So I listened to their stories about the problems and challenges they face in daily life. When necessary I steered the conversation towards the needs and experiences of the children, to get information for my design project. These conversations taught me a lot about these children, and set the foundation for a personal relationship. Even five years later I still talk to some of these parents every once in a while.



Figure 5: A Booklet about Daniel’s ‘world’ completed by his mother

Contextmapping session with caregivers

I planned a contextmapping session with four caregivers from the medical day care centre, to dive deeper into the topic of language learning. Contextmapping techniques aim to bring user insights to designers in the conceptual phase of design (Sleeswijk Visser et al., 2005). They encourage users to express views, anecdotes, and explanations about their daily lives. This includes aspects such as the user’s concerns, motivations and feelings, and the use situation. During the contextmapping session I asked the caregivers to make a collage about the positive and negative aspects that influence the language learning process of children with autism. Next, I asked them to make a cognitive map of a child’s language learning process. To finish off, I asked them to make their ideal language-learning toy for these children with scrap material. Although this session provided me insight into the children’s language learning level and processes, it didn’t bring me that much new information. I had already observed a lot of the issues they mentioned, and the caregivers tended to give theoretical rather than personal information. Getting them to talk about their feelings regarding their work with the children was difficult, especially because they regarded this as ‘unprofessional’.



### *Analysis*

These different methods of collecting information about children with autism resulted in a big pile of data, including video recordings, pictures, transcripts of conversations with parents and caregivers, and the transcript of the contextmapping session. I searched for patterns in the data and selected what was relevant for language learning and play, linked to the theoretical autism knowledge. Pictures and snapshots of video recordings served as examples for the theory in my documentation. I built my own vision of the interaction of my future product with the children, to support them in learning language in a playful way. Building this vision for myself provided structure in my head and helped me to detach from current practice.

### *Idea generation*

Before analysing the data, I was hardly able to generate ideas. I saw some little problems during my visits, which I thought could be easily solved, but the big ideas did not show up yet. For example, Daniel hated brushing his teeth. I thought a visual timer could help him learn how long to continue brushing, and provide him with a nice reward afterwards. But this had no relation to language learning. After the analysis phase, I actively forced myself to generate ideas. Even after all the analysis I had done, it was still difficult for me. This phase was the hardest of all. Each solution I thought of had a disadvantage for one of the children. To let go of all the problems and think more freely, I invited four design students to participate in a brainstorm session (see figure 6). Prior to this brainstorm, they had no experience with autism whatsoever. I presented my insights and asked them to come up with ideas. Unfortunately for me, this session didn't help at all. Their ideas were based on storytelling, using the imagination. Children with autism would never be able to benefit from such products, because they have impaired imagination. So, I had to continue on my own again. I realized the only thing that could help the children was literally naming objects in their immediate environment. These words are useful and concrete. That led to the idea of speech-o-grams. From seeing the children enjoy lining up objects, the idea of blocks was born.



**Figure 6:** Four designers in a brainstorm session.

### *Discussing my ideas with parents*

I discussed the idea of LINKX with the parents of the children. Daniel and Robby were presented with different shaped foam blocks as a test. I liked cubes a lot because of their symmetry, but I wanted to know what the children thought of them. Daniel started to explore the blocks, but was not interested in the cubes (see figure 7). From him I learned that cubes are boring, because they are the same from every perspective. He liked rectangular blocks much better. He enjoyed them so much, that he kept some of them to play with after the test was over. The parents really liked the idea of using speech-o-grams. It was clear and understandable for the children, flexible for changes, and the children could work with their parent's voice instead of an electronic one. The latter mattered especially to the parents.

### *Building a prototype*

After meeting the parents and children, I felt sure about the concept. I started to detail the behaviour of the toy. In the final design outcome, the aim was that language learning and play would be combined. Each action the child performs with the toy that results in language learning, should be rewarded. Therefore, each time the child connects a block with a speech-o-gram, the block fills up with light and plays the recorded word. From this concept, a prototype was built including the physical blocks, electronics, and software.



**Figure 7:** Evaluating differently shaped blocks with Daniel

*Evaluating the prototype with the three children and their parents*

The three boys Daniel, Robby, and Jonas played with this prototype three times each (see figure 8). I wanted to see whether they would remember and enjoy the toy a second or third time. For me, these evaluations were very exciting. Before actually having a prototype of your concept, you cannot predict whether this user group will (really) like it. They cannot tell you based on imagining what it would be like; only their parents can. The first evaluation was with Daniel. It was amazing how after he connected the first block with his mother he was confident and only wanted to play with it alone. He laughed really hard about it, and connected the block again and again. His joy was a relief for me. However, he did not repeat the word yet. The first time playing with Robby was completely different. Robby could talk a bit, and immediately repeated the word after the toy. However, saying the word and understanding what the word means are different things (see chapter 4). When Robby's mother asked what object he was referring to, he said 'lady'. Instead of linking the object with the word, he linked the word to the voice. After his mother explained him the principle, he understood and never forgot it again. The first time with Jonas was interesting too. He also immediately understood what to do and enjoyed the coloured lights in the block. However, in the middle of his play, a bug in the software appeared, making the colours of the lights change and the wrong blocks turn on at the wrong moment. He started to scream and cry, and I couldn't fix it quickly enough. I felt so guilty about the whole situation, because I did this to him. Later when he stopped playing, it was okay again. But it did make me



**Figure 8:** Jonas playing with the LINKX prototype

feel hesitant coming back another time. I fixed the bugs and came back with the toy. Luckily, he enjoyed playing with the toy again. This incident taught me the importance of predictability. After three times playing with each child, I cannot conclude that these children learn to name objects with LINKX. For this, further research would be needed. However, the pleasure during play is visible in the observation videos and some indications of language learning could be found.

### **Lessons learned from the LINKX project**

The LINKX project revealed some lessons that can be applied to other designers who involve children with autism and their caregivers in their design process. Some of these findings even apply to people with cognitive impairments in general, as they are comparable to my experiences in designing ‘the chitchatters’ for people with dementia (see chapter 1).

The most important finding was the importance of involving the children’s caregivers in the project. Only when caregivers are willing, designers can come close to the children and collect rich experience information about them. Trustworthiness was important to convince the caregivers to participate in the project. Especially for professional caregivers, because they are accountable to the children’s parents. After talking to professional caregivers in person, they were more likely to be willing to participate. However, the need for consent from parents hindered professionals from actual involvement. One issue for example, was that children with signs of autism are often still in the process of being diagnosed. Professional caregivers do not want to approach the parents about a design project for children with autism, because they do not want to burden them and confront them directly with the diagnosis, even if they know it. In some cases the ‘name’ seems to be taboo. This left very few parents that could be contacted. The three parents that responded to the designer’s letter were very motivated. They were happy that someone was making an effort to develop new products for these children. Explaining common goals and how collected information was used motivated the parents to initiate and maintain their involvement in the project. For example, shared (interim) reports that were full of pictures and anecdotes about the children and caregivers gave parents ownership over the process and results. This ownership motivated them to continue their participation (van Rijn and Stappers, 2008b).

In the project, the designer often met caregivers while the children were around. At these moments, the designer and caregiver could not keep our full attention on the conversation, even if they tried. The children distracted them and were the priority of the caregiver. Sometimes, this situation frustrated the designer. Only when children were not around, the designer could have an in-depth conversation with the caregivers. On the other hand, in encounters with the children, caregivers played an indispensable role. They mediated the contact between the children and the designer and helped her to feel at ease around them. Actually, the children’s atypical behaviour made the designer curious to discover more about them. This helped her to step over the threshold and be open-minded. Early prototypes provided a way to communicate with the children.

In a way, the children could ‘give’ their opinion and provide relevant information for the project.

When starting to generate ideas, the next challenge arose. Close contact with the children and caregivers brought insight into their experiences in daily life. As result, the designer became emotionally involved with them. She needed much time for detachment; a necessary step for generalisation and idea generation. Analyzing the collected information, and detach from the individual stories took weeks. In the beginning, ideas did not fit the capabilities of the children or were too simple for the designer’s liking. She needed to put effort in idea generation, but also needed time for incubation. Theorizing and creating a design vision helped her in this process.

## **2.5. Tools and techniques for learning about experiences**

Various tools and techniques exist to support designers in building creative understanding about the experiences of users. Most of these tools and techniques rely on verbal communication; so cannot be applied to non-verbal children with autism. These children require other, non-verbal, tools and techniques (see chapter 4). Fortunately, the children have their caregivers around. Designers can use existing tools and techniques with these caregivers to jointly discover the needs and experiences of children with autism in an indirect manner. In this way, caregivers are interpreters of the children’s experiences and can provide designers with second-hand rich experience information. Tools and techniques for learning about experiences in design can be divided into three main classes: direct contact, indirect contact, and no contact (Kouprie and Sleeswijk Visser, 2009; Wright and McCarthy, 2005). Below, these classes are described in more detail and illustrated with examples from the LINKX project.

### **Direct contact between designers and users**

Designers can use direct contact with children and caregivers to learn about their experiences. In direct contact, or encounters, designers enter a dialogue with children and caregivers in which all parties learn about each other’s experiences (Wright and McCarthy, 2005). During this process, designers collect rich experience information themselves for creative understanding. They create their own stories based on personal experience with users. For example, in observation studies (see figure 9), designers can follow children and caregivers in their everyday life (Leonard and Rayport, 1997). They can also use (early) prototypes to start a dialogue with children or caregivers. Prototypes are highly valuable for design, both from the insights they reveal about the prototype, and as a further way to explore the user’s context (Buchenau and Fulton Suri, 2000). Early in the design process designers can use experiential prototypes; versions of the product that function well enough to let the prospective user experience how they could be used and how they would fit in their lives (Buchenau and Fulton Suri, 2000). Experiential prototypes do not need to fully function in a technical sense.

However, consistent feedback from these prototypes is crucial for children with autism (e.g., Pares et al., 2005; van Rijn and Stappers, 2008a). Another tool for learning about experiences is the use of verbal communication. In a discussion, caregivers can share their interpretations of the experiences of the children with designers (see figure 10). Designers can listen to and learn about experiences from conversations and in-depth interviews with caregivers. In generative sessions, designers can explore the context of product use together with caregivers (Sanders and Dandavate, 1999; Sleeswijk Visser et al., 2005). To employ these techniques, designers prepare expressive toolkits, such as a set of images and words. By means of this toolkit caregivers create an artefact, such as a collage about their experiences relating to a specific topic. Next, they explain the motivations behind the resulting artefact. These techniques rely heavily on the ambiguity of the provided stimuli, which must be open enough to stimulate interpretation and discussion (Gaver et al., 2003). Users can tell what it means to them, instead of being limited to what the designer intended with it. This principle puts users in the position of ‘expert’ of their own experiences (Sleeswijk Visser et al., 2005). From the information they collect, designers can make representations such as personas, scenarios, and documentaries. Designers can discuss these representations with caregivers to collect more rich experience information or validate their findings (van Rijn and Stappers, 2008b).



**Figure 9:** Observation at Daniel's house during the LINKX project

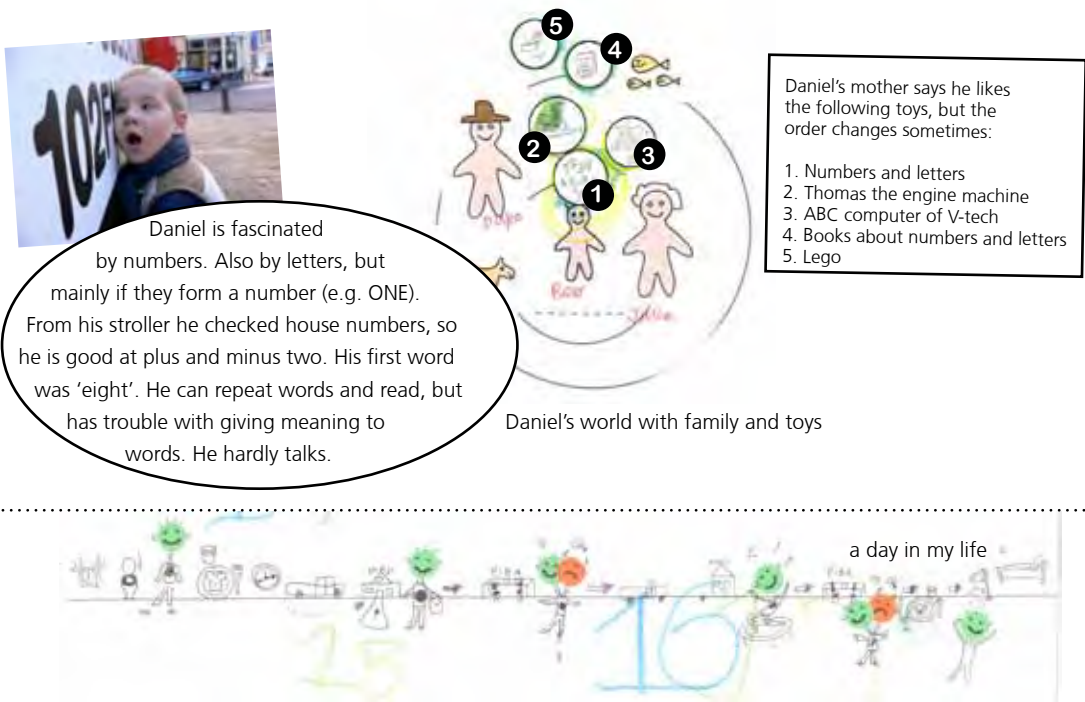


**Figure 10:** A conversation with Daniel's mother during the LINKX project

### **Indirect contact between designers and users**

In design practice, dedicated user research agencies or departments often bring user experience to designers (e.g., Sleeswijk Visser, 2009). In this model, designers learn from indirect contact with users. Researchers conduct the user study on behalf of the designers, and interpret and communicate the resulting rich user information to designers with the use of various presentation methods. These researchers can use the same set of tools and techniques as designers would use in direct contact with users. For communication purposes, generative techniques have some advantages over

observations and interviews. In generative techniques, people make their experiences explicit in expressive artefacts. Researchers can easily use these artefacts when showing their findings to designers, because they are already explicit, tangible, and from the individual's perspective. Raw data, such as photos and videos of people, original quotes, and expressive artefacts, helps designers to make personal connections to the users and empathise with them (e.g., McDonagh-Philip and Bruseberg, 2000; Sleeswijk Visser et al., 2005). Various storytelling techniques have been developed for communicating rich experience information to designers. Examples are personas; fictional people created to represent user information (e.g., Pruitt and Adlin, 2006), scenarios of product use (e.g., van der Lugt and Sleeswijk Visser, 2007), storyboards (van der Lelie, 2006), and design documentaries (Raijmakers et al., 2006). Figure 11 shows an representation of Daniel used in the LINKX project. Design probes enable designers to indirectly communicate with caregivers without involving external researchers (Mattelmäki, 2006). A probe is a package with diverse materials and tasks that is sent to users. Users complete this probe in their personal environment and at their leisure, and return it to designers without actually meeting them. Finally, designers can also use prototypes in indirect contact with children and caregivers. For example, children and caregivers can use prototypes in the absence of designers and report their experiences back to the designers.



**Figure 11:** A representation of Daniel's life from the LINKX project



Technology probes record the activities of users in a database without involving conscious self-documentation. They can collect rich experience information about the use of technology in a real environment (e.g., video, photos, usage frequency), but do not contain verbal explanations from users about the collected information.

### **No contact: designers' imagination**

Designers step into the shoes of children with autism by simulating their condition. By means of imagination, designers try to come closer to and learn about the children's experiences. Various techniques have been developed to support designers in imagination, such as role-playing, body storming, and 'experience prototyping'. An experience prototype is any kind of representation that is designed to understand, explore, or communicate what it might be like to engage with the product, space, or system we are designing for (Buchenau and Fulton Suri, 2000). For example, designers learn about the obstacles a blind person faces by walking around blindfolded for a while. However, these techniques are limited in that they can never understand the lifetime impairment of these people by being blindfolded for a couple of hours. Experiential prototypes help designers to imagine the experiences of users and thereby bring them closer to them. However, few tools and techniques have been developed to support designers in imagining autism. One example is 'het hoofdkwartier' (see figure 12).



**Figure 12:** Daniel in the exhibition 'het Hoofdkwartier' ([www.hethoofdkwartier.nl](http://www.hethoofdkwartier.nl)). Visitors simulate the fragmented perception of people with autism by fragmented and simultaneous sounds, music, images and videos.



## 2.6. Conclusions

This chapter indicated that designers need creative understanding about children with autism when designing for them. In literature, no special tools or techniques are available to support designers in this. In the LINKX project, the author built most of her creative understanding from encounters with children and caregivers. The next chapter elaborates how designers can learn from personal experience in the children's context.



3

# Building creative understanding from encounters










*This chapter describes models and processes on learning from encounters and applies these models and processes to designers. First, we define an encounter between designers, children, and caregivers that are used as means for creative understanding. Next, we use theory and models about the experiential learning process to describe the learning process of designers. Finally, we conclude with how these theories serve the foundation for the framework in chapter 5.*

### 3.1 Introduction

In user-centred design, there is a broad consensus that designers should be informed about their user group (e.g., Koskinen et al., 2003). Chapter 2 described three categories of tools and techniques that can support designers in learning about user experiences: direct contact, indirect contact, and no contact: designers' imagination. In the LINKX project, the author had learned about the experiences of the children in various ways. She read literature, saw movies and documentaries, observed children, and spoke to their caregivers. In hindsight, direct contact with the three children and their caregivers gave the most valuable input for her design (see 2.4). Only after her first encounter did she really understand the challenge she signed up for, and became truly motivated for the project. In literature, many researchers argue that direct contact leads to most creative understanding (Fulton Suri, 2003; Mattelmäki and Battarbee, 2002; McDonagh-Philip and Bruseberg, 2000). Seeing the other's situation, condition, and behaviour with your own eyes provides an understanding that you cannot gather from other sources of information. The hands-on nature of learning about user' experience from direct contact is highly motivating (Battarbee, 2004). It actively involves designers in learning, and makes them more able to understand what they are learning compared to learning from theory. Designers retain, memorize, and act upon this knowledge to a greater degree than when this information is merely presented to them. Although many researchers advocate direct contact in design, evidence about the best way of informing designers was missing. In a comparative study, we explored the effects of different sources of information on designers' ability to empathize and the quality of product concepts they generated (van Rijn et al., 2011). This study, and experiences in the LINKX project, underpin the focus on how designers can learn from encounters with children with autism and their caregivers.

**Comparative study about three ways of informing designers**

This study explored how different sources of information influence design teams' understanding of users, and the quality of product concepts that they generate. Six design teams, each consisting of two or three M.Sc. design students, developed product concepts for children with autism in separate design sessions. As preparation, the teams were informed about the user group using three different approaches: (A) literature, (B) literature and an encounter, and (C) literature and a video of an encounter (see figure 1). For each type of approach, two of the six design teams performed a one-hour session in which they designed a concept for a lunch product for children with autism. The teams consisted of two or three international M.Sc. design students of the faculty of Industrial Design Engineering who volunteered for the study. In order to determine the teams' level of empathy with children with autism, we analyzed the teams' discourse during their design sessions. The amount of time spent discussing the user group was taken as an indicator of empathy, because measurements were difficult to make. In order to evaluate the quality of the proposed product concepts, five caregivers of children with autism blindly evaluated the teams' concepts. Caregivers are experienced with these children, so can provide expert judgements on how well different product concepts fit the experiential worlds of the user group. Results show that having designers participate in encounters with children with autism and their caregivers was the most successful approach of the three. It resulted in the most inspiring and lively discussion within the design teams about the user group, and led to product concepts fitting their needs and preferences. These designers were better able to design products for this user group. This study showed that using literature led to designers making false assumptions, and generating more wild ideas that didn't fit the user group. Moreover, the encounters seem to bring a greater willingness to learn, and demand the attention of designers. Designers hardly have a choice; they have to pay attention in order to react appropriately to the people they are observing or interacting with.

No contact	Direct contact	Indirect contact
 only literature	 literature + encounter	 literature + video
 <b>Team A1</b> All caregivers said this does not fit the user group.	 <b>Team B1</b> All caregivers said this fits the user group best!	 <b>Team C1</b> This addresses the users' weakness. Some regard this as positive, while others not.
 <b>Team A2</b> Two caregivers said this does not fit the user group, while three said parts of it fit a little.	 <b>Team B2</b> Three caregivers said this fits the user group, while two said it fits a little.	 <b>Team C2</b> Three caregivers said this fits the user group, while two said it fits a little.

**Figure 1:** This study shows encounters with children with autism result into most empathy and high quality of product concepts

## 3.2 Framing encounters

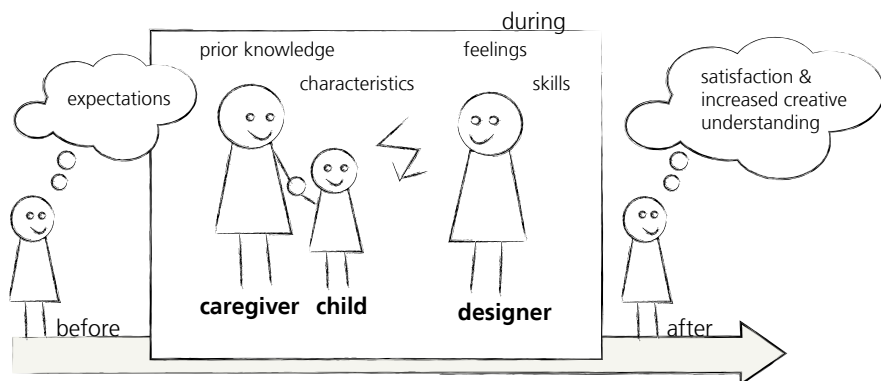
In daily life, encounters between people happen spontaneously all the time. They teach people something about each other, and are often understood as unexpected, sudden, or violent (Hornby, 2005). When designers want to meet children with autism, they need to make some effort to plan an encounter with them. These encounters can include both user observations, and interaction with children and caregivers. Encounters have the specific meaning of an authentic meeting or event between individuals in which individuals correspond to each other and participate either as actor or as perceiver preparatory to action (Warren and Shaw, 1985). In this dissertation, the following working definition of an encounter is used:

*An encounter is a meeting between a designer, user, and caregiver in the user's environment in which these people participate either as observer or actor.*

We argue that this role of actor is especially important for designers' creative understanding about users' experience. Only then do designers actively participate in a dialogue with the children. Chapter 4 elaborates upon this dialogue between designers and children with autism.

### The structure of an encounter

In general, an encounter between people can be structured into three main parts: before, during, and after. Figure 2 shows how this structure is applied to designers, users, and caregivers.



**Figure 2:** The structure of an encounter between a designer, child, and caregiver

### *Before the encounter*

Before they interact, designers, children, and caregivers have expectations about the upcoming encounter. Expectations cause people to look forward to something positive, or anticipate something negative in the future. They influence people's behaviour during the encounter and their feeling of satisfaction afterwards (Gudykunst and Shapiro, 1996). These expectations are a function of people's goals, characteristics, skills, knowledge, feelings, roles, and prior interactions. In this dissertation, the goal of designers is to build creative understanding of children with autism and their caregivers, with particular reference to their design brief. The children most likely have no long-term expectations about an upcoming encounter, but strive for feelings of happiness and safety in any situation. However, they can remember designers from previous encounters and may have expectations based upon this. For example, in the LINKX project, one boy asked his mother when he could play with the blocks again. When seeing the designer for a second time, he definitely expected he could play with the blocks. Caregivers might expect designers to be creative and bring new concept designs for them and the children. Designers can take these expectations into account by explicitly asking caregivers about their expectations and those of the children beforehand.

### *During the encounter*

During the encounter, designers actually meet or even interact with children and caregivers in the children's environment. This interaction is defined by the people's expectations, characteristics, feelings, skills (e.g., empathic skills, communication skills), and prior knowledge. In the situation of a first encounter, people do not know what might happen when they interact with others. This might cause feelings of uncertainty and anxiety (Gudykunst and Shapiro, 1996). These feelings tend to decrease when people get to know each other better and open up to one another. When this happens, they perceive the interaction as relaxed, smooth, open, and involving understanding and attentiveness. The sensation of communication breakdowns is minimized (Duck et al., 1991). In encounters between designers and children with autism, interactions are often not that smooth at first due to the children's impairments (see chapter 4). In the children's environment, caregivers and children are in control. They define whether the proposed activities of designers may take place and for what duration. Caregivers need to guarantee the child's safety. Designers need to take these considerations into account to accomplish the most.

### *After the encounter*

Afterwards, the designer takes all his or her personal experience and collected data from the encounter and uses it to establish creative understanding. In general, satisfaction is an affective reaction to whether an interaction meets or fails to meet our expectations (Hecht, 1978). The extent to which designers feel satisfied about the encounter depends on the established level of creative understanding. Designers are likely to be content when the encounter results in more information, empathy, and/or inspiration for concept development.

### **Underlying relationships**

Encounters are part of a larger picture. In a series of subsequent encounters, people open up towards each other and feel more at ease about sharing their experiences. They get to know each other better and relationships grow between them. Children with autism cannot easily establish long-term relationships with others. Therefore, designers enter a relationship with caregivers to arrange consent for encounters and realize them. Designers enter a relationship during their research, which they may need to nurture, or perhaps terminate in a decent manner. In any design process that directly involves users, designers should consider the management of these users' expectations (Preece et al., 2002). Designers should act sensitively, given the greater potential for misunderstandings and the difficulty of taking away misconceptions. For example, children learn to interact with prototypes during encounters. When the prototype is taken away afterwards, this can be disconcerting or distressing for children with autism (Gabielli et al., 2005). Trustworthiness and respect are important for the growth of relationships. Even after the design project, designers, children, and caregivers can maintain a relationship.




## **3.3. Creative understanding inspires designers**

In this dissertation, encounters are used as a means for obtaining creative understanding of user experiences. Creative understanding is the combination of a deep, cognitive and affective understanding of the other, and the ability to translate this understanding into product concepts and services. In other words, designers are inspired by and can act upon creative understanding (see chapter 2). In philosophy, a number of different terms are used to describe knowledge. However, there seems consensus about what the three main types are: propositional knowledge, knowledge by acquaintance, and procedural knowledge (e.g., Hospers, 1990). Knowledge by acquaintance is referred to with a number of different terms; including experiential knowledge, perceptual knowledge, sensual, or personal knowledge (Niedderer, 2007). This dissertation uses the term personal knowledge for knowledge by acquaintance. These three types can all help to bring designers creative understanding. Personal and procedural knowledge can be obtained from encounters, while propositional knowledge cannot (see table 1).



Propositional knowledge is defined as ‘justified true belief’ such as ‘the sun goes up’ (Niedderer, 2007). An example of this type of knowledge is a scientific article. It is based on objective data, brings proven truth, and is empirical and classified. Making sense of propositional knowledge involves reading, seeing, or listening to the theories and explanations of others. Designers can easily access and share this knowledge, because it is explicitly available in sources such as literature and documentaries. However, designers might have difficulty in really comprehending the experiences of children with autism from the description of theories and explanations and using them in design. These theories and explanations are on a high abstraction level, and they lack lively examples. Additionally, they might not build on the prior knowledge of designers, who often have no background in psychology. Often, propositional knowledge can only be used within the limits where it is claimed. This leaves little room for designers to interpret, so internalize it into creative understanding.

Personal knowledge is based on facts gained from first-hand experience or observation (e.g., Hospers, 1990). It involves close personal observation or direct contact with something or someone (Bate and Robert, 2007). Making sense of personal knowledge can involve the use of aids such as videos and interviews, or recourse to memories and thoughts about the interaction with users. In principle, this knowledge is tacit, so non-tangible and subjective. Designers cannot easily share this knowledge with others, because even when made explicit, a story about an experience is never equal to the experience itself. Designers can easily understand personal knowledge, because they have influence over what they learn. For example, they can ask caregivers to give them information they do not know yet. Personal knowledge has an ‘open’ character, because designers need to interpret it themselves. This makes personal knowledge both informative and inspirational for designers.

	Creative understanding			
type	information	empathy	inspiration	example
 propositional	+	-	-	Literature explaining the impairments in social interaction, communication and imagination
 personal	+	+	+	A close observation of a child that lines up shampoo bottles
 procedural	-	+	+	A child that grabs your hand in interaction

**Table 1:** The combination of propositional, personal, and procedural knowledge brings designers creative understanding about the experiences of children with autism

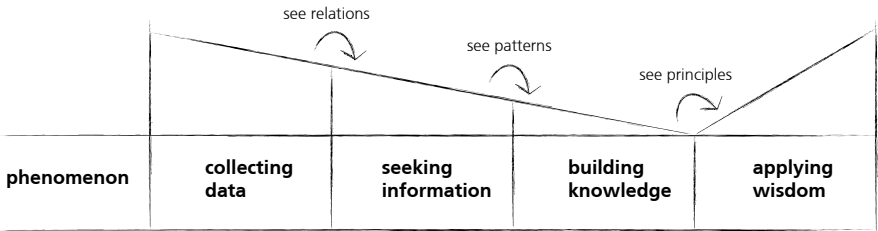
Procedural knowledge is exercised in the accomplishment of a task, and thus cannot easily be articulated (e.g., Grayling, 2003). It is typically unconscious (or tacit) and subjective. Parts of this knowledge can be explicated, while other parts remain tacit. Just like personal knowledge, designers cannot easily share procedural knowledge with others. For example, when designers visit a child with autism for the first time, they might not know how to act around the child, or how to interact with them. After reading a book about this subject, the designer might understand the theory, but not yet feel confident to immediately be left alone with the child. It can help if the caregiver shows and explains the correct way of interacting to the designer. However, this is still not enough. Designer learns the most from trying to interact with the child, because they can apply these interactions into future interactions with new product concepts. This active aspect of acquiring procedural knowledge inspires designers.

### 3.4. Building creative understanding

Creative understanding is the outcome of learning. Designers need to conduct learning activities and go through a learning process. This section describes models and processes for building creative understanding from encounters.

#### DIKW: information hierarchy model

When building creative understanding, designers collect data and seek new information relevant to their specific design brief. A general process for sense-making in research is by creating an information hierarchy (or DIKW) where each level represents patterns in the level below it (Ackoff, 1989). This process can also be applied to sense-making of user data in design (e.g., Sanders and Stappers, 2012; Sleeswijk Visser, 2009). Figure 3 below illustrates the DIKW model referring to four levels: Data, Information, Knowledge, and Wisdom. The first level is ‘collecting data’. Data is the most basic level, and refers to captured elements of the phenomenon studied. The higher the level, the more abstract its content. Data is transformed to the next level, ‘seeking information’, by looking for relationships. Designers select data that appears relevant, interesting, or inspiring for the design project. In the information level, data is interpreted.



**Figure 3:** DIKW model.  
Adapted from Ackoff (1989).

Next, patterns are sought within the information and interpretations are compared and generalized. In this step, information is transformed to the third level, 'building knowledge'. The patterns between chunks of information form them into a meaningful whole. Clusters are made of information that contains the same overall message. Finally, by seeing principles behind the knowledge, the knowledge can be applied to and used in concept development. At this point, the designer has reached the final level, 'applying wisdom', where the knowledge is put to use. In this process of sense-making, designers increase their creative understanding in several ways. For example, in data collection, designers might recognise room for improvement. Ideas generated during data collection are often based on the current situation, and result in redesigns of existing solutions. During sense-making, designers see (new) relations, patterns, and principles. Interpretation can bring new ideas and thoughts. Finally, as designers move to the highest levels of the information hierarchy, they let go of the data, and thereby the current situation with existing solutions. They can apply their acquired wisdom, or creative understanding, in a new manner to come up with innovative product concepts.

#### *Factual and inferential processing*

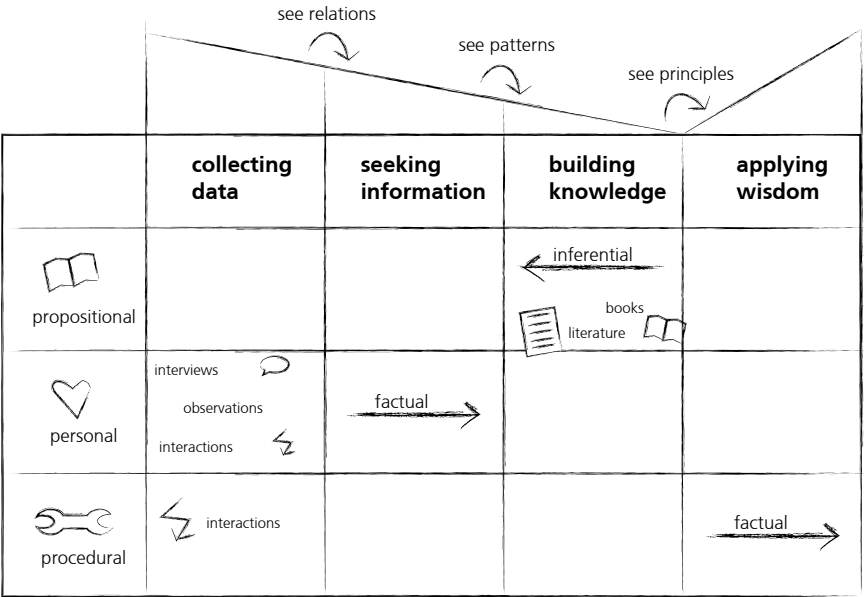
The DIKW model describes a grounded or factual way of processing information. In factual processing, designers work bottom-up; they experience the research process personally and collect data themselves during encounters. In order to support themselves in the task of selecting relevant information, designers can explicate their collected data by making records such as transcripts of interviews, video annotations, or reflective journals. From these records, they select information, and process this information into personal and procedural knowledge. Acquiring propositional knowledge, on the other hand, requires inferential processing. In inferential processing, designers work top-down; they use existing theory rather than building their own theories. Other people (mostly researchers) have completed this knowledge into a 'closed' theory, not open to the designer's own interpretation.

These different ways of processing affect how designers will deal with collected user data. Figure 4 explains these effects by showing how the three knowledge types and ways of processing can be combined in the DIKW information hierarchy. It contains examples of data sources for each of the three knowledge types.

For propositional knowledge, designers collect literature, books, and documentaries as data. The challenge lies in connecting propositional knowledge to the phenomenon. Only then, designers truly understand this knowledge, make it part of their creative understanding, and use it in concept development. Figure 4 visualizes this with an arrow in the level of propositional knowledge. The arrow points to the left, illustrating the inferential way of processing (top-down).

For personal knowledge, designers conduct interviews, observe, and interact with users to collect data. Designers search for relations, patterns, and principles themselves. This data is open for the designers' own interpretation. Figure 4 visualizes this with an arrow in the 'seeking information' level of personal knowledge. The arrow points to the right, illustrating the factual way of processing (bottom-up).

For obtaining procedural knowledge, designers interact with users to collect data. These interactions teach designers about how users interact with objects and people. This brings the designers the ability to predict user behaviour with future product concepts. In the figure, this is visualized with a star and arrow in the 'wisdom' level of procedural knowledge. The arrow points to the right, visualizing the factual way of processing (bottom-up).



**Figure 4:** Three types of knowledge and two types of processing all combined in the DIKW model.

The DIKW model describes how designers build creative understanding from encounters over time. In this process, collecting data during encounters with children and caregivers is a starting point for learning. The next model describes the learning process of designers from another viewpoint; namely focusing on the encounter itself, and what happens during and around it.

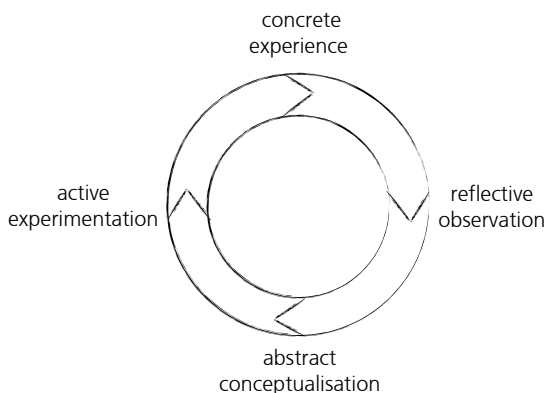
### Kolb's experiential learning model

In social sciences, the process of making sense from direct experiences is defined as experiential learning (Itin, 1999). David Kolb is known for his theoretical model about how people learn from direct experiences (Kolb, 1984). This model proposes an experiential learning cycle that includes both the learning of theory as well as the obtainment of practical skills. He states that the ideal learning process requires going through the whole cycle, which includes four steps or activities: concrete experience, reflective observation, abstract conceptualisation, and active experimentation (see figure 5). Each activity corresponds to a specific learning style. People naturally prefer one style: their dominant learning style (Kolb, 1984). They tend to start in that style and/or spend most time in it. Switching between styles is favourable for learning, but does not come easily or naturally to most people. Notably, the cycle can start anywhere.

#### *Experiential learning of designers*

In design education, this model has been used as tool to support the learning process of design students (Thieme and van Boeijen, 2011). For this dissertation, Kolb's cycle and corresponding activities are useful to describe and support the experiential learning process of designers during their encounters with users.

The cycle starts with designers having concrete experience in the children's context. In concrete experience, designers closely observe or interact with one or more children. For example, they visit the children at school and observe them. Designers closely experience aspects of the children's lives, such as their daily routines, habits, dislikes, and preferences. Concrete experience is followed by reflective observation. In this step, they have an opportunity to reflect upon their experiences with the children and/or caregivers. For example, designers reflect on their observations when back at work. They can use logs, recordings, and reflective journals to re-think and make sense of their experiences. Next, designers may conceptualize and draw conclusions about what they



**Figure 5:** The experiential learning cycle.

Adapted from Kolb (1984).

have experienced, observed, and reflected upon. In abstract conceptualization, they often use discussions and brainstorming as tools to do this. They analyze their findings for similarities, differences, and analogies, and theorize about the experiences of users. The final step leads to future actions in which the designer experiments with new behaviours and interventions. In active experimentation, designers try out new ideas based on their experiences, reflections, and interpretations. For example, when designers are learning about their user group, they try to adapt their behaviour to establish a better interaction with the children. Later in the design process, they use their creative understanding to develop ideas, concepts, or prototypes of products to improve the current situation. For example, trying the foam blocks in the LINKX project with children with autism gave the author insight into how children experience the shape, material and weight. It also revealed that they enjoy a certain form of sensory stimulation. These aspects provided inspiration for the eventual product concept.

After this last activity, the cycle begins again as people have new experiences based on their experimentation (Oxendine et al., 2004). Designers can go through all the different learning styles in different encounters, but also within one encounter they may alternate between styles. This learning cycle involves both concrete components (concrete experience and active experimentation) and conceptual components (reflective observation and abstract conceptualisation), which require a variety of cognitive and affective behaviours. The concrete components involve affection, while the conceptual components involve cognition.

### 3.5. Conclusions

Designers need to achieve creative understanding of user experience in order to design. Creative understanding is a type of knowledge designers can act upon. It can be built from propositional, personal, and procedural knowledge. This chapter described models of how designers learn from experience and build creative understanding. These models form the basis for the framework in chapter 5. But before this, the next chapter describes the limitations of children with autism and the designers' possibilities in learning from encounters with them.



4





# Encountering children with autism for design

*This chapter provides a theoretical background on autism, to understand the impairment and its implications for designers, especially concerning contact with users. This chapter is mainly based on literature connected with examples from the behaviours of Daniel, a boy with autism. It presents some historical facts about autism and explains research on the behaviour of children with autism, followed by research on cognition. These explanations about autism are used to describe the consequences of autism on encounters between designers, children and caregivers.*

## 4.1. Introduction

Leo Kanner was the first person to describe early infantile autism as a syndrome (1943). In his publication, Kanner mentioned ‘extreme autistic aloneness’ and ‘insistence on sameness’ as key identifiers of the syndrome. One year later, Hans Asperger (Asperger, 1944) described the autistic characteristics of four children in his doctor’s practice. The number of references on the internet exceed the 24 million and grows every day (Roeyers, 2008). Because of this enormous body of knowledge, this chapter only provides a short overview that is relevant for designers.

In the last decades many terms were used to describe autism and related disorders. Most common now is the term ‘autistic spectrum disorder’ (ASD): affected children may display a range of impairments at many levels such as impairment in social interaction, communication, and imagination (Wing, 1997). The spectrum includes all types of autism with different nuances. The most common types are autistic disorder, Asperger’s syndrome, and pervasive developmental disorder-not otherwise specified (PDD-NOS). Autism is a neurobiological developmental disorder, which affects around 1% of all people worldwide (Health council of the Netherlands, 2009). It affects three to four times more males than females (Fombonne, 2003). This ratio is now a hot topic in the discussions, because recent studies underline that girls with autism are missed (e.g., Holtmann et al., 2007; Gould and Ashton-Smith, 2011; in ‘t Velt-Simon Thomas and Mol, 2005). It is found at all IQ levels, but an intellectual disability accompanies the disorder in 25% of all people diagnosed with autism (Health Council of the Netherlands, 2009; Rogers and Dawson, 2010). Autism is a life-long disorder, so not restricted to childhood.

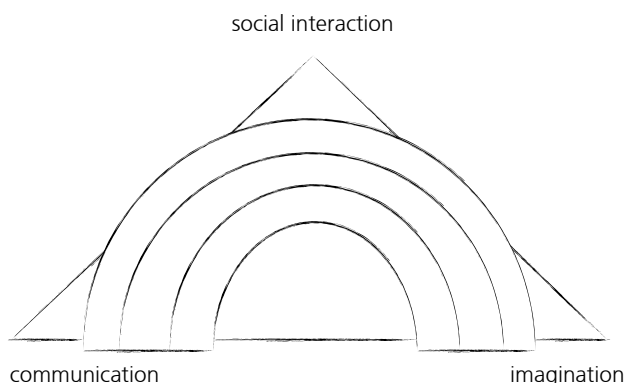
### Three levels of researching autism

Research on autism is undertaken on roughly three levels; neurobiological, behavioural, and cognitive. On the neurobiological level autism is described as a multi-factorial condition with a high genetic component of 90%, but there has to be a trigger or triggers to let autism develop. Relatively little has been conclusively determined regarding the actual brain area or pathway involved. Currently, autism can only be recognized and diagnosed on the behavioural level. Research on this level brings designers insight into the way children with autism behave towards people and objects (see 4.3). Research on the cognitive level provides explanations for unusual behaviour and indications of brain dysfunction (see 4.4). These explanations can bring designers understanding about autism and provide inspiration for design solutions such as treatments and products.

The start of this chapter showed a photo of Daniel, a Dutch boy diagnosed with the autistic disorder. Daniel was involved in this Ph.D. project, together with his mother and little sister Maud. In this chapter, Daniel’s actions provide examples of behavioural phenomena that characterize autism. His unique behaviour shows potential for design solutions.

## 4.2. Research on the behavioural level

Wing's triad is common to all children diagnosed with autistic spectrum disorder (Wing, 2001). This triad contains impairments in social interaction, communication, and imagination (see figure 1). Here, we give an overview of behavioural characteristics of the autism spectrum disorder based on this triad.



**Figure 1:** Wing's triad of the autism spectrum disorder, based on (Wing, 2001)

### **Impairment in social interaction**

The first impairment in Wing's triad is social interaction. This impairment results in the shortcomings to form relationships. Children with autism lack reciprocity in social interaction (Roeyers, 1997). They tend to exhibit a lack of eye contact and facial expressions, show an inability to share and direct attention, and do not understand and interpret emotions intuitively like children with typical development. They seem to have impaired recognition of affection, and problems to imitate and understand the social behaviour of others. These impairments in social interaction can manifest in different ways. Wing described a sub-typology with three social phenotypes (Wing, 1988). These are the 'aloof', the 'passive', and the 'odd'. Children described as 'aloof' are most disconnected from social contact. They barely take part in social interactions. Children described as 'passive' react to the initiative of others, but they rarely take initiative themselves. Children described as 'active-but-odd' approach other people, but do this in a naïve, egocentric, repetitive, and strange way. They are not interested in the response of others. In none of the phenotypes do children interact with other people in a symmetrical and equal manner.

### **Impairment in communication**

The second impairment in Wing's triad is communication. Communication includes both verbal and non-verbal communication forms, and also refers to the overlapping issue of social skills. Use of gestures such as pointing and nodding are considered communicative behaviour, while facial expressions belong to the social interaction domain. Communication is considered a cognitive process, in which perception plays a crucial role (Noens and van Berckelaer-Onnes, 2002). It involves both expressive and receptive language skills.

#### *Expressive skills*

Expressive skills refer to the ability to express oneself. All children go through several stages of expressive use of communication such as using gestures, joint attention (see figure 2), using visual information, and using language (Hogan, 1997). Children with autism go through the same stages, but may remain at one stage for a longer period of time, or may pass through these stages in a different order. Some children with autism never come as far as functional speech, and have little or no other way of communicating. Other children develop spoken language, but do not use it in a communicative way. Moreover, they exhibit immediate or prolonged echolalia, reversion of pronouns, abnormalities in rhythm and intonation, and absence of gestures. Other children speak correctly and fluently with a large vocabulary, but cannot maintain a conversation with



**Figure 2:** Daniel's little sister Maud points at something she sees. Her mother found this remarkable, because her older brother Daniel, never did this. Children with autism often do not understand the principle of joint attention. When seeing you pointing at something, the child looks at your finger instead of the object you are pointing at.

someone. Also, they often have problems expressing their feelings (Wing, 2006). About 25% of all children with autism are non-verbal. The language of children that do speak often lacks a social quality. In contrast to most children with autism, children with Asperger's syndrome use long-winded language.

### *Receptive skills*

Communication also involves receptive language skills; the ability to give meaning to expressions used in communication. Communication is in essence sense-making, the exchange of meanings (Noens and Van Berckelaer-Onnes, 2004). This sense-making can take place at roughly four levels: sensation, presentation, representation, and meta-representation (Noens and Van Berckelaer-Onnes, 2004; Verpoorten, 1996). Understanding the child's current level of sense-making is needed for caregivers and designers to establish a connection with the child, and develop interventions and design solutions that fit the child's experiences and abilities. The levels of sense-making are explained by the example of drinking a beaker of milk.

#### *Level 1: Sensation*

At first, infants experience their world at a sensory level. They experience their world by sensations such as sucking and touching a beaker of milk without understanding its meanings.

#### *Level 2: Presentation*

At the level of presentation, the child perceives information in a concrete context. The beaker only has meaning to the child when it is filled with milk. An empty beaker is meaningless.

#### *Level 3: Representation*

At the level of representation, the child understand a word or pictogram refers to an object or activity. The word 'beaker' or its pictogram represents a beaker or refers to drinking. If children do not speak, they have reached this level when they know that an object, gesture, or a pictogram refers to the action 'to drink', even if the beaker of milk is out of sight. They understand the hidden meaning; the reference function of the object, the gesture, or the pictogram. The development of object permanence is a necessary condition to achieve the level of representation. By using a symbol, one needs to be able to represent (or imagine) the referent while that referent in the concrete form is not present (Piaget, 1952; Werner and Kaplan, 1963). Representation implies a certain amount of awareness that the symbol and the referent are not identical, but two separate entities.

#### *Level 4: Meta-representation*

The final level is reached when information is given beyond the literal meaning, for example by saying a sentence in such a way that others know that it is a joke. Human language is full of meta-representations; for instance those hidden in proverbs, expressions, and irony. Primary messages often contain a secondary message. In fact, messages in which only the primary content counts are so rare in common conversations that people tend to imagine hidden meanings behind the primary content, even if this is not the intention (Frith, 1989). Children with autism rarely reach the level of meta-representation, and sometimes do not even master the levels of presentation and representation. They remain at the level of concrete literalism (Noens and Van Berckelaer-Onnes, 2004).

Communication can occur at all levels of sense-making and use of different expressive stages. Impairments in communication do not imply no communication at all. In order to establish communication, determination of the available level of sense-making is crucial (Noens and Van Berckelaer-Onnes, 2004). In contrast to caregivers, designers are unfamiliar with determining these levels, and with using expressive stages other than spoken language.

#### **Impairment in imagination**

The third aspect of Wing's triad is the lack of imagination of people with autism. In young children, this can strongly influence the play development. Children with autism show a striking absence of spontaneous pretend or 'symbolic' play (Van Berckelaer-Onnes, 2003). So, while a normal 2-year old will pretend that a toy brick is a car, and let the car drive, a child with autism (even of a much higher age) will simply mouth the car, throw it, or spin the wheels. Some children never reach the level of symbolic or imaginative play.

Ungerman and Sigman (1981) researched the toy play behaviour of children with autism, based on the four phases of toy play development outlined by McCune-Nicolich (1980). These phases are: simple manipulation, relational play, functional play, and symbolic play. We will describe these phases and the findings about toy play behaviour of children with autism for each phase (Black et al., 1975; Demeyer et al., 1967; Van Berckelaer-Onnes, 1991; Wing et al., 1977).

### *Phase 1: Simple manipulation*

The first phase in toy play development is the simple manipulation of objects. Manipulating objects serves as an important exploratory function in young children who are developing in a typical manner. They try to detect the characteristics of the different objects and these experiences to help them give meaning to the toys. Children with autism do not have exactly the same experiences. The manipulation of the object seems to be their end goal, rather than a means of making sense of it. Simple manipulation is limited, obsessive, and stereotypical. Children with autism repetitively conduct the same action such as turning wheels, tapping with objects, or licking them. They tend to restrict themselves to a limited selection of objects.

### *Phase 2: Relational play*

The second phase of toy play development is relational play. By combining different objects, children explore what is useful to combine and what is not. For children with autism, combining objects tends to be restricted to a small number of stereotyped, repetitive activities such as tapping with a stick, turning knobs, banging two blocks against each other. These combinations are often strange, and without any variation.

### *Phase 3: Functional play*

The third phase in toy play development is functional play with objects. When a child plays in a functional way, he or she uses objects in the way they are intended. For example, putting a cup on a plate. Children with autism score better in this phase. The amount of functional play does not differ greatly from control groups. However, it seems likely that children are trained in this aspect of play. It is carried out in a very mechanical way, and the actions are isolated and not part of a theme. So for example, they combine the cup and saucer and may even pour water into the cup, but do not progress to a tea party.

### *Phase 4: Symbolic play*

The fourth and final phase in toy play development is symbolic play. In this phase, children start to substitute one object for another. For example, a hairbrush can be a microphone. Children with autism seldom reach the phase of symbolic play. They get stuck on fragmentary stereotyped actions. Drinking from an empty teacup has no meaning for them.

## Observed behaviours

Below, we describe a number of behaviours of children with autism that stem from their lack of imagination.

### *Repetitive activities: line up and spinning objects*

In children with autism, pretend play seems to be replaced with repetitive activities, which may become an obsession. The child may line up objects in a certain arrangement and become upset if they are interfered with. They do not really play with toys. Daniel was observed doing this during encounters. He lined up his Thomas the Tank Engines, shampoo bottles in the shower, and different types of fruit (see figure 3). Moreover, many children with autism spin objects. Daniel started to spin objects when he was about two years old. He would spin many types of objects such as books and toys.



**Figure 3:** Daniel lines up his Thomas the Tank Engines (upper left) and apples (upper right) and plays with his predictable V-tech laptop with numbers (below)





**Figure 4:** Daniel's special interest is numbers. He looks at them at the gasstation (left), bookstore (upper right) and parks (lower right)

### *Preference for repetition*

Many children with autism have a preference for repetition. They like to reassure themselves that they know what will happen when they do something. Electronic toys are excellent for this (see figure 3). When you push a button, you get the same reaction over and over again.

### *Special interests*

In general there is a great preference for facts, and the obsessive functional play of the young child may give way to obsessive interests; for example in railway timetables and bus routes. Many children with autism have a special interest. Daniel has a special interest in numbers and letters. When he was still in a stroller he liked to look at house numbers. Because of this, he could write odd and even numbers at the age of three. He writes numbers and letters everywhere, in the sand on the beach, in the snow, on the window or in the condensation on the shower screen (see figure 4). Children with a higher IQ preoccupy themselves with special subjects and themes such as railway timetables, birds, or Roman Emperors. These subjects may change over time. Mostly, there is resistance to unpredictability or sudden changes (Wing, 1997, 2006).

### *Stereotyped behaviour: flapping, jumping and swinging*

The stereotyped behaviour of children with autism has many manifestations. Some children exhibit stereotyped body movements such as 'flapping' with their hands or spinning around in circles. They prefer performing one activity over and over. Many children with autism enjoy the repetitive movement of jumping and swinging. Many children with autism like to swing and jump, including Daniel (see figure 5). His mother bought a trampoline so as to make less noise for the neighbours downstairs.

### *Preference for sensorial play*

Instead of symbolic or imaginative play, children with autism enjoy sensorial experiences. For example, deep pressure on their body, touching beans, looking into lights, or staring at bubbles (see figure 6).



**Figure 5:** Daniel jumps on trampolines (upper and lower left) and swings in his playroom (right)



**Figure 6:** Daniel enjoys looking at soap bubbles

### 4.3. Research on the cognitive level

Since the early seventies, this field of study has witnessed the emergence and consolidation of a few dominant psychological models of autism. Several theories exist to explain the behaviour of children with autism. Cognitive theories aim to span the gulf between biology and behaviour, between brain and action, with hypotheses about the mind. Cognitive theories aim to provide explanations of behaviour. Moreover, these theories can assist designers to imagine the experiences of people with autism better. The sections below present three main theories based on research about cognition in autism.

#### Executive functions

The theory of executive functions (EF) focuses on the self-organising elements required for general learning (Pennington and Ozonoff, 1996). These elements guide attention, inhibit irrelevant responses, abstract rules, and generate goals that are maintained in the mind during task execution. According to this theory, the process of general learning in autism is characterized by perseveration and poor self-regulation. This includes having difficulties with change, reduced forward planning, and ineffective problem solving skills that lack coordinated reasoning and ongoing adjustment to feedback (Ozonoff, 1997). In other words, children with autism have another way of processing information. Therefore, they lack organisation and planning skills. They have difficulties with knowing the correct order of things. Their problems in executive functions result in difficulties with performing tasks. Providing structure to these tasks is used to help them. One example is the use of pictograms to structure the child's day, and teach the order of specific activities (see figure 7).



**Figure 7:** Pictograms support children in each step of the activity of going to the toilet (left) and communicate which toothbrush belongs to which child (right)

### **Central coherence**

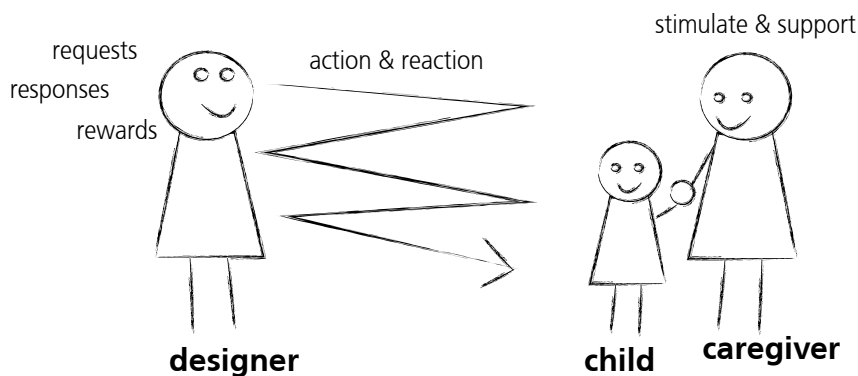
The theory of central coherence (CC) describes that people with autism have the tendency to process all stimuli in a fragmented fashion, focusing on details (localized processing) rather than integrating those details into meaningful wholes (configural processing) (Happé and Frith, 1996). In their 'Weak Central Coherence' hypothesis, they delineate an internal social world that is piecemeal and disjointed, lacking the overall coherence that defines social context and meaning. As described earlier, children with autism have difficulties in sense-making. This makes them easily lose overview and sometimes causes panic. For children with autism, details are important. They cannot distinguish between prominent and side issues. A highly intelligent adult with autism in the Netherlands described his own detail-focused processing style (van Dalen, 1994). He described, for example, the successive steps he needs to reach the functional concept of a hammer. First, he perceives details, which are then combined into a coherent whole, which leads him to the association with the label 'hammer'. Finally, he can understand the functional meaning of the hammer; a tool to use in carpentry. People with autism perceive the world differently. This is important for designers to realize.

### **Theory of mind**

The theory of mind (ToM) proposed that children with autism have problems in attributing mental states to others and themselves (Baron-Cohen, 1995). The presence of 'theory of mind' is often tested with false-belief tests. Normally, children aged around four pass these tests, and thereby prove they have developed a theory of mind. However, autism can be diagnosed from the age of three. If the theory of mind explains autism, there must be precursors of 'theory of mind' present earlier. Deficits in joint attention have been identified as the main precursor of the lack of 'theory of mind' in autism (Charman et al., 2000). Another central deficit identified as a precursor is imitation (Rogers, 1999). They imitate others less than children with typical development. Imitation is a key component of social learning that is also thought to be an important mechanism facilitating intersubjectivity and empathy (Rogers and Dawson, 2009). Moreover, children with autism often prefer an inanimate environment to social interaction (Dawson et al., 1998; Klin, 1991; Mundy and Neal, 2001). In conclusion, their drive or motivation to engage in social interaction with others is often different to that of a child with typical development (Dawson et al., 2002; Klin et al., 2003; Mundy, 2003). In the theory of mind, Baron-Cohen explains the social and communication difficulties in autism by reference to delays and deficits in empathy, while explaining the areas of strength by reference to intact or even superior skills in systemizing (Baron-Cohen, 2009). In the studies that form the basis of this thesis, designers try to empathize with children with autism, while the children cannot return the favour.

## 4.4. The impact of autism on encounters

The impairments in social interaction, communication, and imagination that have just been described have consequences for the interactions between designers and children with autism. Here, we explain how the theory above affects the interaction, and brings possibilities for designers. Ideally, designers strive for an interaction with the child that can be described as a dialogue of attunement and reciprocity (Seach, 2007). The dialogue itself consists of a pattern and sequence of interactions such as action-reaction by means of requests and responses (see figure 8).



**Figure 8:** The dialogue between a designer, child, and caregiver

Turn-taking plays a crucial role in this dialogue. The dialogue stops if a child or designer does not take their turn. Turn-taking can be seen as 'action and reaction'. An action is someone's initiative in the dialogue, the reaction the other's response. Examples of actions are making requests such as asking a verbal question or making a movement, and attempting to make eye contact. Examples of reactions are agreeing to the request, imitating the action, and providing rewards such as compliments or smiles.

Potter and Whittaker (2001) carried out research that identified some of the ways in which spontaneous communication with children with autism could be encouraged. The most effective strategy was to encourage children to respond to objects. Play with objects is non-directive, meaning both children and designers can start to play with them. Importantly, children do not have to wait for a cue from the designer. They can initiate a request or choice, leading to self-discovery and exploration. When shared with another person, in this case designers, it creates potential for children with autism to make more use of spontaneous communication. Moreover, objects implicitly ask for child-directed instead of adult-directed communication. Adults tend to over-use verbal prompting and questioning, which limits the extent to which children are able to communicate spontaneously (Potter and Whittaker, 2001). In adult-directed communication there

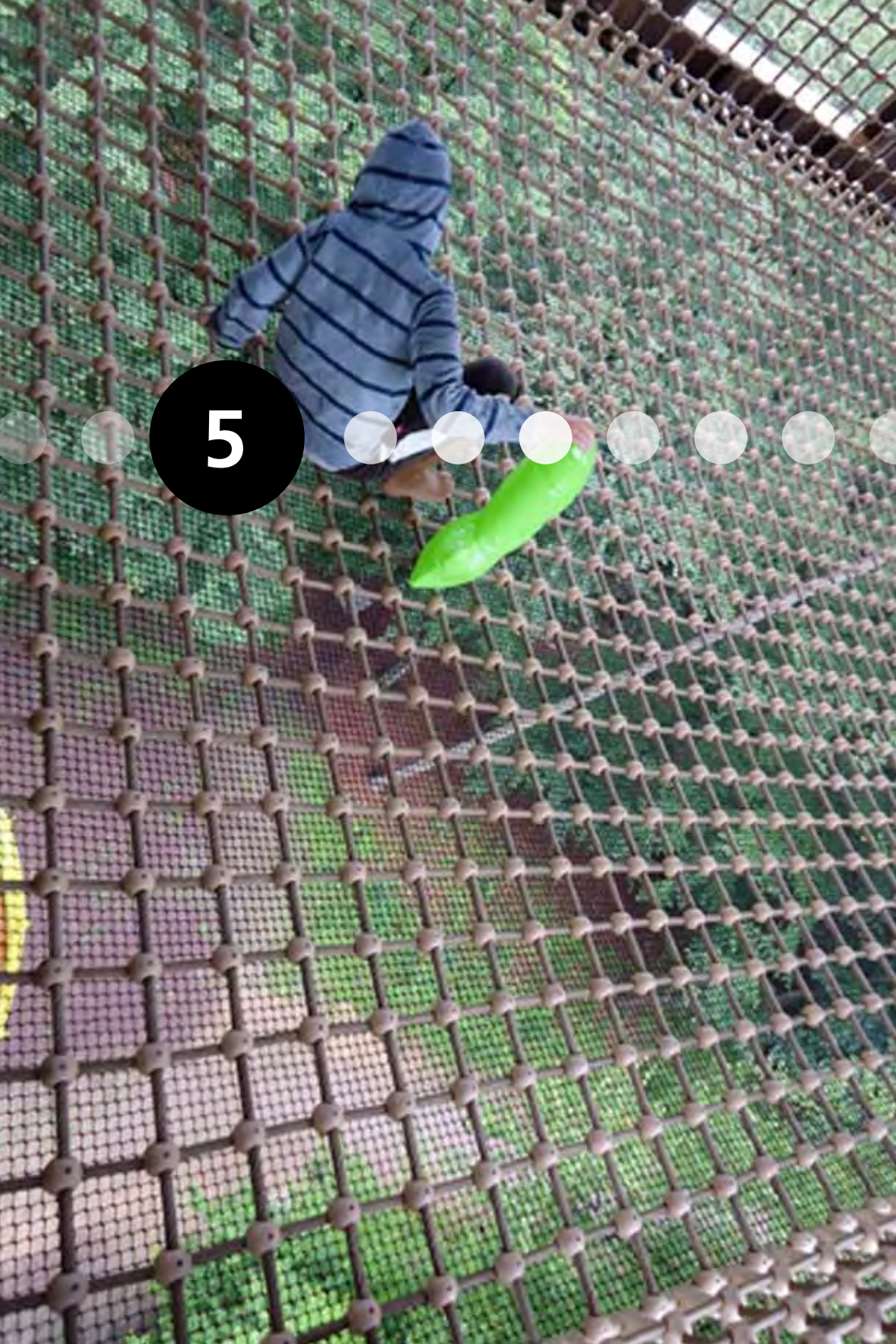
is less potential for spontaneity and generalisation of the acquired skill. Child-directed communication gives children the opportunity to respond to objects, and even join in play with more intention and independence than might previously have been observed.

Encountering others always involves an awareness of their emotional and perceptual sensitivities. The quality of the connection in the dialogue lies in recognizing how to be with the other person, and not seeking or demanding what has to be done. By intuitively following the child's responses and reactions, the play partner remains positively engaged in the interaction (Seach, 2007). Designers can use an understanding of the levels of sense-making and phases of play development to interpret the children's behaviour during interaction. For example, the designer can try to determine and adapt to the child's level of sense-making, because they know the child cannot adapt to theirs.

## **4.5. Conclusions**

Children with autism behave and think differently from children with typical development. In encounters, designers can observe the children's behaviour and try to interact with them, even though the children have difficulties engaging in social interaction. Objects can be helpful to enhance interaction between designers and children with autism. They provide opportunities for spontaneous communication. These playful interactions can bring designers creative understanding about the experiences of children with autism.





5



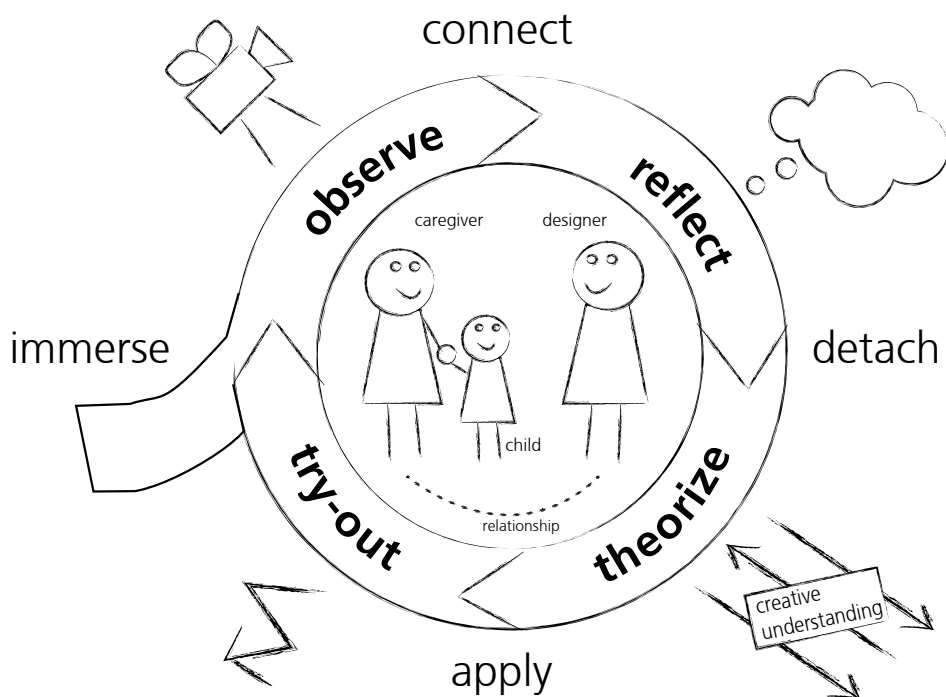
# Framing encounters in a design process

*The exploration of the previous chapters comes together to form a framework in this chapter. This framework has two functions. Firstly, it describes how learning takes place, by connecting and structuring theory and models from previous chapters. Thereby, it serves as an interim answer to the main question. Secondly, it delivers input and starting points for the development of new tools and techniques, which are evaluated in the studies. In this way, it serves as a frame to further investigate the main question.*

## 5.1. The framework

Figure 1 presents a framework for describing how designers can build creative understanding from encounters with children with autism and their caregivers. Encounters are a means for designers to build creative understanding. They are used for a cognitive and affective understanding of users and inspiration, which gets translated into product concepts and services (see 2.3).

The three people involved in the encounter (designer, child, and caregiver) are illustrated inside the cycle diagram. The cycle drawn around them represents the experiential learning process of designers. It consists of four activities: observe, reflect, theorize, and try-out. The activities are depicted outside the cycle. Each transition from one activity to another is labelled: immerse, connect, detach, and apply. Designers preferably start with concrete experience in the field. This framework can also be applied to other user groups dependent on caregivers such as young children or people with cognitive impairments (e.g., dementia, amnesia, or down syndrome).



**Figure 1:** Framework for how designers build creative understanding from encounters with children with autism and their caregivers

## 5.2. Inside the cycle: the setting of an encounter

The setting of an encounter is depicted inside the framework's cycle (figure 1). This setting was described earlier (see 3.2), so is only reiterated here. It includes three people: a designer, a child with autism, and a caregiver, and takes place in the children's own context. The child is dependent on his or her caregiver, so they hold each other's hand. The designer is positioned separately, but a dotted line connects him or her with the caregiver. This dotted line represents a professional relationship between designers and caregivers. Designers build up this relationship with caregivers, because caregivers are essential in determining whether the children may participate in an encounter with them.

Designers and caregivers prepare themselves for encounters based on their feelings and expectations about the upcoming encounter. These feelings and expectations are based on what they hope to achieve from the encounter. The main goal for designers is to increase their creative understanding about something. They want to support and inspire concept development. Children and caregivers have different goals. They are not related to the design process as such. Caregivers always strive to maintain or even improve the quality of life of the children, or other future children, while guaranteeing the children's safety and happiness. During encounters, children have no predefined goal. They strive for a feeling of happiness and safety. The people involved in the encounter have different goals, and thereby different expectations and feelings about the coming encounter. These goals, expectations, and feelings determine the effect of the encounter on each party.

## 5.3. The cycle: four activities & transitions

A cycle is drawn around the people involved in the framework (figure 1). This cycle represents the experiential learning cycle of designers, based on Kolb's experiential learning cycle (see 3.4). The cycle is constructed of four parts, each corresponding to one of Kolb's four steps: concrete experience, reflective observation, abstract conceptualisation, and active experimentation. The framework presents the corresponding activities for designers in these steps, which are: 'observe', 'reflect', 'theorize', and 'try-out'. As visualized in the framework by the prominent diagram of the encounter, experience is the starting point. Without concrete experience, designers have no observations and experiences to 'reflect' upon or 'theorize' about. They can only 'try-out' a wild guess. The order of this cycle as followed by designers may differ depending on their goal in the design process. For example, the activities 'observe' and 'try-out' may take place during encounters. 'Reflect' and 'theorize' may take place before and after, as preparation for or an encounter or in its aftermath.

In each transition from one activity to another, designers change their relationship with the children and caregivers they are learning about. In total, the framework contains four activities, so also four transitions. These transitions are labelled: 'immerse', 'connect', 'detach', and 'apply'. Designers start with immersion, as is illustrated with the

starting arrow. The first three transitions represent steps from the empathy process (see 2.3). The final transition is 'apply', because that is why designers wish to learn about users in the first place; so that they can apply their obtained creative understanding in design.

This section describes all activities and transitions in a clockwise order. The activities represent concrete actions, while the transitions represent steps in the empathy process and thereby are a mix of cognitive and emotional activities. Although these activities and transitions are presented as separate phases or steps, in reality they occur as a gradual transition with many overlaps. For example, during 'observe', designers can already be connecting observations to their personal experience, or briefly entering 'reflect' to interpret what they see.

### **1. Immerse**

Ideally, the cycle begins with concrete experiences that designers have with children in the field. When entering the cycle, designers immerse themselves in the world of the children. They participate in natural interactions with them, without actively experimenting. This transition includes 'discovery' and 'immersion' from the empathic learning process. Discovery stimulates the designers' curiosity and willingness to learn about the user group. Designers enter the children's world, and discover that this world contains different objects and people and follows different rules for interaction. Immersion gives designers time to wander around in the user's world and be surprised by various aspects. Without judging or thinking of design solutions, the designer becomes more open-minded and experiences the child and caregiver's world for a while.

### **2. Observe**

Designers subjectively collect data about users in observation. This data collection includes the designers' observations, but also their personal experiences. For example, emotions and impressions like 'wow, these children have a noisy classroom'. Already during immersion designers are subconsciously sensing the situation. They see what the children do, hear the sounds they produce, or experience being touched by them. These experiences colour their data collection. Especially in a new situation, the designers' attention is geared towards the interactions that are happening. In addition to observation, they experience the situation themselves. Immediately from the start, designers open up their senses. Recording data supports designers in collecting, memorizing, explicating, and sharing these experiences afterwards. Thereby, recording from the very start of an encounter supports the learning process of designers.

### **3: Connect**

In order to move from observation towards reflection, designers need to connect the experiences from their encounter to their prior personal experiences. Connections are made by explicitly recalling comparable prior experiences in their own lives, and letting them resonate with the observed experiences of the children. For example, they observe the children's difficulties in learning language and compare this to their own language skills during their childhood, or perhaps their experiences with a nephew or niece around the same age.

### **4: Reflect**

Designers ask themselves questions to interpret the experiences they take from encounters in reflection. This activity takes place in the designers' mind, so it can be done anywhere; during and after the encounter. This framework mainly focuses on reflection after encounters with users. In order to reflect, designers need to think, explicate, and interpret their experiences from the encounter. In this step, both affective and cognitive components are important to understand the user's experiences and what these experiences mean for them. Designers verbalize these thought processes in their mind. Instead of keeping their reflections internal, designers can also externalize them, for example by means of writing them down or sharing them with others. Reflection stimulates awareness and thereby helps designers in their experiential learning process about them.

### **5: Detach**

In order to move from reflection towards theorisation, designers need to detach from any personal experiences they may have connected with earlier. Designers need to step back from their involvement on an emotional level. Only in this way are they able to generalize their experiences from observing a couple of children towards a whole target group (e.g., children with autism). In their minds, designers need change the children from subjects into objects.

### **6: Theorize**

In theorisation, designers analyze their interpretations from reflecting on personal experiences together with external findings. In order to do this, designers search for similarities, differences, and analogies. They make their own theory, drawing upon all the personal, procedural, and propositional knowledge they have collected. This activity results in creative understanding. Although creative understanding is the aim of learning, it is just a means for designers to reach another goal. Creative understanding is 'sufficient' if designers can use it as a stepping-stone for conceptualisation.

## 7: Apply

In order to move from theorisation towards 'try-out', designers need to apply their newly gained creative understanding to the situation of children and caregivers. They translate their own theory into interventions such as behaviours and artefacts. In this transition, designers come closer to the children again. In their mind, they imagine the behaviours these interventions would elicit from children and caregivers.

## 8: Try-out

Finally, designers experiment with their interventions in order to better understand the children and caregivers in 'try-out'. In developing these interventions, designers embed their presumptions about how they expect children to behave during an encounter where the intervention is present. When testing their presumptions about the children in a face-to-face encounter, they are confronted with these presumptions. These presumptions may even colour the outcome of the encounter, and the way that designers interpret what they see. In a way, they cannot come closer to the children and their caregivers other than by entering an interaction. 'Try-out' stimulates designers to apply theory, test presumptions, and experiment in encounters with children with autism and their caregivers.

## 5.4. Research questions

The main question of this dissertation is:

*How can designers learn from (and about) children with autism, through encounters with them?*

This main question is followed by:

- |                  |                                                                                                                            |
|------------------|----------------------------------------------------------------------------------------------------------------------------|
| <b>Study I</b>   | <i>What are the designers' experiences in a first encounter with children with autism and their caregivers?</i>            |
| <b>Study II</b>  | <i>How can tools and/or techniques support designers in observation? How can caregivers contribute to this?</i>            |
| <b>Study III</b> | <i>How can tools and/or techniques support designers in 'try-out'? How can children and caregivers contribute to this?</i> |
| <b>Study IV</b>  | <i>What is the influence of experiential learning on a design process and team dynamics?</i>                               |
| <b>Study V</b>   | <i>What are the preferences of designers concerning different information sources?</i>                                     |

## 5.5. Conclusions

This chapter presented a framework that describes how designers can learn from encounters with children with autism and their caregivers, which was used as the basis for studies. It described four learning activities and transitions that take place, by connecting and structuring theory and models from previous chapters. This framework delivers input and starting points for the development of new tools and techniques for learning activities, which will be evaluated in the studies. In this way, the studies investigate these specific activities and transitions in order to evaluate, nuance, and develop the framework.

6





# The studies

*This chapter presents five studies. Each study investigates a part of the framework that was presented in chapter 5. Study I describes the designers' experiences of observation, during an initial encounter with children with autism. Study II evaluates a tool that supports observation. Study III evaluates a set of toys that supports 'try-out'. Study IV investigates the effects of uninformed designers entering an existing design team that already has creative understanding from encounters. Finally, study V describes the designers' thoughts and opinions about different sources of information when designing for children with autism. The studies are presented in the same order as the proposed learning process for reasons of clarity. In reality, they took place in a different order. Each study concludes with the main findings for the framework. Prior to presenting the actual studies, we describe the general setup of these studies.*

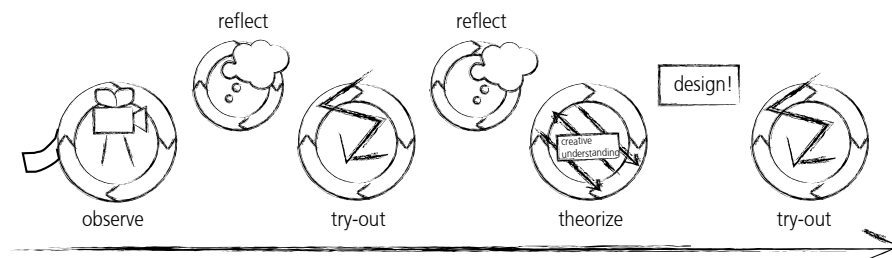
## 6.1. The set up of the studies

Designers followed a design process that included all four activities of the framework (see figure 1). The studies mainly focused on the activities of observation and 'try-out', because these activities actually took place during encounters, not before or after. The design process in each study was similar in setup to allow comparison.

Firstly, designers visited a school as a team to get acquainted with the situation, learn about children with autism, and gain knowledge about how to interact with them. They were instructed only to observe the children at this point. Afterwards, all designers reflected upon their experiences in three ways: individually, with their team members, and in class meetings. Individually, they wrote insights in a notebook that served as a reflective diary. As a team they made a video diary; telling their expectations and initial reactions into the camera right before and after each visit. Jointly, they discussed their insights with the other teams in class meetings.

About a week later, the teams visited the same school again, but this time to interact with children themselves. In each study, this interaction was setup differently. Common for all the studies was that designers could enter a dialogue with the children. In this way, they could learn first-hand about the children's preferences, dislikes, and needs. Afterwards, designers reflected upon their experiences in the same ways as before.

Next, the teams developed theories based on their observations in a four-hour analysis meeting. The week after, all teams presented their insights about children with autism as a starting point for concept development. Each team developed ideas and designed product concepts, and built caregivers.



**Figure 1:** The design process followed in the studies includes all four activities of the framework.

### Participants

Participants in the studies were M.Sc. design students, children with autism, and their caregivers. We planned encounters between children and caregiver at fixed dates and times for each design team.

### Designers

The participating designers were M.Sc. design students from the Faculty of Industrial Design Engineering (Delft University of Technology). Students participated in one of the following three courses: the elective course RichCollections 2009, the course Interactive Technology Design 2009, and the elective course RichCollections 2010 (see table 1). They could voluntarily sign up for the two elective courses in which they would learn about and design products for children with autism. The course Interactive Technology Design was an obliged master course, but the students could select the theme 'design for children with autism' from a total of six themes. As result, the students who participated were those who were willing to learn about and design for children with autism. Their motivations included: *"a true design challenge"*, *"like to learn more about autism"*, and *"love to design for children"*. Although the projects were open for both male and female students, the majority who signed up were female (36 out of 40 students). The softer side of design as included in these courses, e.g., user research, Autism Spectrum Disorder, and design for children, seemed to be more attractive to female design students. The age of the students varied from 22 to 29 years old. In the studies, the students are product designers, which is abbreviated to designers. All have a unique combination of team letter and number (see table 1).

**Table 1:** Overview of participating designers and courses per study

Study	Course	Team	Designers	Total
I + III	Elective Rich Collections 2009	A	A1, A2	13 designers
		B	B1, B2	
		C	C1, C2, C3	
		D	D1, D2, D3	
		E	E1, E2, E3	
IV	Interactive Technology Design 2009	C	C1, C2, C3, C4, C5, C6	18 designers
		D	D1, D2, D3, D4, D5, D6	
		E	E1, E1, E3, E4, E5, E6	
II + V	Elective Rich Collections 2010	F	F1, F2, F3	9 designers
		G	G1, G2, G3	
		H	H1, H2, H3	

*Children with autism and their caregivers*

The participating children lived with their parents in and around the city of Delft in the Netherlands. They varied in age, gender, diagnosis, intelligence and speaking abilities. We approached the children’s caregivers for participation by contacting their special education schools. When schools were willing to participate in the design project, they forwarded our letter to parents. In this letter we explained the design assignment, and asked parents for participation and consent. Children with permission from both the school and their parents could participate in the studies. As a result, all participating children go to primary schools for special education (Rijksoverheid, 2012). Special education is intended for children with learning disabilities, educational problems, or other needs for special care. It is divided into four clusters, each addressing the needs of a group of children with specific impairments. In the studies, the children attend cluster 2 and 3 schools (see table 2). Cluster 2 schools provide special education for children with hearing-impairments, serious speech problems, and impairments in communication. Cluster 3 schools provide special education for children with physical and/or mental impairments. The children and caregivers have been given fictional names for privacy reasons.

**Table 2:** Overview of participating children and schools per study

Study	School	Cluster	Group	Children	Total
I + III + IV	Kind & Zo (Ipse de Bruggen)	3	Pirates	Dennis, Florian	2 children, 1 caregiver
		2	Pelican	Timo, Esther	2 children, 1 caregiver
	Scholengemeenschap Effatha (Kentalis)	2	Giraffe	Daniel, Valentin, Dana, Abel, Timothy	5 children, 3 caregivers
	Diagnose en behandelcentrum (Kentalis)	2	Purple	Eduard, Danny	2 children, 1 caregiver
	Cor Emousschool	2	4	Robby	1 child, 1 caregiver
II + V	Scholengemeenschap Effatha (Kentalis)	2	Butterfly	Steven, Anton, Nina, Maren	4 children, 1 caregiver
			Giraffe	Daniel, Dana, Abel, Pete, Timothy	5 children, 1 caregiver
			Zebra	Sharon, Nathon, Mohammed, Sem, Mel	5 children, 1 caregiver

## Methods

In the studies, we explored how designers can learn from encounters with children with autism and their caregivers for design. In order to understand how designers experience an encounter with these children, we kept track of the designers' thoughts, feelings, and experiences throughout their design process. Designers annotated their experiences and thoughts in a reflective notebook. They made video diaries before and after an encounter, and participated in class meetings. The information collected from these rich self-reports and discussions served as research data. Each study focused on a specific moment in the design process, in which designers conducted a particular activity from the framework. We investigated these moments by means of questionnaires, structured interviews, and/or observations.

### *Multiple roles*

The author had three different roles in these studies: researcher, teacher, and tool-designer. As researcher she investigated how the students learned about and designed for children with autism. The students however, looked at her from a different perspective. They were participants in courses where they studied how to learn about and design for children with autism. For them, the author was their teacher. She instructed them to follow a specific design process, with scheduled encounters with children and caregivers. Because of her authority as teacher, they might have been influenced to give socially desirable answers. Measures were taken to limit this effect, by using various methods for data collection, and by calling on the perspectives of multiple researchers, designers and caregivers. The video recordings of the encounters enabled them to research the phenomena without any interference. In order to validate the interpretations, they individually reflected upon the entire design process after grading. Finally, the author developed special tools and techniques in the role of tool-designer to investigate encounters in the design process. In this research, the author took a design-inclusive approach (Horvath, 2007). This means that the activity of designing, and evaluating the tools and techniques that were designed, was done with the specific aim of bringing new knowledge for the framework. The author's design education and experiences in designing for people with cognitive impairments (see 1.1 and 2.4) motivated the choice for this approach. Inevitably, the different roles conflicted with one another at some moments. As researcher, the author truthfully described what happened, and was precise and thorough in this. As tool-designer, on the contrary, she searched for plausible outcomes and easily made assumptions and choices. If she took all the details into account that she learned in her role as researcher, it would be impossible to proceed to the activity of designing. The challenge for the validity of this research was in effectively ordering, combining, alternating, and balancing these roles over the course of time. Design activities resulted in tools and techniques that were evaluated in the studies. The students used these tools with children and caregivers, without explicitly being told that the author had designed them. Along the way, most of them discovered this. Another researcher evaluated the tools and techniques to avoid socially desirable answers. The author was silently present. In this way, the effects of the role of tool-designer on the results were limited.



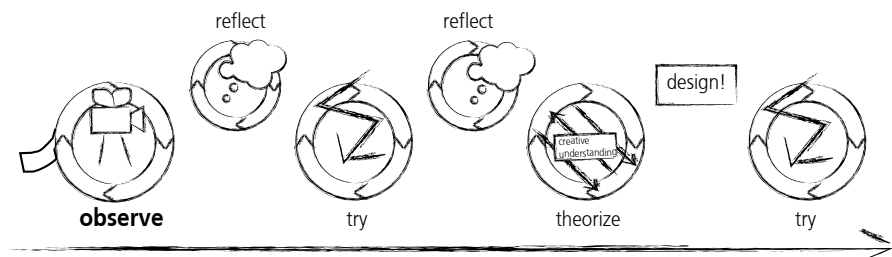
# Study I:

## Designers' experiences in observation

This study aimed to gain insight into how designers experience their first encounter with children with autism and their caregivers. These children live in an experiential world that is different from that of other children. Designers might not know what to expect from an encounter with these children. The author's first encounter (see 2.4) encompassed many different feelings and thoughts such as excitement, fear, and sympathy. This study describes the experiences of 13 designers during their first encounter with children with autism. These descriptions give a lively view of the research context of this dissertation.

### Background

The study was part of an elective course, in which 13 designers could expand their knowledge about learning from encounters with users for designing. In teams of three or two, designers learned about the experiences of children with autism. Each of the five teams were introduced to a special school and/or family with one or more children with autism. As result, twelve children with autism from four different schools participated in this project with their family, teachers, and therapists (see table 2 in 6.1).



## Methods

We used three different self-report techniques to capture the experiences of the 13 designers before, during, and after their first encounter with children with autism and their caregivers. Firstly, designers individually kept track of their experiences throughout the course in reflective notebooks. Secondly, they created video diaries just before and after an encounter with their team. Thirdly, after the encounter they discussed their experiences in class meetings with the other teams and the researchers/teachers.

### Research question

- What are the designers' experiences in a first encounter with children with autism and their caregivers?

### Procedure

At the start of the project, all designers were introduced to their team (A, B, C, D, or E). Each designer received a gift-wrapped notebook in his or her team colour (see figure 1). After unpacking them, designers knew with whom they should form a team. They could individually write or draw their reflections, thoughts, experiences, insights, and ideas in their notebook throughout the entire design process. There was no existing content except for a personal message and instructions from the researcher. An envelope was attached to the cover. This envelope contained assignments to introduce themselves through writing reflections about a number of topics: their background and skills, experience with children and people with impairments, motivations for the project, and knowledge about autism (see figure 1).



**Figure 1:** Stickers for the notebook containing reflective questions concerning prior knowledge about children with autism (left). Designers receive their notebook for reflection during the design process (right)



One week before their first encounter with the children and caregivers, the teams attended a kick-off meeting. In this meeting, we informed them about the overall design process and introduced them to 'their' group of children and caregivers. They received an A4 presentation sheet with photos of the children and short descriptions from their parents (see figure 2).

At the end of this meeting, all teams received instructions for their first encounter: (1) go and meet the children on the specified date and time, (2) complete the assignments for your notebook, and (3) make a video diary according to the instructions. The assignments for their notebook were in two closed envelopes, labelled with 'before' and 'after' (see figure 3). They were instructed to open the envelope labelled 'before' at home, to prepare themselves for the encounter. The envelope contained assignments concerning their expectations and feelings about having contact with the children. After the encounter, they could open the envelope labelled 'after'. This envelope



**Figure 2:** A presentation sheet about two children the designers are about to meet.

contained assignments about the nature of the contact, what they learned from it, and their ideas and thoughts. The stickers invited them to reflect, but they could choose whether or not they did so. The instructions for the video diary were written on a filmstrip. The teams received these instructions and their video camera at the end of the class meeting. They were asked to introduce themselves on camera just before entering the school or the family’s home. Together they should explain where they are going, what they will do there, and how they feel about it. After leaving the building after the encounter, they could open the sealed filmstrip for the second part of the instructions. The assignment was sealed to prevent them from thinking ahead about what they would say. In telling their first reaction to the camera, they should tell how the encounter went, what happened, what the children did, and how they felt about it. This resulted in five-minute movies of teams in front of the school building telling their most striking findings. This gave a situated feel for the designers’ feelings, expectations, and satisfaction concerning the contact.

The week after, the designers came back to the university for a reflection meeting to share their findings on children with autism and reflect on their experiences. This provided us insight into the designers’ experiences in encounters with children with autism and their caregivers.

At the end of the study, a qualitative analysis was conducted. First we collected, photocopied, and returned the 13 notebooks of the designers. We transcribed the team’s video diaries and class meetings. Next, we categorized the designers’ reflections per assignment to create an overview.



**Figure 3:** Stickers for the notebook containing reflective questions concerning their encounter with the children with autism

## Results

These three self-report methods resulted in rich verbal descriptions of the experiences of designers during encounters with children with autism and their caregivers. The notebooks gave the most insight into the designers' experiences and reflections. All quotes derive from the designers' notebooks unless otherwise stated. The video diaries gave an impression of the atmosphere. The class meeting afterwards showed the overwhelming amount of information that designers had obtained by observing these children for about an hour. We had difficulties steering them towards reflecting on their personal experiences, instead of only sharing what they learned about the behaviour of the children from observation. This section describes the designers' experiences and expectations before, during, and after the first encounter.

### *Feelings and expectations before the first encounter*

In the kick-off meeting, the designers asked many questions about what the children were like, how they behaved, and especially what they were supposed to do. For example, a designer asked: *"Do you have a document or movies to get me prepared?"* (kick-off meeting). None of them had met children with autism before, and they mentioned that they were afraid of harming the children. Generally speaking, the designers felt curious, enthusiastic, excited, and a little nervous about meeting the children. *"Great anticipation. I really want to see them. It will be a big challenge I think to make contact, but I am up for it. Still, I really wonder how I will react"* (C1). *"Excited! I'm very curious, I don't really know what to expect, but I'm looking forward to it"* (D2). They had difficulties imagining what to expect from the meeting. *"A bit insecure about what to expect, but open and interested"* (A2). Table 1 and 2 provide an overview of all designers' expectations and feelings about meeting the children, from their notebooks. Sometimes, data is missing from the tables (...), because we did not force designers to fill in everything, but rather invited them to use the notebook for reflection.

### *Feelings and experiences during the encounter*

During the encounter, the designers were instructed to observe the children and learn about them, by being a 'fly on the wall'. Although the designers felt they did not make that much contact with the children, it was impossible to completely avoid this. *"Just observing is impossible, because of the children's curiosity"*, and *"they are more reactive than we expected"*. However, in some cases the children hardly reacted to the designers' presence (see table 3). *"The children did not really notice us. They did their own things and I think they didn't act different than usual. They weren't even looking at us or asked who we are"* (D1). The designers waited for the children to take the initiative, because they didn't want to distract them. In many cases they felt ignored by them. Soon they realized they really could not talk with them. On the children's initiative, they physically interacted with them. *"I tried to talk, but they don't understand. Or they do, but don't talk. They made contact with us by means of sleeping on my shoulder, trying to give my partner a kiss, and pulling my hair"* (B2).

**Table 1:** Overview of the designers feelings about meeting the children

About meeting the children I feel...	
A1	Enthusiastic! I cannot wait to finally meet them! Interact with them! They can teach us so much I think.
A2	A bit insecure about what to expect, but open and interested.
B1	Excited and enthusiastic! I'm a little nervous whether it will go well or not, but I believe it will be inspirational.
B2	Really excited, I don't know what to expect, nervous.
C1	Great anticipation. I really want to see them. It will be a big challenge I think to make contact, but I am up for it. Still, I really wonder how I will react.
C2	...
C3	I am a little nervous, because I haven't had quality time with kids for quite a long time (baby sitting is over...).
D1	I am nervous and quite excited. I really like to know more about them and play with them. But I am also afraid that it would be disappointing. I might fail in making contact with them. I have very mixed feelings about it.
D2	Excited! I'm very curious, I don't really know what to expect, but I'm looking forward to it.
D3	Excited
E1	...
E2	Excited, because I heard now some things about the children. I really want to meet them. So I can experience how they are, what their problems are, how they handle things, and how smart they are. I am also confident that everything will go well with me and the children and I will manage to react easily at the children's behaviour.
E3	Nervous, exciting. Now I am looking forward to encounter this exciting journey, although I feel nervous and braving myself to many unexpected surprises, wonderful surprises of course.

**Table 2:** Overview of the designers expectations about the upcoming encounter

	I expect to learn for myself...	I expect to learn for my project...
A1	Who they are... What they are... how they behave!	Can't wait to start!
A2	More knowledge about autism and children who behave different.	I wonder if I already come up with design ideas or just be an observer/researcher
B1	I'm interested in children and hopefully the visit will be inspiring. It will make me learn how to do an observation and get closer to the subject.	I want to know the character of the children, especially their interaction with people and objects around them. I would like to see their interest too.
B2	Know how to interact, how I need to behave, without making them scared...	Excited, a lot of confidence because of the organisation.
C1	I'm not sure what, but something important.	Understanding, a door of communication.
C2	One can read a lot about autism from a lot of different sources, but it is always more beneficial and exciting to learn it through experience.	Probably get a change to evaluate how comfortable I will feel around them and how to behave around them. It is very important for our project that we get a warm up day before actually interacting with the children.

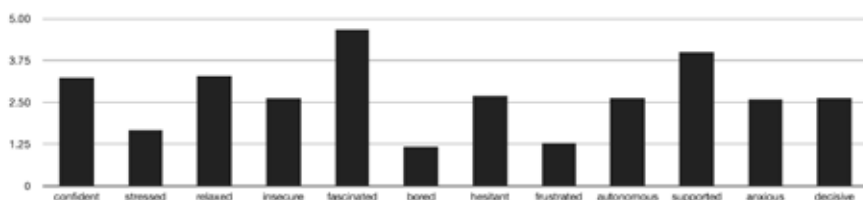
C3	...	...
D1	I hope I get insight into how to interact with a child with autism. And understand more about them. I also hope to learn how to react on different situations.	I hope I get ideas and insights with what and in what way we could get rich information for designing.
D2	...	...
D3	...	to design something useful for them.
E1	I am really looking forward to meeting the children. I want to see what they are like and I am very interested in their way of communication.	I hope I get a lot of information by observing them and talking to the teacher. Because I will only see a couple of children with autism, I am afraid I will get a distorted view about autism. I hope discussing with the whole group will give me a good view.
E2	How I react and how should I react to the children? How do the children react on me?	With what the children play? What they like? How they react on new things?
E3	To deepen my sympathy, learning about different kind of people.	At this moment, I still have no idea.

**Table 3:** Overview of the designers responses

On my presence, the children...	
A1	...
A2	Reacted really different. Robbie and Eduard did not pay so much attention. Mindy started waving, saying hello.
B1	Some of the children noticed us, but some do not give any reaction to our presence. There were two boys that we think got really attracted with my partner and kept sitting beside her. And there was one boy who really looked at me very close and shakes my hand. He also tried to give me a kiss twice.
B2	...
C1	Hardly reacted, but didn't ignore. They looked and sometimes made contact, but didn't attempt any conversation or typical action-reaction communication.
C2	...
C3	The teachers said the children didn't act differently. They were aware, but not paying so much attention.
D1	The children did not really notice us. They did their own things and I think they didn't act different than usual. They weren't even looking at us or asked who we are.
D2	...
D3	I feel somehow we have contact; they know our presence and try to be acknowledged.
E1	The children were not that much different during my presence, but some were putting their selves out and had a hard time during their task.
E2	They were not disturbed by my presence for what I could say. But the teachers expected that we would disturb when we were with three designers in the classroom. So we split up and visited 3 different classes for half an hour each. Only one boy was disturbed when I visited his class. The teacher said they forgot to pick him up that morning to bring him to school by bus, so he was too late and stubborn all day.
E3	In this class, the children did not interact with me.

**Table 4:** Overview of the designers responses about contact with the children

Do you feel you made contact with the children?	
A1	...
A2	Not a lot. I did not really try to enter, I did not want to distract them. Eye-contact. Only Eduard's friend was really curious, waving saying hello.
B1	Yes, I did get in contact with the children, but they took the initiative. I didn't because it is time for observation, and because I was too nervous too. Timothy said "Heyow" and I said "hello". The other kids shook my hand and tried to kiss twice, but I refused it. Now I feel really sorry for that.
B2	I tried to talk, but they don't understand. Or do, but don't talk. They made contact with me, shoulder to shoulder, sleeping on my shoulder, try to give My partner a kiss and pulling my hair.
C1	It is not easy to make eye-contact with the children. Even if I could, it is still difficult to figure out what they are thinking. I don't think the teachers can tell either.
C2	Yes! At the gym, Valentin and Dana sat with us at the bench.
C3	Kids suddenly came sitting next to you. I tried to ask Daniel to draw a '4'. He listened but did not react. I think I will get contact through objects.
D1	I did not make contact with the children, they were mostly ignoring us. It did not seem they have noticed us. But one time, Dana walked to me and showed me a book. I holded it. For a few seconds and before I could do something, she walked away. I am not sure she really 'saw me'. Abel holded on to my partner. The rest ignored us.
D2	When we entered the classroom, the children were sitting at the table playing by themselves. I don't know if they noticed us entering, but they didn't react. It was like this the whole morning. They didn't search for contact with us. We were ignored. Because of this, we decided to take it slow, not forcing anything. Therefore, we just observed. Dana took the initiative by showing my partner a book. Abel took my partner's arm and holded on, but that's all he did, that was the only contact he made.
D3	They smile back, their eyes 'looking'. I can feel it. The child took initiative, Abel held my arm, Valentin smiled.... I tried to express my happiness with them.
E1	I got contact with some children. We played and search for response such as laughter. I led the children take the initiative. Mostly this was quickly established. I tried to play and talk with them. The latter did not work out.
E2	With Florian I had to take initiative, but I didn't got contact with him. Dennis noticed me when I arrived and asked his teacher who I was, but not directly to me. After a while, he started to interact with me a little. In the other classroom, the children were playing and did not notice me.
E3	I used the method I knew best in a new surrounding, which is 'SMILE'. The boy liked to blow my hair and he jumped at me. But we are almost the same size so we felt almost down.



**Figure 4:** Average scores of how the designers felt during their first encounter with the children. The responses show they had 'mixed feelings'.

The designers were open and alert to be involved in any interaction if the children initiated it. *"I used the method I knew best in a new surrounding, which is SMILE"* (E3). If they made contact with the children, it was pleasant, but difficult, and different from what they were used to. *"It was an incredible feeling when a boy held my arms; so soft and carefully"* (D3). The designers reported that the children have a different way of communicating. *"Everything that they did was not in my common sense"* (D3). *"I did not really know what their behaviour meant. I make assumptions that could be wrong"* (D1). They said the contact was inspiring and interesting; and not boring at all. *"Every second I got surprised"* (B2). But none of the designers mention in what way this inspiration could be used in a design process. *"It is wonderful to learn the new world of children with disabilities"* (E3).

The designers reported many different feelings they had experienced during their encounter (see figure 4). The most common feelings were 'fascinated' and 'supported'. To a lesser degree they felt confident, relaxed, autonomous, decisive, but also insecure, hesitant, and anxious. They rarely felt stressed, bored, or frustrated. In their notebooks, the designers explained what had made them feel this way.

All designers felt fascinated by the children. *"They were so in their own world, a world we couldn't reach..."* (A1). *"They kept doing the same"* (B2). *"All these kids are so different than I am used to!"* (E1). No designer felt bored at all. *"Every moment was surprising, lots of new insight. But being passive all the time was not easy"* (B1). *"There was a lot to see and experience in 1,5 hour"* (E2). *"One of the children jumped on me and we both fell down"* (E3).

Moreover, they had positive experiences with the children's caregivers and felt supported by them. *"The teachers were very willing to help and explain"* (A2). *"Teachers were very nice to us and kind to the children. They have a lot of patience with them. They provided us information, not only when we asked about it. This showed me that they liked it that we were there and thinking with us, considering what would be interesting for us to know"* (D2). *"The teachers were very interested in what we were doing and explained a lot"* (E2). The caregivers informed them about the children and the context. The designers also mention the support of their team members. *"Being there as a team made it a lot easier. We could ask more questions, get more information and be more comfortable"* (C2).

Most designers felt confident, although this was not true of everyone. *"I am sure about being invisible for them"* (A1). *"They did not seem to explode so easily, not so unpredictable"* (C3). *"I felt confident with the teachers around, but when Dana spilt some drink on her clothes without a teacher around, I felt confused: help or not?"* (D1). Some designers said they felt not that confident. *"I don't know the place or the people"* (A2). *"I did not understand them. I did not understand what they wanted"* (B2). Only one designer reported she felt stressed. *"I had stress about my inability to speak Dutch. I wish I could talk to the teacher more"* (E3).

Most designers felt relaxed. *"First I was a little nervous, but after meeting the teachers, that was gone"* (D2). *"The children were also relaxed, and the teachers too"* (E2). *"I was there with my group mates"* (D3). However, two designers did not feel relaxed at all. *"I was too worried to do something wrong"* (B1).

Although most designers felt relaxed, they also felt insecure. *“A little insecure, but very friendly people”* (A2). *“Especially in the beginning the first time I entered the classroom I felt insecure. It was chaotic and it took some time to understand the situation”* (B1). *“I could not communicate in my way”* (B2). *“It’s unknown territory, unknown rules”* (C1). One designer mentioned she was not feeling insecure at all: *“The teachers took good care of us, they told us what to do and where everything was”* (D1). Many designers mentioned that they felt a bit hesitant. *“I did not want to step out of line”* (C1). *“I wasn’t sure how the children would react. I tried to not do anything sudden. I was careful”* (D1). Two designers did not share this feeling at all. *“The children searched for contact”* (E1). *“I trust my team members, the teachers and the children”* (D3).

None of the designers felt frustrated about meeting the children. *“I don’t have any reason to feel frustrated”* (D2). One designer wanted to stay longer and was frustrated about going away. *“I was frustrated that we could not stay longer. And also a bit, because I could not communicate with them in sign language”* (D1). Overall, the designers did not feel anxious. *“Not at all. The teachers were around and the children seem so nice”* (D1). *“I wasn’t scared, only healthy excited”* (D2). However, the designers reported they did feel anxious when the children suddenly approached them. *“I felt anxious when some children tried to interact with us and I was not sure how to react on them”* (B1). *“I am a bit anxious when the children do unexpected things”* (D3). Two designers reported that they felt decisive about the project. *“The visit makes me sure that this project is interesting!”* (B1). *“I wanted to learn more about autism and these children in particular”* (D2). Two designers reported that they felt passive in the interaction with the children. *“I was waiting for the next thing to happen”* (D1). One designer said: *“I am very strait for children”* (E2).



**Figure 5:** Designers in their first encounter with the children



### *Designers' feelings after their first visit with the children*

After all the teams had visited a school, they gathered together for a class discussion. They enthusiastically shared their experiences and looked for patterns in the behaviour of their user group, leading to more empathy. They were interested in the experiences of the other teams, and through this meeting were able to realize the differences in the behaviour of children with autism. Through sharing their experiences and noticing the variety in them, they learned the reason for the term 'spectrum disorder'. One designer mentioned in her notebook that she was not satisfied. *"There was so much I did not understand and would like to ask, but the teachers were busy all the time"* (D1). Another designer felt grateful: *"There are so many things to learn from them"* (D3). Finally, one designer felt surprised: *"Autism is not what I expected, because all these children have a different way of how they express it"* (E1).

**Table 5:** Overview of the designers feelings about the past encounter

About meeting the children I now feel...	
A1	...
A2	Good, it really brings more understanding of their behaviour and responses on their surroundings
B1	That I need to be more open and relaxed. I was a bit nervous, and being too careful, because I was afraid to 'hurt' them. But now I realize that what I need to interact with them is being easy.
B2	Waaw!
C1	Kind of familiar, even though I had no real conversation. As if there is no emotional bond that is usual for humans. I could compare them with cats: singletons, yet communicating to get done what they want. And you have to derive from their behaviour what they are thinking.
C2	I feel a lot more comfortable being in Effatha and around the children. I feel connected to the children and more eager to improve their daily experiences at school through products especially designed for them.
C3	I'm looking forward to meet them again. It was not that hard, I expected more problems!
D1	Even more excited! I did not expect it would be so challenging to keep them concentrated. It is still hard for the teachers to communicate with them. I am not sure how we are going to do that next meeting.
D2	Excited! It will be a challenge to make contact next time, but I'm looking forward to it. I want to learn more about them and their characters and personalities.
D3	Soo 'stupid' as I didn't be grateful enough for what I have... I even don't organize my stuff and put stuff back.
E1	I can't understand what it is like in their head, but I understand what helped them, if they wanted to play, etc.
E2	Excited to see them again and play with them. I like to see different groups of different ages.
E3	Happy.

## **Conclusions for the framework**

The study explicated the experiences of designers during their first encounter with children with autism. The results of the study revealed how designers enter the proposed learning cycle. The original framework proposed that designers start with the activity of observation and the process of immersion in the children's context. This study indicated the necessity of two steps prior to this. These were the activity of 'familiarisation' and the process of 'discovery'. Before the encounter, designers expressed that they had no idea what to expect. They knew the children they were about to meet would be different than children with a typical pattern of development, but had no clue about the actual meaning of this. They felt excited, and even a bit nervous when instructed to meet these children. They were pulled out of their comfort zone. Not knowing the territory and the rules made them uncertain. Over time and through the process of becoming familiar, these feelings drifted away. Mostly, they felt fascinated and curious about the atypical behaviour of the children. The discovery that children with autism interact differently with the world around them fascinated designers, and raised their curiosity and willingness to learn more. Therefore, familiarisation and discovery have been added to the framework. The study drew out the nuances of 'observation' and 'immersion' for the framework. The designers were instructed only to observe, and not to initiate interaction with the children and caregivers. Most of the time the children barely noticed the designers. This made the designers feel more confident. However, sometimes the children approached the designers, because they were intrigued, or expected some help from them. At these moments, the designers realized they could not avoid interaction. The children forced designers to immerse themselves in the context. During these interactions, the designers felt insecure and even anxious about whether they should help the child, or wait for the caregiver to arrive. At these moments, the children were in control of the course of the interaction. As designers experienced little control over their interactions with the children, they focused on reacting appropriately to those interactions which occurred. At these moments, designers had little opportunity to consciously register their personal experiences. The next study therefore presents a tool that supports designers in memorizing and sharing personal experiences.





**Publication:**

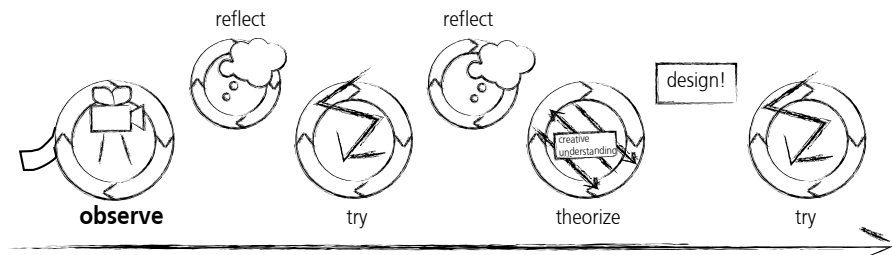
Rijn, H. van, Sleswijk Visser, F., Stappers, P.J. (2011). Stories at the spot: Designers learning from caregivers of children with autism. IASDR2011. Delft, The Netherlands.

# Study II: Tick & Watch in observation

This study aimed to gain insight into how designers can be supported in observation and reflection. The previous study showed that designers needed time for familiarisation, immersion, and observation. For this situation, the author developed a tool to support designers and caregivers in remembering, sharing, and using learning moments in later design activities. This study evaluates the use of this tool in the design process.

## Background

This study was part of an elective course, in which three teams of three designers could expand their knowledge about designing for children with autism. 'Scholengemeenschap Effatha' (Kentalis) briefed the teams to develop educational aids for children with autism at their school. Each team of designers was linked to a specific teacher and her group of children. Each class had four to six children, from which two or more had been diagnosed with autism. The teacher formulated an assignment corresponding to the special needs of her group of children. Thereby, each design team learned about and designed for a different group of children. The teachers kept the final prototypes for use in their class.



### **Tool considerations**

For this study, the author developed the tool ‘Tick & Watch’. The considerations behind the tool were derived from the results of study I and the author’s experiences in the LINKX project.

#### *Designers have no attention for data collection*

In a first encounter, designers are occupied with familiarisation with and immersion in the new context. They have little time and attention to consciously register their experiences with the children or their observations. The tool should support designers in remembering ‘learning moments’ for later, even while they are busy participating in interactions with the children.

#### *No time for conversations during encounters*

Some experiences or observations raise questions. Caregivers can help to answer these questions and inform designers about the children using stories, anecdotes, and explanations. However, during the encounter itself, designers cannot immediately ask caregivers because they are occupied with their responsibility to take care of the children. The designers’ presence is always a lesser concern. The tool should support caregivers in remembering these experiences and observations for later while taking care of the children.

#### *Children move around*

Children might go outside and play, run around the classroom, or be engaged in a therapy session. Caregivers and designers follow them around while interacting with them. The tool should be mobile.

#### *Objects attract attention*

Designers visit the children’s context to observe them in their daily activities. Objects might attract undesired attention from the children. Especially when these tools provide feedback such as lights and sounds (van Rijn and Stappers, 2008a). The tool should not disturb the children in their daily activities.

#### *Time for conversation after encounters*

It’s important that designers have the opportunity to discuss their experiences in encounters with others. This supports them in the process of interpreting the behaviour and experiences they observed. Discussion implies that experiences become explicit, compared, and interpreted. In the course of discussion, designers move towards the activity of reflection. The tool should help designers and caregivers in recalling learning moments from the encounter and enhance their conversations about these moments.

### The tool: Tick & Watch

Based on the considerations above, the author developed the tool ‘Tick & Watch’. The tool aimed to support designers and caregivers in remembering, sharing, and using learning moments in the design process. It consisted of a video camera with which the designers would record the entire session (either hand-held or on a tripod), a set of four ticker-watches, annotation cards, and a software program. In total, four people could use the tool simultaneously. Below, we describe the intended use of this tool.

#### *Observation: Remember the ticks*

Designers and a caregiver wear the ticker-watch around their wrist (see figure 1). This watch consists of a button mounted on a wristwatch base. When this button is clicked, a small light on the watch flashes to give feedback, and the laptop registers the time stamp and ID of the watch. In this way, they can ‘tick’ a moment whenever they think they see something of interest. For example, a moment at which a designer does not understand what happened, or a moment that a teacher has something to explain to the designers but is occupied with her teaching responsibilities. Annotation cards accompany the watch, to let designers write down their reason for a ‘tick’. Caregivers did not receive annotation cards, as we expected that this would interfere too much with taking care of the children. Although the author is aware that this small light and soft clicking sound might distract the children, this feedback is needed for the observer. Because the observers wear the watch around their wrist, they can hide it, in their sleeve for example.



**Figure 1:** Three designers and a teacher wear a tick-watch during a two-hour observation session (left). A designer makes a ‘tick’ (upper right) and annotates this tick on her annotation cards (lower right).

*Dialogue: Share the ticks*

After the observation session is finished, the video recording can be reviewed on the laptop, as depicted in figure 2. Software visualizes the ‘ticks’ of designers and caregivers as markers on a timeline. By clicking on a tick, the designers and caregivers can look back at the video recording related to that tick and discuss their experiences during that moment. The software also allows designers and caregivers to see their ticks in relation to those of the other observers. Moreover, it visualises periods that were important because of the amount of ticks around that time. This helps the designers to compare and share their experiences. The annotation cards can help them to memorize their exact experiences and thoughts during the ticks, and serve as a tangible reminder. Just by starting the software, the designers and caregivers can review and discuss these experiences any time during the design process. Moreover, they can keep these experiences alive and make sure they are not forgotten along the way.

This tool was developed especially for this study, to support multiple people in participant observation and allow them to compare and share their experiences. The functionality of the tool itself is not innovative, because many tools exist to ease the process of recording observations (e.g., Yanagisawa et al., 2009). The author developed this tool to explore how designers and caregivers can be supported in observation and reflection, because there were no other suitable tools available to combine the view of multiple observers in a simple manner.



**Figure 2:** Three designers and one teacher discuss their ticks together with the Tick & Watch software



### *Design: Use your ticks*

Any time during the process, designers can launch the software and look at the ticks they made during the encounter.

## **Methods**

The tool was used in an initial encounter between three designers, one caregiver, and four to six children. During the encounter, the researchers were present at the school. After the project was finished, the authors conducted semi-structured interviews with the nine designers about their design process. As preparation, the designers completed a sheet with open questions about their process, including questions about involving caregivers and the use of 'Tick & Watch'. The answers to these questions were the basis of the interview.

### *Research questions*

- How can tools and/or techniques support designers in observation?
- How can caregivers contribute to this?

### *Procedure*

At the beginning of the project, all the designers came together to become acquainted with their team. They were grouped in three teams of three designers and received a coloured notebook, similar to that in study I. Further along in the process, they again received envelopes with assignments for reflection.

One week before their first encounter with the children and caregivers, the teams attended a kick-off meeting. In this meeting, the teams received information about the overall design process and 'their' group of children and caregivers. Similar to study I, they received an A4 sheet of paper with photos of the children and short descriptions from their parents. In this meeting, designers were given instructions in preparation for their first encounter with 'their' children. They were told to use Tick & Watch during this encounter. We explained the functionality of the tool to them and answered any questions that they had. After that, the teams went home.

The next week, we went along with the teams to the school to facilitate use of the tool. We prepared and started the camera, put the watches around the participants' wrists and handed out their annotation cards. After that, the designers went inside the classroom of the caregiver for a two-hour session of observing the children. We stayed outside. The observation session was planned at the end of the school day, providing an opportunity for discussion afterwards between the designers and the teacher. We prepared the software application for this discussion by setting up the application in the classroom and importing the ticks and video recording. We set up the video camera again, and left the room. After that, designers and caregivers could start a discussion about their experiences. They could use the software application in any way they wanted to during this discussion.

In the class meeting after the encounter, all designers received a DVD with the software application, ticks, and video recordings of their observation and discussion. They could take a look at their ticks again any time during the design process.

Six months later, when the entire design project was finished, the designers individually completed a questionnaire about using this tool. Their answers in this questionnaire served as the basis for a structured interview, where a researcher asked them questions about their use of the tool during their design process. The author and another researcher separately conducted these interviews with different designers for the purposes of triangulation. Next, the author conducted semi-structured interviews with two caregivers about using the tool, and more generally about participating in a design process. The author transcribed all audio recordings of the interviews.

### *Data analysis*

The two researchers participated in a three-hour data analysis session for triangulation. As preparation, each researcher received the transcripts and were asked to mark relevant findings, and come up with labels and interpretations. In the meeting, these labels were discussed and clustered.

### **Results: evaluation of Tick & Watch**

In general, Tick & Watch supported designers and caregivers in observation and discussion; it helped give structure to the visit. All teams used 'Tick & Watch' during observation as they were instructed. However, two of the three teams deviated from the initial setup in the discussion phase, because of the limited time of the teacher and the teacher's preferences. Almost none of the designers utilized the ticker-software in design activities later on in their process. Below, we provide more details about how the different parts of the tool were used in the design process.

### *Observation: Remember the ticks*

The ticker-watches were helpful for the designers, but forgotten by most of the caregivers in the observation. Here, we explain how designers and caregivers used the ticker-watches during the observation of children with autism.

Firstly, all of the designers made many ticks. Two designers mentioned in their interview that wearing the ticker-watch made them more conscious and focused on observation. Moreover, one designer said: *“Positive was that you can grab the moment, you do not need to write down what happened and you can look back to see what happened. It makes it easier.”* For another designer, the watch served as an icebreaker with the teacher. It made her feel at ease. One designer’s watch distracted one little girl. She kept pushing the button of a tick-watch all the time, because she enjoyed the lights. This designer said this was a problem. However, a designer from that same team said this designer distracted the child herself: *“The child’s reaction is dependent on your reaction. You should act as if it is a ‘normal’ watch. If you keep pushing to turn on the light, the child stays focused on it.”* Designers struggled to keep the camera focused, because children often walked outside the frame. At these moments they felt that they missed out on something. The designers received cards to annotate their ticks. These cards were too bulky to carry around during the observation. Designers preferred making notes in a personal notebook. Three designers mentioned that the watch should show a number after each tick. *“If the watch shows the tick-number, we don’t need a special annotation cards.”*

The caregivers made ticks with their ticker-watch whilst simultaneously taking care of the children. They forgot about the ticker-watch most of the time. In one team, a speech therapist joined the observation, while another teacher was taking care of the children. This therapist made many ticks, just like the designers. She paid full attention to the observation. We expected that caregivers could use a Tick & Watch in interaction. The interviews afterwards revealed the caregivers’ difficulties in focusing on supplying the designers with information, while they were occupied with dealing with the children. The small amounts of ticks made by caregivers support this statement.

### *Dialogue: Share the ticks*

The structured way of using Tick & Watch forced designers and caregivers into a discussion immediately after the observation session. A designer said: *“Most valuable is that teachers can tell you what happened. You can interpret something completely different yourself”*. Both designers and caregivers appreciated this discussion. For the first time in their life, the designers had encountered children with autism. The unusual behaviour of the children raised questions for the designers, which could be immediately answered in the discussion afterwards. For example, a designer said: *“If you have no time during the day to discuss it is useful. It forces you to talk about unclear moments”*. Another designer mentioned another advantage. He said: *“Everybody was in the same observation. That is good for discussion.”* The designers also said that the amount of ticks indicate the importance of a moment.

Each team used the ticker-software differently in discussion. One team used it as we had described, but the other two teams deviated from our initial setup. One team only had limited time for discussion. The other team deviated because the involved caregiver preferred to watch the video and explain to the designers what was happening along the way in a regular video player. The interviews showed that the caregivers appreciated a ‘normal’ conversation, as opposed to a discussion supported by technology. The caregivers appreciated the discussion, but found the duration too long. One teacher said: *“During the observation, it is not a burden at all, you are just doing your work. But the conversation is a bit much. I understand it is valuable, especially in the beginning. I think you have to find a way together”*. We planned a 30-minute discussion, which became 1 hour for two of the teams. These teachers said in hindsight this was a burden. The designers wished to stay longer, because they had too many questions that needed clarification. The duration of this discussion should be reduced in the future. For instance, designers can shorten the duration by means of shortening the duration of the observation session, or by organizing their questions for the caregiver first.

#### *Design: Use your ticks*

Three out of nine designers utilized the ticker-software later in the process. These designers individually watched the ‘learning moments’ again for analysis purposes. They found it useful to look back at these moments. The entire observation took two hours, but the software only shows the selected moments. A designer explained: *“During analysis, I found it very useful to look back specific bits of video. You do not have to look at the whole two-hour video”*. Another designer disagreed, because he already had his annotations. *“But at home, installing, I tried to use it, but it was not really helpful for analysis, because I already had the notes. I missed the function for adding a new tick. When reviewing I found new moments, but cannot really add them”*. This designer wanted extra functionality to make the ticker-software useful for the continuation of the process. Designers hardly used the video later in the design process. Rather, they used their own annotations, and used the analysis cards as visual reminders. Against our expectations, the ticker-software was barely used later in the process. Designers used their memories of experiences, or the insights they wrote down in their notebook. They often transformed events into anecdotes, which they could easily recall throughout the design process. This study showed designers often did not take the time to extensively annotate video observations, even when they had a pre-selection. Compared to 2D visual information such as written text, pictures, and screenshots, video costs much more time and effort. The findings underlined that the actual experiences were more inspirational to designers than recordings of these experiences.

### **Conclusions for the framework**

In order to explore how designers can be supported in observation, this study proposed the use of the tool Tick & Watch in an initial encounter between designers and children with autism. Although Tick & Watch structured the visit, supported the designers in observation, and included caregivers in the role of informant, it inhibited immersion. Firstly, the results helped us to further develop the designers' activity of observation and the process of immersion in the framework. Compared to the designers of study 1, these designers felt more confident. Tick & Watch assured them that their experiences and observations were being recorded. Still, it inhibited immersion instead of enhancing it. It instructed them with a clear goal, and created a barrier to interaction. The functionality of the tool prescribed the capture of as much information as possible about the children. The camera stood literally in between designers and children. Designers could 'hide' behind the camera, which prevented interaction. Secondly, the results underlined that caregivers can contribute to the observation in the role of informant. This role is valuable for the designers' learning during and after encounters with the children. Finally, the study showed that the experiences themselves are informing and inspirational for the design activities, not the recordings. Designers barely utilized the tool in individual reflection or theorizing. The memories about special moments play a much larger role in the designers' learning process. As designers consider interactions as an important source for learning, the next study presents a set of toys as tool to support designers in 'try-out'. In these interactions, designers 'force' these special moments to occur in encounters.



**Publication:**

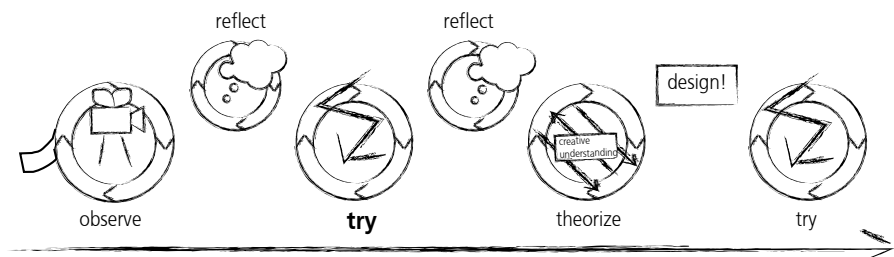
Rijn, H. van, Sleswijk Visser, F., Stappers, P.J. (2009). Connecting through interacting: Toys that help designers learn from children with autism by playing with them. IASDR 2009. Seoul, South Korea.

## Study III: Try to play!

This study aimed to gain insight into how designers can be supported in try-out. For this study, the author developed a set of toys to support designers in trying to interact with children with autism and their caregivers. The designers are inexperienced in interacting with children with autism. The developed toys aim to support designers in play and seeking contact, because children are attracted to objects (Potter and Whitaker, 2001). Designers can learn about the capabilities, needs, and preferences of the children in try-out.

### Background

This study was part of a similar elective course to study I. Thirteen designers could expand their knowledge about learning from encounters with users for designing. In teams of two or three designers, they learned about the experiential world of children with autism. A total of five teams participated, and each was introduced to a special school and/or family with one or more children with autism. As result, twelve children with autism from four different schools participated in this project with their family, teachers, and therapists.



## Methods

The specially developed toys were used in the designers' second encounter with the children. Three designers, one caregiver, and one child participated in each encounter. The designers recorded their interactions on video and reflected upon the toys in three different ways: a reflective journal, a video diary, and class meetings. Researchers were not present at the school. Afterwards, the author transcribed all data. The data was analyzed with three other researchers in a one-day session.

### *Research questions*

- How can tools and/or techniques support designers in 'try-out'?
- How can children and caregivers contribute to this?

### *Procedure*

At the beginning of the project, all designers came together to become acquainted with their team. They were grouped in three teams of three designers and received a coloured notebook, similar to that in study I. Further along in the process they again received envelopes with assignments for reflection. One week before their first encounter with the children and caregivers, the teams attended a kick-off meeting. In this meeting, the teams received information about the overall design process and 'their' group of children and caregivers. They received an A4 sheet of paper with photos of the children and short descriptions from their parents. In this meeting, designers were instructed about their first encounter with 'their' children. In this encounter they were told to use the set of interactive toys as an aid. We explained to them the functionality of the toys, and answered any questions that they had. Afterwards, the teams went home. We realize that the children's disorder determines the constraints for contact, not these tools and techniques.

The next week, each design team visited a school to get acquainted with the situation, learn about children with autism, and discover how to interact with them. They were told only to observe the children. Two weeks later, they visited the same school again. They were instructed to interact with the children using the toys described in the next section, and record these interactions. In total, each designer played with two to five children. The aim of these interactions was to learn about the children's preferences, dislikes, and needs, from first-hand experience. Next, the teams analyzed the recordings that they had made. Finally, they presented their insights about autism as a starting point for design activities. Throughout this process, designers kept track of the insight they gained in three ways, similar to study I and II. Individually, they wrote insights in a notebook that served as a reflective diary. As team, they told their expectations and first reactions to the camera right before and after each visit, as a video diary. Jointly, they discussed their insights in class meetings.



### *Data analysis*

Afterwards, the author photocopied all notebooks and transcribed the audio recordings of video diaries and class meetings. Three other researchers participated in a one-day data analysis session for triangulation. As preparation, each researcher received the transcripts and three notebooks of designers to browse through. They were asked to mark relevant findings and come up with labels and interpretations. In the meeting, these labels were discussed and clustered. Further, the researchers looked at two videos of the designers' encounters with the children in order to verify the designers' explanations with the actual observed behaviours.

### **Tool considerations**

For this study, the author developed a set of seven toys to support designers in try-out. In designing these toys she considered a number of aspects based on; earlier experiences in designing LINKX for children with autism, literature on interaction with children with autism, and theory about learning from experiences. These aspects are as follows:

#### *Designers need help to get started*

Designers use this tool in their second experience in the field. They explore new behaviours and interactions with the children, for the purposes of learning. However, most designers are inexperienced in interaction with the children. They might feel hesitant, or do not know what they can or could do with them (see study I). Tools should facilitate interaction between designers and children. They should give designers the confidence to approach the children, find starting points for interaction, and provide a means to keep the interaction going.

#### *Designers learn from exploration*

Exploration has a positive effect on learning. An object that can only be used or understood in one specific manner provides little room for exploration. Objects that have multiple possibilities for different interactions stimulate exploration. Children with autism attribute different meanings to an object, depending on the addressed toy play level of Ungerman and Sigman (1981). The four levels are: (1) simple manipulation, (2) relational play, (3) functional play, and (4) symbolic play (see also 4.2.3). Designers are likely to start play on the levels of functional and symbolic play, while these are difficult to master for the children. Tools should address these four levels of play simultaneously, because they stimulate the designers' discovery of other play levels.

### *Caregivers want to explain*

Caregivers are around to watch over the children when they interact with designers. They feel acknowledged in their role of caregiver if they can contribute to the interaction. In daily life, caregivers are accustomed to explaining the children's unusual behaviour to other people. They enjoy working with the children and sharing experiences about their work. To conclude, tools should put caregivers in their expert role, and motivate them to explain to the designers about the behaviour, needs and preferences of the children.

### *The values of children with autism in interactions*

Children with autism value different qualities in objects and interactions than children with typical development (see the next section). For example, many children with autism have special interests, enjoy repetition, and do not recognize themselves in the mirror. Enabling these aspects can serve as a motivation for children to interact with the tool, and at the same time serve as source of information for designers.

## **The puzzling life of children with autism**

In designing LINKX, we developed guidelines for other designers to help them consider what children with autism value in interactions with their environment. They are based on literature study, expert interviews, generative techniques, and evaluating prototypes with children with autism and their caregivers. Figure 1 depicts an overview of these guidelines as an open-ended jigsaw puzzle, inviting others to think about it themselves and help to complete it. In this section, we will explain each guideline or puzzle piece.

### *1. Give them the feeling of being in control*

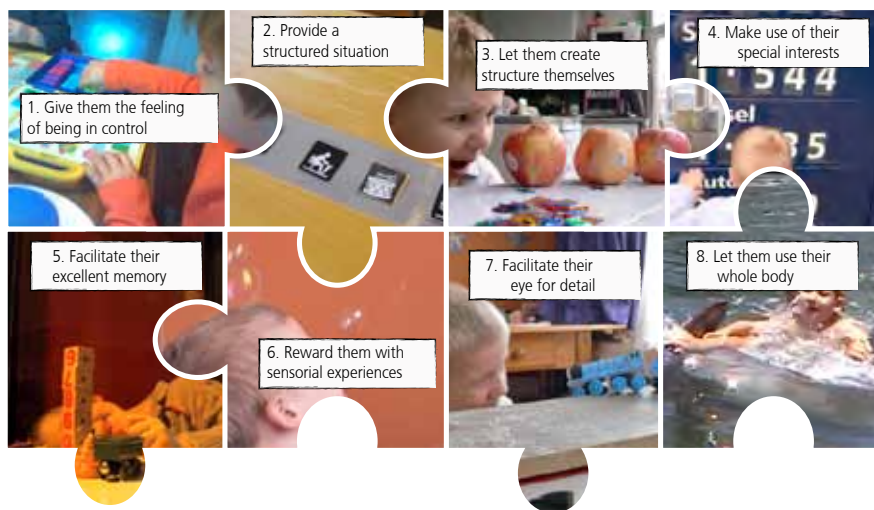
Children with autism often have no idea how to make sense of their surroundings. Their way of processing information makes them feel they have little or no control over the situation. For that reason, the children enjoy interactions that make them feel in control. In the literature, this preference of children with autism is described in several cases (see, e.g., Pares et al., 2005; Robins et al., 2005). Daniel illustrates this preference with his alphabet toy computer. For example, he likes to press the letter “B” and hear it say “bee” over and over. On other days, he prefers the letter “A” or “C.” He adores the lights and sounds that are triggered at his command. The same goes for his little number computer, which is depicted in the puzzle piece. This example shows how a product makes him feel in control by means of direct feedback, given immediately afterwards. In that way, children can predict the effects of their actions. By triggering action over and over, the children reassure themselves that they are in control of the toy.

## *2. Provide a structured situation*

Children with autism have difficulty changing from one activity to another (Cohen and Volkmar, 1997). Their way of processing information makes it difficult for them to know the order of activities, or what will happen in what situation. Activity schedules have proven to be successful (see, e.g., (see, e.g., Bryan and Gast, 2000; Pierce and Schreibman, 1994). Visual prompts such as the day-planner (depicted in the puzzle piece) stay visible at all times. The day-planner provides a structure, because the child is informed about the activities over time. When an activity is completed, the corresponding pictogram is flipped over, indicating it is time for the next activity. This structure helps them to both learn actions such as the sequence for going to the toilet, as well as providing a safe and structured environment in which a child can learn.

## *3. Let them create structure themselves*

Not only do the children enjoy experiencing a structured situation, they enjoy creating a structured situation themselves. They like to play with toys they can organize, such as the game “memory” or jigsaw puzzles, and they especially love to complete those games. A missing piece can cause panic. The children enjoy looking for similarities and differences. They create structure by making differences explicit. Another thing they like to do is arranging objects in space. For example, Daniel loves to arrange objects such as apples in a sequence, as depicted in the puzzle piece. After arranging, he looks for differences and similarities.



**Figure 1:** An overview of the design guidelines for how to design for children with autism.

This puzzle is left unfinished on purpose, to indicate that we expect more insights will follow, and want to invite others to think about it themselves and help to extend it.

#### *4. Make use of their special interests*

Some children develop special interests to create structure. Focusing on specific aspects of perception helps the children to make sense of the things they see, feel, and hear. For example, Jonas has a special interest in colours, Robby in sound (music in particular), and Daniel in numbers (as shown in the puzzle piece). These elements are everywhere, and the children experience them as important regularities in daily life. These special interests can serve as a means to elicit them to interact with something and learn.

#### *5. Facilitate their excellent memory*

Children with autism have a much better (visual) memory than children with typical development. An example that illustrates their excellent memory is the fact that Daniel can arrange the alphabet from “Z” to “A” in a few seconds. We have to “think backwards” but he just “sees” it. If designs make use of the memory skills of children, we may help them understand more and learn better.

#### *6. Reward them with sensory experiences*

Children with autism often enjoy specific sensations. For example, Robby is sensitive to sounds. The low pitch of a truck that drives through his street distresses him. However, he loves to put a little vibrating toy, which is meant to be looked at, against his ear to hear a low-pitched sound. Jonas’ mother said, “*stimuli are less disturbing when they are expected*”. It helps a lot when the child is in control over the stimuli.” Although these children can be highly sensitive, or insensitive, to stimuli, they truly enjoy sensory rewards such as sounds, music, and vibration, and deep pressure, as described by Grandin (1996). The puzzle piece shows how Daniel enjoys the foam bubbles in therapy.

#### *7. Facilitate their eye for detail*

Part of the children’s excellent memory is their great eye for detail. When something changes, even a tiny detail, an autistic child will often notice immediately, while our blunt senses overlook it completely. For example, Robby has a detailed view of books, CDs, and DVDs. When his father adds a new DVD to the row of DVDs, he notices immediately, only by looking at the sides of the covers. In the puzzle piece, Daniel investigates and notices the smallest details around him.

#### *8. Let them use their whole body*

Children with autism explore the world, just as other children, through play. By letting the children use their whole body, the learning activity becomes a multisensory unity of action, perception, cognition, and emotions. Hengeveld et al. (Hengeveld, 2011) list more advantages to tangible interaction for children with multiple disabilities such as more room for social interaction, a more personal interaction style, a slower pace, and

a more active interaction. This multisensory unity is visualised in the puzzle piece with a picture of Daniel during his dolphin therapy in Florida. During the activity itself, he learned how to interact with the dolphin and got rewarded by the sensory experience of the warm water, involving action, perception, cognition, and emotions.








### **The tool: A set of seven toys**

The author developed a set of seven interactive toys (see figure 2). The toys and their functionality, aim, and design considerations are given in table 1. The toys were distributed to designers in a bag, accompanied by pictograms of the toys, a video camera, and blank postcards. The pictograms were intended to help structure the interaction and facilitate communication between the designers and the children. The video camera was to record observations and interactions for analysis purpose. The blank postcards were present in the bag to invite designers to inform (absent) caregivers about their encounter and thank them for this. This helped to open up communication channels for the continuation of the design project. When interacting with the children, the designer could use the toys in whatever way worked best, because the situation was different for each encounter. Each team met different children, at another location, in a different time period, and with or without the presence of caregivers. To



**Figure 2:** A designer and child play with the set of seven toys in an encounter

**Table 1:** The seven toys with its functionalities, play levels, intentions, and design considerations

Toy	Function	Addressed play level
	In the mirror a child can look at the reflection.	1: Simple manipulation 2: Relational play
	Light memory contains 16 push buttons. Pushing a button gives a coloured light. Pushing two buttons of the same colour, results in all buttons flashing in that colour.	1: Simple manipulation 2: Relational play 3: Functional play
	Animal sounds contains four buttons with an animal picture on a row. When pushing the button, the toy plays the animal sound. One button (belonging to the cricket sound) is hard to push.	1: Simple manipulation 2: Relational play 3: Functional play
	Tumble makes the sound of a sea gull when turned around its axis. Shaking gives a squeaking sound.	1: Simple manipulation 2: Relational play
	House contains a roof, a window, a door, a working doorbell and three dolls.	1: Simple manipulation 2: Relational play 3: Functional play 4: Symbolic play
	Moving lights contains two sensors and seven red lights. When covering one sensor, the closest light will turn on. When also covering the other, one by one all lights turn on.	1: Simple manipulation 2: Relational play
	Recording sounds contains a red recording button, a green play button, and a microphone. When holding red button, a sound is recorded. When pushing the green button, sound is played back.	1: Simple manipulation 2: Relational play 3: Functional play

Intended to let designers experience that the children...	Design considerations
... don't all have self-awareness ... enjoy the sensory experience of the reflecting mirror	... Things can be put in or on top of the mirror.
... enjoy the lights ... enjoy direct feedback ... do not always understand the game's rules	... The buttons are made of pleasurable-to- touch rubber ... The on/off button is a little switch on the back to avoid children to use it
... enjoy the animal sounds ... enjoy direct feedback ... ask for their help to push the cricket button	... The linear lay-out of the buttons elicit interaction ... Pictures help the child predicting the sound ... The cricket elicits a child to ask for help
... enjoy the sounds ... enjoy direct feedback	... The holes on top show the game's orientation ... Holes are put in a circular pattern for visual aesthetics
... lack fantasy play. For them the elements often are meaningless objects ... enjoy the vibrating sound	... Shaped like an archetypical house to elicit storytelling by the designer ... The mechanical bell keeps ringing to reassure the child of its control
... enjoy the red lights ... enjoy direct feedback. ... prefer to play alone	... The linear lay out of the sensors and lights elicits interaction
... have difficulties learning the procedure. ... do not always recognize their own voice. ... enjoy listening back.	... The (difficult) red button elicits the designer to help ... The designer is free in choosing what sounds to record (e.g., child's voice, own voice, making sounds)

aid comparison, we encouraged them to use all seven toys. For children to enjoy the toys it was important that the toys offer immediate sensory feedback such as coloured lights and sounds, and enable repetition (van Rijn and Stappers, 2008a). All toys were white, because colour can distract the child from the intended purpose of the toy.

### **Results: evaluation of the toys**

The designers utilized all seven toys whilst interacting with the children as instructed. The children, designers, caregivers and toys all played a role in this. Because of their autism, most children preferred to play by themselves with the toys. The children communicated this with their body. Sometimes, the children pushed the designers away or kept the toy to themselves. If the children could not operate the toy, they sometimes asked the designers or caregivers to help. At these moments, the children grabbed the adult's hand and used him or her as an instrument. Caregivers contributed to the interaction by means of informing the designers about the children's toy play behaviour and mediating the interaction between the designers and the children.

Many designers used the toys as a means to test the cognitive abilities of the children, instead of exploring their needs and preferences and going along with their play. For instance, they tested if the children understood a specific game, and if not, their goal was to help the children to learn how to play with the toy. This seemed to relate to the personal interaction style of the designers. Some were very reactive to the child's behaviour and actively tried to be part of their game. Others took on an observer's role, and tested how the child reacted to each specific toy. Some designers felt difficulties in enticing the children to play with the toys at specific moments. *"I did not want to force the children to play with these toys at that moment"* (class meeting). Although we gave the designers the advice to interact with one child and one toy at a time, one team left all toys on the table, resulting in chaos. In fact, the moment of switching toys was an important one for the designers. When the child did not want to change, he or she sometimes started to cry. The designers tried to prevent this every time by letting the children decide themselves when to switch toys.

The different toys had different impacts on the interaction. The house, memory game, and animal sounds contained manipulative elements such as buttons and dolls. These toys provided starting points for interaction and enabled simultaneous use. The observation videos show that the designers intervened more frequently in the child's play with these toys than with toys that only had one manipulative element. For example, the children kept the tumble toy for themselves, because shaking or turning one object cannot easily be done together.



The play levels a toy addressed had effect on the interaction and learning too. The house brought the most insight, because people can play with a house on each of the four levels. The house made the designers feel confident in their interaction with the children. Even though the children did not always perceive the toy as a house, the designer knew actions that he or she could try with the dolls, the doorbell and the house. The possibility for functional and symbolic play provides the designer with starting points for interacting with the children. In this interaction they discovered that the children had not yet reached that level. After this general evaluation of how the toys were used in interaction, we describe below our findings for each specific toy.

### *Toy 1: Mirror*

The mirror brought out the lack of self-awareness of the children. Designers of all three teams mentioned that the children did not recognize themselves in the mirror. Designers held the mirror in front of a child to explore his or her self-awareness (see figure 3). Also caregivers explained to the designers about the lack of self-awareness, while using the mirror. One teacher whispered in a designer's ear: *"He has no self image. He does recognize me (the teacher), but not himself"* (video). A mirror directly refers to the psychological theory that teachers have available. Moreover, the designers experienced that the children enjoy the sensory experience of the mirror. *"Almost every child looked into the mirror from real close"* (class meeting). Interestingly, many designers tried making contact by indirectly looking at the children, waving to them, or giving feedback on what they could see.

### *Toy 2: Light memory*

Light memory brought many different insights. It showed designers the children really enjoy cause and effect, and coloured lights. Many mentioned that the children liked to look into the lights from very close by. *"It's something normal children would not do. They really like to stimulate their senses in an extreme way"* (notebook). In addition, designers learned about the characters of the children, and their preference for repetition, soft materials, and colours. The toy gave many starting points for interaction, because there were 16 buttons to push. The child could not possibly keep them all for himself. Often the designers were pushed away, but the buttons provided the opportunity to explore to what degree they were allowed to join in (see figure 4). Multiple layers of functionality within this game created misunderstanding between the designers and the children. The designers often tried to explain to the children the game's purpose, by pushing two identical coloured buttons, while the children enjoyed pushing one button and looking into the light. The small switch to turn the game on or off, gave nice visual rewards with less effort. After switching, the buttons flash in red, green, and blue lights in a row. Surprisingly, many children discovered this switch. *"This child really understands how to get the lights with the on/off switch"* (notebook). Although switching repetitively was annoying for the designers, this was a valuable lesson about their preference for repetition and the requirement to be thoughtful when designing rewards.

### *Toy 3: Animal sounds*

Animal sounds showed that some children enjoy sounds a lot. One child was very sensitive to sounds, and did not like to listen to the animals. Interestingly, almost all children had problems with pushing the button belonging to the cricket sound. Therefore, the children asked the designer for help, or grabbed the designer's hand and thereby used the designer as an instrument to push. The designers experienced that they were only needed for that part, because the children did not like them to push the other animals as well (video). One special moment occurred when the child and the designer developed a sequence. They took turns in pushing the animals. *"At that moment I felt included in his play"* (notebook). Also, the animals were a good starting point for verbal communication between the designer and the child. Timo for example repeatedly asked the designer to name the animal each time he pushed one (see figure 6).

### *Toy 4: Tumble*

The tumble toy did not always give feedback. It only made a sound when tumbled with the top facing upwards. The designers expected this toy to be boring, because it cannot do very much. Indeed, the children ignored the toy when they did not understand how to produce any sound. However, some children really liked it. One boy played the game over and over, and only in one manner. He laughed every time the sound came out. *"He is playing with the toy in a very structured way, following the pattern he knows. He really likes it though"* (notebook). And the pedagogue said: *"this is autism"* (video). Robby for example loved to shake the toy near his ear and listen to the sound (see figure 6).

### *Toy 5: House*

The house offered many opportunities for interaction, although its main intention was to let designers experience the children's lack of fantasy play. Interestingly, this toy gave designers easy starting points for interaction, because the house has meaning to the designers. The dolls invited the designer to talk to the children and try storytelling such as *"hello"* and *"I am mommy"* (video). Designers knew what to do with the house, even though the children did not react as they expected. It was impossible for the child to keep the toy to himself, because it contained three dolls that could be freely moved around. This evoked exploration, because the dolls could walk away, slide off the roof, or fall on the ground. One designer hid one doll from the child, and the child noticed this. *"The child knows there are three puppets. He is constantly counting them"* (notebook). Daniel used the toy as a box with peek holes (see figure 7). Finally, there was a mechanical doorbell. Almost all the children loved to ring the bell continuously. The children enjoyed the vibrating sound, but the designers did not. *"For the children the bell was pleasant, for us it was irritating"* (notebook). However, the bell made the house interesting for the children for a longer period of time. The children repeatedly reached for the house and rang the doorbell again.



**Figure 3:** A designer explores whether the boy recognizes himself in the mirror



**Figure 4:** A designer explores if the child allows her to push a button.



**Figure 5:** A child asks the designer to name the animals he pushes



**Figure 6:** A child listens to the sound of the toy when he shakes the toy next to his ear



**Figure 7:** The child lifts the house and looks into it from real close. The designer grabs a doll



**Figure 8:** A rare moment on which the child lets the designer occupy a sensor



**Figure 9:** The child pushes the buttons to listen to its clicking sound



**Figure 10:** The designer has put the pictograms on the table to structure play

### *Toy 6: Moving lights*

The two opposite sensors of the toy were intended to force the designer and child to play together. However, often this did not happen. The children could easily reach the two sensors with both hands. The designers were left watching, because the children preferred to play alone. Interestingly, sometimes designers were allowed to join in, as shown in figure 8. Each time the designers move their finger; the interaction becomes unpredictable for the children. As a solution, one little girl forced a designer to keep her finger on a sensor, so she could play by herself with the other sensor. This toy clearly expresses to designers the difficulties children have with turn-taking and sharing.

### *Toy 7: Recording sounds*

Many designers reported that this toy was not helpful for interacting with the children, because the operation was too difficult for them to understand (class meeting). However, some designers reported interesting moments. One child used the toy as a phone to call his daddy. This made the designers curious about his home situation. Accidentally, one boy recorded his own voice. He was surprised and laughed hard about it. His laughing made the whole team laugh. *“It is very nice to see his expression”* (notebook). According to these designers, this toy brought them together with the children. Another boy loved to record his own voice and even gave commands to his dog through the toy. *“He could enjoy himself for hours with this toy according to his mom”* (notebook). Probably, other designers were disappointed that the children only listened to the buttons’ clicks without recording any sounds, such as Valentin in figure 9. The children might dislike the recording changing all the time. They probably prefer to repetitively listen to the same sound.

### *Postcards and printer*

The designers were assigned to send (absent) caregivers a postcard about their encounter with the children. Clearly, the designers enjoyed decorating the postcards and we received enthusiastic reactions from parents and caregivers. The postcards also aimed to open up the communication channels between designers and caregivers for the rest of the project. The designers did involve parents and children several times during the continuation of their design project, to gain more information and evaluate prototypes. The exact role of the postcards in this process is difficult to pinpoint, but we think they were important for keeping all parties informed.

### *Pictograms*

Two out of five teams used the pictograms to ease the transition of switching from one toy to the other (see figure 10). One team played with the same child two times; once at home, and once at school. *"It really helped him to stop and go on with the other. It just went smoothly at school"* (class meeting). The other team used the pictograms to ask the child to change the toy. *"I just showed one child a pictogram, and he would get the toy by himself!"* (class meeting). These two teams learned from experience the value of using pictograms in communication with these children, and were proud when they succeeded.

### *Video camera*

Video enabled the designers to look back at their own interactions, and also those of other teams with the same toys and different children. The designers said this made them realize that each child is unique. *"Each child is different, not all kids react to the same toys in the same way."* In the second phase of the project, the videos were shared with the new team members. The designers felt they knew much more than what was visible in the movies.

### **Conclusions for the framework**

This study explored the use of a set of toys in assisting interaction between designers and children with autism. The results helped us to add nuances to the designers' activity of try-out in the framework, and understand the role of objects in this. The children contributed to the designers' learning through toy play behaviour. Objects or toys bring out particular behaviours in the children, give designers a hand-hold to structure the interactions, and allow designers to explore the possibilities of interacting with the children. The house with dolls revealed the importance of mismatches (or miscommunications) between the designers' expectations and the actual behaviour of the children. This toy addressed all four play levels, which almost guarantees mismatches. The designers often tried to help the children play the game according to its 'purpose', while the children enjoyed something else about the toy. *"It was too much, he became nervous. The boy thought, don't explain me something I cannot understand. Just let me play!"* (class meeting). Also, the children often reacted differently than what the designers expected. *"We learned most from the unexpected moments, these moments stick to you and are easy to communicate to others"* (notebook). Caregivers contributed in try-out by explaining the children's behaviour in the role of informant and supporting the interaction between children and designers in the role of mediator.



## Study IV:

# Differently informed designers in a team

This study aimed to achieve insight into the effects of having differently informed designers in a design team. Three design teams developed interactive prototypes for children with autism. At the beginning of the project, half of each team had participated in encounters with children with autism, while the other half had not. Often in practice its only possible for a few designers to have direct contact with users, due to limited time and budget. Sometimes it's not possible at all. Therefore, these results are relevant to design practice. We investigated how this situation affects the individual designers, collaboration among team members, the setup of the design process, and ideation.

### **Background**

This study was part of the course 'Interactive Technology Design' in which 18 designers learned how to build interactive prototypes for children with autism. The course took five months. Designers were grouped into three teams (C, D, and E) of six designers each. Prior to this, half of each team had followed an elective course (see study 1 and 3). This half had already had two encounters with children, so had prior knowledge about the children and their caregivers. These designers are referred to as 'informed designers'. The other half had not. These designers are referred to as 'uninformed designers'. At the start of the project, the informed designers communicated their insights to those without prior experience on autism in a class meeting. During the course, they generated ideas and built prototypes. The children and caregivers from the elective could participate in their design project when the designers needed them. All designers were free to approach children's caregivers for more information, evaluation of prototypes, or any other information. At the project's end, they were instructed to evaluate their final prototypes with children and caregivers.



## **Methods**

We conducted questionnaires and structured interviews with 14 designers to investigate the influence of encounters with children and caregivers on the design process.

### *Research question*

- What is the influence of experiential learning on a design process and team dynamics?

### *Procedure*

After the course, all designers received a set of both open and closed questions. These questions addressed personal information, encounters with children and caregivers (when, why, how) during the design process, and the influence of this on team dynamics, motivations, empathy, and inspiration.

The questionnaire was set up as follows:

- Build a timeline of your contact moments with users, including their aim and who was involved.
- Indicate whether in hindsight contact with users should be less, equal or more.
- Explain your role in the team and contribution to the design process.
- Explain the influence of your or other's encounters with children and caregivers on the motivations and group process.
- Explain how encounters affected your understanding, empathy, and inspiration for the project.
- Provide tips and tricks for another design team working for children with autism.

Designers completed these questions as preparation for the structured interview in which they explained their answers. The author transcribed the interviews and analyzed the results in a qualitative manner.

## **Results**

In total, 14 (out of 18) designers returned their questionnaire and participated in the interview. These individual questionnaires and interviews give multiple views on the same design process and teamwork. The differently informed designers in one team revealed the effects of encounters on motivation and willingness, empathy with the children and caregivers, inspiration for idea generation, and team dynamics. In order to provide a setting for the results, we start with a description of the design process of the three teams.



### The design processes of team C, D & E

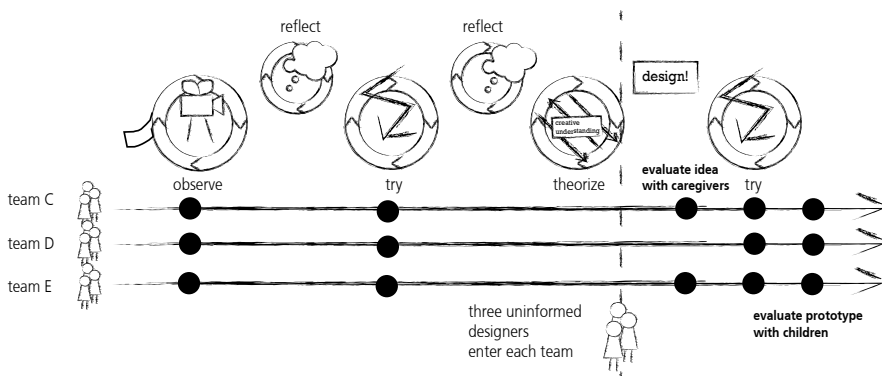
Each team planned one or two encounters to evaluate ideas with parents and/or prototypes with children during design activities (see figure 2). Each team assigned one (or two) designers to communicate with the caregivers and arrange encounters with children and caregivers. These designers are the ambassadors.

In the first month, none of the teams arranged an encounter. The informed designers communicated their creative understanding to the uninformed designers. The uninformed designers did not encounter children themselves. So the entire team depended on the understanding of the informed designers for idea development. Team D explained that the uninformed designers first intended to arrange a visit, but that did not happen in the end. *“We asked ‘the others’ multiple times to visit the school, but they did not”* (D1). In hindsight, the uninformed designers mentioned that this would have been helpful. *“I should have had contact earlier, to discover whether our thoughts about the children’s behaviour were right”* (E6). Sharing creative understanding and motivating the entire team towards the same design direction took up most of the team’s time. In the beginning, they had difficulties with bringing the uninformed team members to the same level of knowledge and motivation. This made the teams struggle with choosing a design direction that they agreed upon, and coming up with ideas. Moreover, the constraints and limitations of the children blocked the informed designers’ ability to generate ideas.

The second month, two teams contacted parents by email and/or phone to evaluate their design direction and first ideas. The ambassadors mailed or called the parents for more information regarding this direction. Team C also had difficulties in choosing a design direction together. They were uncomfortable with contacting any caregivers, as they did not feel properly prepared.

In the third month, ideas were selected. Teams divided the tasks of concept development and prototyping, which had a positive effect on collaboration.

The fourth month, all teams evaluated their first prototype with children and caregivers. The ambassadors arranged an encounter in which they were also present. For



**Figure 1:** An overview of the process over time. The black dots illustrate the team’s encounters with children and caregivers. After theorisation three new designers enter each team.

some of the previously uninformed designers, this was the first time they had visited the children. The teams videotaped their visits to enable the entire team to observe the children's reaction. Team C scheduled this meeting somewhat later, because they wanted to improve their prototype first. In the fifth month, all teams evaluated their prototype with two or more children, according to the instructions. Due to limited time and other obligations within the course, the designers said that this amount of encounters was the upper limit, even though they considered them valuable. In the last encounters, many of the previously uninformed designers went to the children for the first time. The designers that had encountered the children once encountered them for a second time, and took along a fellow uninformed designer. Many designers mention that in hindsight, they should have met the children before they started designing. In the end, it was too late. *"The others did not stimulate us interacting with the children, but now I went, I think everyone can do it. So much fun!"* (C6).

### *Individual motivation and willingness*

Encounters had a positive influence on the designers' motivation, and their empathy with children with autism. The informed designers automatically enrolled in the design brief for children with autism. The uninformed designers chose this design brief out of a selection of five projects. The choice for the assignment indicated that they have a degree of intrinsic motivation and willingness for the project. However, the stance of the informed designers suggested that they were more motivated than



**Figure 2:** A designer plays with Valentin on the first prototype of the interactive jumping pillow they developed (left) and Timothy plays by himself with the pillow (right)

the uninformed designers. They felt sympathy and wanted to help the children they met. *“I really wanted to make something for them, to fulfil their needs”* (D1). *“You see what difficulties they encounter, you want to help them and if that is possible with a product you can make, that is great!”* (D2). Another informed designer explained that the encounters motivated her to help the parents. *“When you see the trouble the parents go through every day, you are really more motivated to help them as good as possible”* (E6). However, encounters also sometimes inhibited the informed designers at the start of idea generation. For instance, one designer explained: *“I would like to help the parent, but was a little afraid that our product would have a negative effect on the children, and thereby creating a difficult situation for the parent”* (D6). Later in the process, the teams developed prototypes, which they evaluated in encounters. The observation of the children’s joyful play with the prototypes they had developed stimulated both the informed and uninformed designers’ willingness to improve their design. Designers said: *“But the reaction of the children made it worthwhile”* (C6). *“To actually see the children play with your product motivates you, because you know you design for that boy and girl”* (E2). *“When we discovered in our first prototype evaluation with children that jumping was a real good choice, it was so much more fun to continue with it”* (C3).

Empathy with the children

The encounter stimulated the designers’ empathy with the children. For example, one uninformed designer explained: *“The contact really helped me to get better acquainted with their habits and structure”* (C6). Imagining of what the children are like is impossible without an encounter. For instance, an informed designer said: *“You cannot understand these children, if you have not met them. They are all different, and theory doesn’t explain everything. You have to experience it yourself”* (D2). Reading books or watching a documentary cannot give the same understanding as seeing these children in real life. *“The contact was totally different from what I read or heard. It is nice to keep a real person in mind to design for”* (D1). Empathy includes information, but also is dependent on a feeling for the children and their reaction to people and objects in their environment. Although designers found this feeling difficult to explicate during the interview, they related it to the experiences they had had with the children. Table 1 shows examples of how the designers think that this feeling contributed to design. Designers mention familiarity with one another, and experiences with the prototypes designers brought.

Table 1: Some responses of designers concerning empathy

Designers’ feeling for the children	
C6	“I really liked them. I didn’t understand them, always, and they probably didn’t understand me, but the experience was priceless”
D1	“You see what they like and dislike and how they behave. This helps us ‘to form a picture’ about what could help them in daily life”
D2	“They recognize you a little and because they are a little affectionate. They are a little bit ‘our kids”
D3	“We interacted with them and know them”
E3	“During the first user test, we developed ideas and inputs on how they reacted to our product”

### *Inspiration for idea generation*

The designers were given the assignment to utilize their creative understanding in ideation. However, at the beginning of concept development all designers had difficulties in developing ideas that would fit the needs of the children and caregivers. The informed designers experienced two main struggles. Firstly, they did not complete the process of detaching from and making sense of their experiences with the children. For example, an informed designer explained: *“The uninformed designers were better in letting the users go, and got fresher ideas. For myself, I found it hard to switch from researcher to designer”* (C3). Learning and designing are different activities, which might explain why uninformed designers hardly spend any time searching for additional information. Secondly, the solution space for design seemed limited because of the children’s limitations. For example, an informed designer said: *“Knowing also gives a lot of restrictions. On the one hand, I found it positive to be more into the subject. On the other hand, we saw more restrictions.”* An uninformed designer mentioned this problem too: *“It is difficult not to be limited with the package of knowledge. On the one hand, it is great that you know so much. But since with this user group there is so much impossible, this can work against”* (C6). The informed designers rejected all the ideas they had, because none seemed to fit the children. An informed designer explained: *“In the beginning, I found it difficult not to reject ideas or express my doubts about ideas”* (C3). Moreover, the designers experienced that all of the children had different needs and preferences. The user group was complex to understand, and thus to design for. For instance, a designer said: *“Sometimes it was very challenging, because the children are unique. It is hard to come up with something that fits all of them”* (D1). Uninformed designers struggled just as the informed designers, but in different ways. They lacked personal knowledge, so were not restricted by it. However, generating ideas without any knowledge is difficult as well. For example, a designer said: *“I found it hard not to see them, before designing”* (C6). *“Contact was almost too late for us, but in the beginning it would have been helpful. We needed more criteria and wishes actually”* (D6). Although the informed designers struggled with ideation, they did not approve the ‘wild’ ideas of the uninformed designers either.

The encounters inspired designers, but they could not always explain in what manner. For example, an informed designer said: *“The contact inspired me a lot, because inspiration comes automatically when interacting with these children”* (D2). Other designers mentioned that the difficulties of the children they observed in encounters inspired them. They said they found various problems they could solve with design. For example, an informed designer explained: *“The contact inspired us a lot. By calling with parents and the school, we got a clear view on the problems and how they solved it”* (E2). This problem solving without detachment is relatively easy according to the designers. The challenge lay in letting go and designing something completely new for these children. For instance, an informed designer explained: *“The contact did not give so much inspiration, because you have to abstract your experiences first, before you come up with ideas. But you can evaluate an idea in your mind by thinking back on the interaction”* (E1). Once an idea was chosen, the teams collaborated on equal footing. The discussion of early ideas with parents, or evaluation of prototypes with children

was inspirational. Designers said: “Sharing our early prototypes with one of the parents inspired us a lot” (E3) or “the inspiration came more from the parents than from the children. If we see them as users as well, contact with users inspired us a lot.” (E6).

### *Team dynamics*

Having differently informed designers in a team brought tension into the team dynamics. Informed designers took leadership, especially concerning the planned encounters with the children. They felt they had power because of their personal knowledge about the user group. An informed designer explained: “I felt we know more about autism, so the rest should listen to our experience and agree on ‘our decisions’, although we listened to their ideas. I think the others saw me as very bossy, but I am convinced that they agree when they met the children” (D1). The uninformed designers had difficulties in fitting in and contributing to the design. An uninformed designer said: “Two of the previous group members were already friends and mostly scheduled themselves from the rest and acted like they know more about it than we did. This did not really influence the decision-making or cooperation, because we did not accept it, and kept giving new input and ideas” (D4). Another designer said: “Half of us did not know anything. It was difficult they were ‘our teachers’ in that way” (E6). This division in knowledge was difficult to overcome, because personal knowledge is difficult to put into words and share with others. On the contrary, we observed that shared experiences of designers in the encounter have positive effects. In the studies, designers mostly visited the context as a team. We observed that they helped each other out during encounters and understood each other more quickly afterwards. However, the shared experiences of the informed designers made it even more difficult for the uninformed designers to fit in. For example, an informed designer said: “We understood each other quicker, and we knew which role is good for which group member. However, for the new members this was harder, because we understood the same language” (D3).

### **Conclusions for the framework**

This study explored the influence of experiential learning on a design process and team dynamics by means of having differently informed designers in a design team. Prior to the design activities, half of each team met children and caregivers, while the other half did not. This study underlined the difficulty in sharing creative understanding with others. The absence of shared experiences inhibits idea generation. The designers did not understand the origin of each other’s ideas, so were not enthusiastic about the ideas of the others. On the contrary, the three informed designers had a common ground of creative understanding, which bound them together. The study showed two main struggles for idea generation. Firstly, creative processes were inhibited when designers were still making sense of user experience. Secondly, the observed impairments and/or difficulties blinded the designers at first. Even though knowledge inhibits at the beginning, it is necessary when designing for children with autism. Uninformed designers struggled with ideation as well.



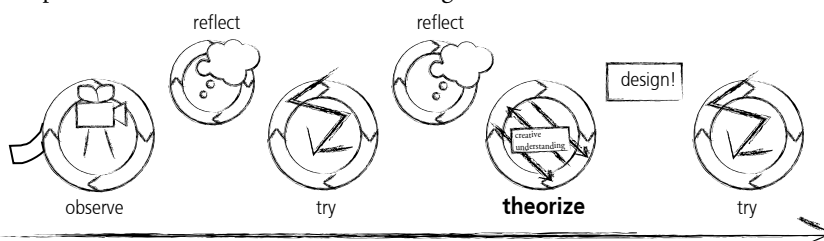
## Study V:

# Learning from different sources of information

This study aimed for insight into the preferences of designers, regarding different sources of information. Three design teams developed educational products for children with autism. In learning about the children, they used various sources of information such as; encounters with children and caregivers, consultations with experts, literature, books, videos, and blogs on the internet. By means of structured interviews it was investigated how these different sources of information are used by designers during their design process.

### Background

This study was part of a similar elective course to that of study II. In this course, nine designers could enhance their knowledge on learning from encounters with users for designing. 'Scholengemeenschap Effatha' (Kentalis), briefed three teams of three designers to develop educational aids for children with autism at their school. These teams (F, G, and H) were each linked to a specific class with one teacher and four to six children. In each class, two or more of the children had been diagnosed with autism. The teacher formulated an assignment corresponding to the specific needs of her group of children. During the design process, designers learned from various sources of information. Examples are: encounters with these children and teachers, consultations with experts, literature, books, videos, and blogs on the Internet.





## Methods

We used questionnaires and structured interviews with nine designers to investigate the influence of different sources of information on the design process.

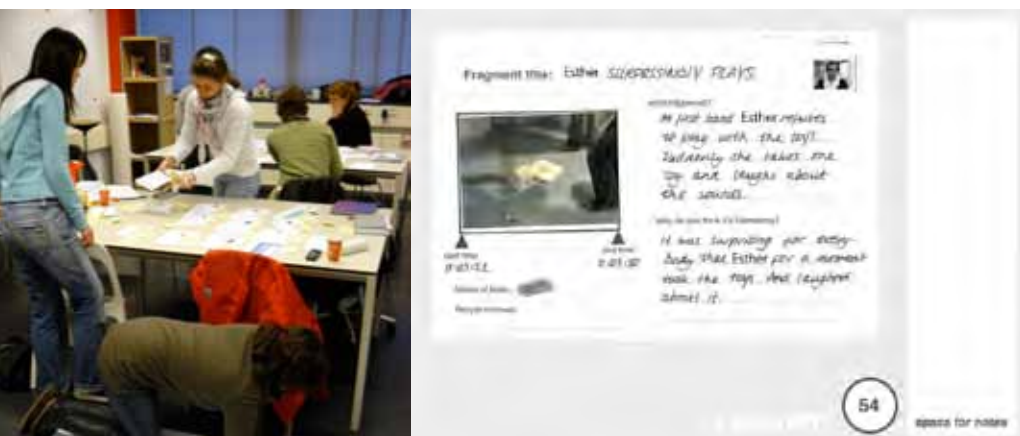
### Research question

- What are the preferences of designers concerning different information sources?

### Procedure

All designers had access to the same sources of information. In the beginning, they received three articles about autism (Happé and Booth, 2008; Noens and Van Berckelaer-Onnes, 2004; Van Berckelaer-Onnes, 2003) and one book with an introduction to psychological theory about autism (Happé, 1994). Additionally, they could borrow books from the course book shelf (e.g., Grandin, 1996; Haddon, 2004). The course website provided tips for movies and documentaries such as Rainman (Levinson, 1988), the horse boy (Scott, 2009), and Mozart and the whale (Næss, 2006). The amount of external sources grew throughout the course of the project. For example, interesting articles found by designers was forwarded to the other designers. The first encounter with the children was arranged. After that, designers could gather and learn from any type of data that suited them.

We planned a 4-hour analysis meeting in which the teams could jointly draw conclusions from the data they had collected. In this meeting, designers selected and explicated relevant data, while leaving out the rest. In preparation, they were instructed to individually investigate all data (video recordings, photos, transcripts) and select design relevant information. They received specially developed analysis cards with space for selected raw data (transcript, screenshot or photo), a description, and their interpretation or a statement about this raw data (see figure 1).



**Figure 1:** A design team analyzing their data collection using their analysis cards (left) and an analysis card of a designer (right)



After the project was finished, the author and another researcher separately conducted semi-structured interviews with the nine designers about the use of different sources in their design process. In preparation, they completed a sheet with open questions. These questions addressed the sources of information that were used, the designers' level of empathy/information/inspiration during the design process, what the different sources of information brought for their design process, and the origin of their final concept. Designers explained their answers in the interview. The interviews were transcribed. The results were analyzed in a qualitative manner in a three-hour session.

#### *Preparation questions*

- Make an overview of the sources of information you used during your project
- Draw an overview of your personal level of empathy, information and inspiration
- What did each information source bring you in terms of empathy, information and inspiration?
- What was the spark for your final idea? Where did it come from?

### **6.4.3. Results**

These interviews gave multiple perspectives on similar design processes and teamwork. The results showed that designers have personal preferences when it comes to the choice of information sources. All designers appreciated the active approach of learning from encounters. *"It's good to let designers find information by themselves"* (F2). They valued encounters with the children. *"I did not look back into literature, because there was so much other information. The information from practise is for me personally so much more valuable and the things the teacher said were focused on what we need to know"* (H1). Most designers used the additional sources for sense-making and generalizing their findings. Two designers (H1 and G1) mentioned that they appreciated the mix of information sources in the project. *"Direct experience is important, but also that all the things have to be mixed. How we did it now. Because in the beginning it is very weird, because as long as you are only reading and discussing, but haven't seen anything, you have no idea what you're talking about. But when you are observing and can discuss every once in a while, and read why something happens, it makes more sense"* (H1). The section below describes the designers' response regarding each type of information source.

#### *Observation and interaction in encounters*

All designers mentioned that they valued the encounters with children for their design project. For example, they explained: *"the behaviour of the children is the most direct feedback for the design concept"* (F2) or *"contact with the children I think, is better than reading a book"* (H2). In contrast to study III, designers were not instructed to interact with the children. Still, interactions with the children and caregivers appeared to be the useful moments for design.

### *Reading literature about autism*

Designers differed in their preferences regarding literature. Most designers mentioned that they only scanned the provided literature. *"Inspiration is minimal, because these papers are too theoretical and not from the designers' point of view. They can only give us theory to explain the phenomenon"* (F2). Two designers preferred to read design related literature. *"I did not read the three articles letter by letter, it didn't happen. I did read the one about co-designing LINKX, because that was more relevant. It is about designing"* (G2). *"Design related literature is useful"* (F2). Moreover, literature is not directly linked to the children the designers met for their project. Although literature can help designers in generalizing, the spectrum of autism makes this process difficult. *"For me it was much more fun to visit the children and play with them, than reading dry literature. Also because you don't know whether it applies for our kids."* (F1). One designer mentioned that she thinks the literature should be provided after encounters with the children. *"I think that it might be better to offer the articles later in the process, when I have a better view on autism and it brings an addition"* (H1). Two designers mentioned that they enjoyed reading the literature. *"Yeah, it was pretty much theory, but I think compared to other topics, our one is really I think personally about teaching and learning. Our assignment was to really teach them some symbolic information. So I think it can be more with theory. And personally, I am interested in theory"* (F3).

None of the designers thoroughly read the provided book, although some of them scanned it. The book gives an overview of existing theory, but was too difficult or too thick for designers. *"I scanned it and read parts of it, but stopped quite quickly"* (G2). *"Oh no, not the book. I didn't read, it's a bit too much. And it is not really easy to understand in once, so I more depend on the paper"* (F3). Two designers selected a novel written from the perspective of an individual with autism. Both did not finish the book. *"Well, I started, and started again and again, and than I stopped. It was not interesting enough to read for fun, and I did not see it as study material"* (H1). *"I read the first 30 pages and then I got crazy myself. I didn't finish it, it was a very weird book. The man was autistic and I didn't get it so well"* (F1).

### *Watching movies about autism*

Two designers mentioned that they watched movies on the Internet. *"I looked up random play movies of children on youtube"* (G2). Although we expected designers to mention the Hollywood production 'Rainman' (Levinson, 1988), the movie they had watched was 'Mozart and the wale' (Næss, 2006). This movie brought one designer empathy. *"Mozart and the whale gave me a lot of empathy, because I had a lot of feeling for the the person in the movie"* (G2). Another designer mentioned the horse boy: *"And the Horseboy. Here you saw parents that were devastated and wanted to find a solution. I don't think it was a pure informative movie, but it was inspiring. These children can drive you mad. That boy was really autistic"* (F1). Although the movie 'the women who thinks like a cow' was online at the project website, none of the students mentioned it. However, one designer found Temple Grandin on Ted Talk (TED, 2010). He asked the author to inform the other designers in the course. *"The empathy bulb during ideation*

is the TED video. At that moment, I understood autistic children as human beings. Watching the video and listening to her talking in English, in understandable language, but still autistic, is real. Our children were deaf, could not speak to other children, but I feel enhanced, the level of understanding increases in a short time by watching the video. I also watched more movies on the internet” (F3). One designer mentioned that watching movies alone brought him more empathy than watching them together with his team members. Alone, designers watch movies as human beings, while with their team, they watch in a professional manner. “Here, I am a normal person and maybe just a person watching a movie and there we watch together with the design team” (H2).

### *Photos of children with autism*

Often, autism cannot be easily seen from the outside. Still, pictures helped to inform and support designers. They can physically hang on the wall, while movies remain digital and more inaccessible on computers. Daniel’s mother has a website on which she posts pictures and stories about Daniel. Two designers mentioned that website. “I can remember a photo that he draw a whole wall full with numbers. His mother wrote that he loved numbers. I think that is interesting, because you can look at a picture of a child drawing or painting on a wall, and that doesn’t tell he has ASD. But a ‘normal’ kid would not have the idea to really past numbers on such a structured way. So that picture I found very illustrative for a child with autism” (H1).



**Figure 2:** The photo with numbers from Daniel’s blog

*The four roles of caregivers in encounters*

The results of this study show four roles in which the caregivers contributed to the designers’ learning process. These roles are: enabler, user, mediator, and informant. The role of enabler relates to the caregiver’s relationship with the child. The children’s dependency ties caregivers to this role whenever the two are together. The role of user relates to the eventual product. Caregivers prepare, oversee, support, or finalize the child’s interaction with products. In the interviews, designers mentioned that the caregivers were involved as informants and mediators in the encounters (see table 1 and 2). As informant, caregivers explained the children’s behaviour to the designers, and in doing so offered relevant information on the spot. *“If you’re reading, you only absorb what is there. You can wonder things, but you cannot ask them. As soon as you have a conversation with someone, you can ask for more information and like that it was always a very good specific addition to what you wanted to know. And the teacher always made sure that we knew before we knew we had to know something, we got to know it.”* (H1). Designers valued the caregivers’ explanations of the observed behaviour. The children can react in unexpected ways to a prototype. Designers might conclude that their design is inappropriate, while caregivers can explain the influence of external causes such as a lack of sleep. The designers also mentioned that caregivers informed them in design decisions. Later on in the process, when designers evaluated prototypes with children, caregivers provided valuable information about the children’s reactions. Even when designers were absent, they could gather information for them and pass it on. As mediator, caregivers enable designers to interact with the children, even if they are not skilled to do so.

**Table 1:** Designers’ responses about the caregivers’ role of informant

Caregivers as informant...	
F1	“The teacher can explain he went to Eurodisney this weekend, so he is upset. Normally he is enthusiastic, but now he is completely in his own world, full of impressions”.
F1	“The teacher used the prototype every day when we were not there. She gave us useful information by email about how it went. The children are used to her and if she can test the prototype over a longer period, she is the stable factor. If she explains, they might understand it quicker or they are less distracted”.
F1	“If you play with the children, you get deeper insight into their experiential world. And if you after that ask ‘I found it weird he just started lying on the floor’ than this empathy gets bigger. But it’s not the basis so to say”
F2	“When a child didn’t react okay, and we thought it is our design problem, but the teacher explained he lacked sleep”.
G2	“Most valuable is that teachers can tell you what happened. You can interpret something completely different yourself. For example, Sharon seemed very shy, but actually liked it a lot”.
G2	“The teacher gives information that is related to the observation or the interview we were working on”.
H1	“The teacher speaks for the users. The children cannot speak for themselves, but Tris can. She explains what is needed for the children. For example, changing the cards on the blocks was our idea, but this was based on what the teacher said, that it should be flexible, because for Abel it is different than for Pete or Dana.”
H2	“We talked about the volume of the blocks and how many we needed to develop. She said maybe 14 or more. So we know how many to build then.”

**Table 2:** Designers' responses about the caregivers' role of mediator

Caregivers as mediator...	
F3	"The first and also second visit, we did not know how to approach the children. But just the fact that the teacher is present in the room, feels, makes me more comfortable. Because when something goes wrong, e.g., Steven gets aggressive, Tina directly comes to control his behaviour. We cannot really do that. We can make them stop, but maybe that is not allowed or not good for them. We don't know and are not teacher. We are just students, involved for some months, and cannot behave like that. We are more passive, try to observe from the outside, because we don't know how much we can approach them".
F3	"The teacher can communicate much better between us and the children, because they have some simple sign language, like this or that. So observing this behaviour, the real communication behaviour, we can understand. Even their level of communication. Observing the interaction between teacher and child is also good"

**Table 3:** Designers' responses about the involvement of experts

The involvement of experts...	
F1	"During the meeting, the questions don't really immediately come. And I didn't know what she could and had done in the past. Her background wasn't that clear. Because I did google her, and she is even a wikipedia subject, so that is funny. And that is the only thing I knew".
F2	"We need other students to involve in our idea generation, in this part, one or two students of the major in autism, if that exists".
G1	"I thought we could have her a lot more in the beginning, because we had a lot of questions".
H1	"There was a threshold to contact her, because she is the professor from Leiden, very busy, and if you want to reach her, you must have a good idea of what I want to know from her, or have something I want feedback on. I don't have that with the teacher, because you had contact on a much more personal level during the whole process".
H1	"Questions come later, when you are in your bed"
H2	"We did not get any further recommendations or suggestion from her. Maybe some confirmation, but no other information, so she can be involved earlier."

### *The lack of involvement of parents*

Designers had little to say about parents, because only one team sent a probe to the parents. One other team looked at the scrapbook of the children that parents and teachers use to communicate with each other about the child's progress and behaviour. In this way the team could get a glimpse of the child's home situation. But none of the designers spoke to parents, mainly because parents let the researcher know that the designers could interact and observe their children, but they didn't always wish to be contacted for more information. In this study, teachers were always present during the observation sessions of the design teams.

*"I would have found it interesting to know. Now we only know how they act at school, but at home is one black hole. We know something from the book that goes back and forward from school to home, but Anthon had nothing from his parents in it. And then I think, this is one black hole what that boy does when he goes home. He is per day 1,5 hours in the bus back and forth from home to school. That was all the information I had and that was quite difficult. I don't know whether it was useful for our process, but I am curious about it"* (F1).

### *The involvement of experts*

Before designers started ideation, they presented their findings to a professor who is an expert on children with autism. Most of the designers valued this conversation and wished that they had talked to her earlier. Unlike the teachers involved in the study, the professor had theoretical knowledge about autism and could explain the common behavioural patterns of the children. *"The professor explained for the first time things we didn't understand"* (G3). *"The professor could give more background information and a solid base, which we think is good"* (G1). However, some designers were hesitant to contact her, or could not think of the right thing to ask (see table 3 for more responses about involving experts).

### *Relating to personal experiences*

We did not instruct designers to connect their experiences from the encounter to prior personal experiences. Still, without instructions, some designers made connections to experiences of their own that resonated with those of the children. For example, a South-Korean designer related autism to his personal experiences of going to the supermarket in the Netherlands without understanding Dutch. *"I go to the supermarket like other times, and saw a lot of Dutch words, I couldn't understand. That maybe can be a bit similar to their situation. I imagined the meanings of the groceries. For that, I used the picture and colour of the packages."* (F3 in class meeting). As proposed in the framework, connection to personal experiences might indeed have a positive effect on empathy with users for design.

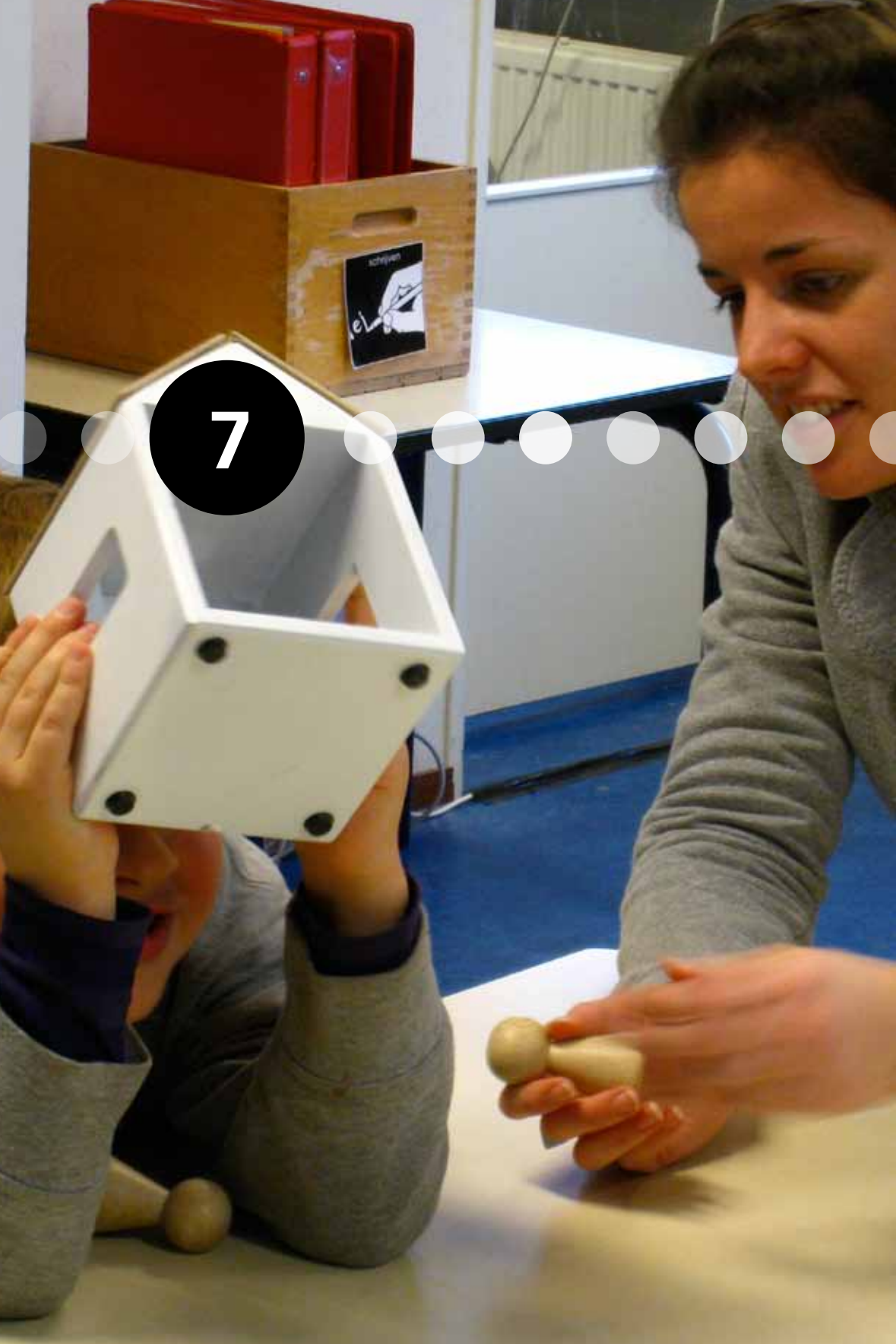
### *Theorisation inspires designers*

Designers analysed the collected data in a 4-hour analysis meeting. This brought an overview of the information to designers. Before analyzing they felt overwhelmed by all the data. Afterwards they were in charge. *“I later made new A3 papers of all information when I had more time. It’s pretty much the same as the whole, but I arranged it in a better way”* (F3). Designers could also improve this overview over time, and as their creative understanding grows. Analysis is important to shift from the role of user researcher to that of designer. The overview brings a capacity to work with and from the data, and even the process of analysis itself can be inspiring for designers. *“Making the framework inspires me, because you think and memorize the moments and you put it all into an overview”* (H1). Designers mentioned that most of their inspiration was derived from the outcome of analysis. For example, *“Inspiration came mainly from the outcome of analysis, because there you get the relevant information, which will inspire you for your design”* (H1), and *“most of the ideas came from analysis. I just found one idea of bringing different levels of abstractions in different orders. They already practice language skills with pictograms, pictures, and words together. But maybe we can present them in a different order in our concept?”* (F3).

### **Conclusions for the framework**

This study investigated the preferences of designers concerning different sources of information. It showed that most designers prefer a bottom-up approach as proposed in the framework. Additional sources of information assist designers in their learning process, but most of them need concrete experience in the field to understand what they read or see in these sources. Which type of other sources they need depends on the designers’ learning preferences. Most ideally, they would have a caregiver around that explains the behaviour of individual children, and an expert who relates these individual explanations to theories on autism spectrum disorder. Designers should ideally have access to different sources of information and be able to combine them throughout the process. This study confirmed that encounters bring the most inspiration, according to the designers themselves.

7





# Conclusions and general discussion

*The aim of this dissertation was to gain insight into how designers learn from, and about, children with autism through direct contact. Before, little was known about the actual processes that take place when designers are learning from encounters. An explorative research approach was chosen to develop a framework for designers, to guide them on this matter. The studies investigated in detail first encounters, which allowed the development of nuances of the proposed framework. This chapter discusses these nuances, the main themes revealed by utilizing encounters in the design process, and methodological issues. The next chapter concludes this dissertation with guidelines for practice based on the findings from this research.*

The framework developed during this thesis (chapter 5) proposed an interim answer to this question, based on theory. It described an experiential learning cycle for designers, consisting of four activities (observe, reflect, theorize, and try) and four transitions (immerse, connect, detach, apply). This cycle was created based on theory about designing (chapter 2), learning from users (chapter 3), and autism (chapter 4). It served as basis for the development of special tools and techniques to support designers in these learning activities. In the studies (chapter 6), designers used these tools and the proposed learning cycle as techniques. With the findings from these studies, the framework was developed further.

The framework below is the final answer to the main research question for this dissertation. Section 7.1 presents and explains findings about the developed framework. Section 7.2 discusses the main themes revealed by utilizing encounters between designers, children with autism, and caregivers in the design process. Section 7.3 discusses methodological issues, and section 7.4 concludes with recommendations for further research. Chapter 8 translates the findings from this research into guidelines for practice.

## **7.1. Main conclusion: the development of the framework**

The developed framework (see figure 1) is a fundamental part of the answer to the main research question. The studies showed that the proposed cycle adequately describes how designers learn from encounters with children with autism, and their caregivers. All activities (observe, reflect, theorize, and try) were given as instructions to participants in the studies, and the outcomes clearly observed. The proposed transitions (immerse, connect, detach, apply) were more difficult to observe, because they are processes that take place in the designer's head. Nonetheless, the outcomes of the processes 'immerse' and 'apply' are evident in the designers' interactions with the children, and the observed interventions. The transitions 'connect' and 'detach' take place outside the encounter, so could also not be directly observed. Still, we found some evidence for these transitions in the designers' reflective notebooks. For instance, in the studies three out of eighteen designers expressed stories about prior experiences that related to those they had during the encounter, and compared those with the children's experiences. Two out of eighteen designers indicated their explicit need for detachment.

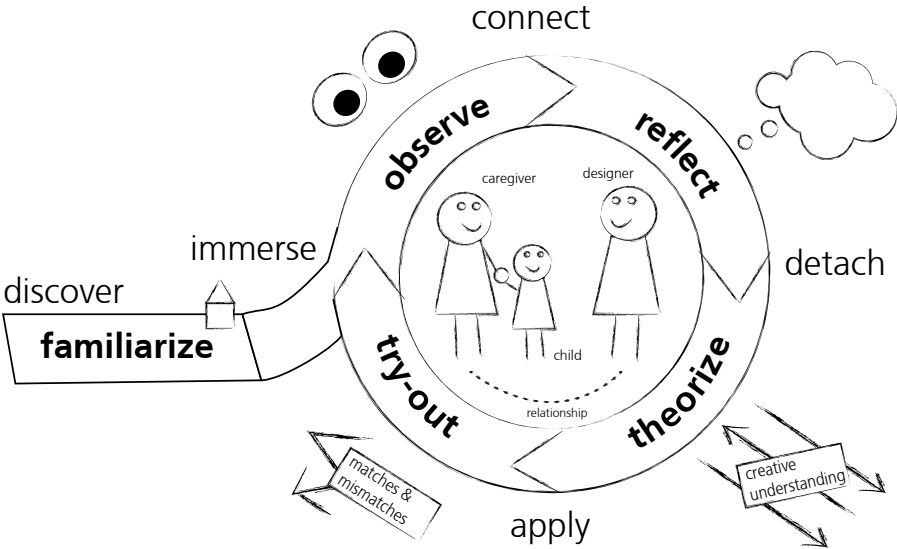
The studies investigated in detail the first encounters between designers, children with autism, and their caregivers. This brought the following three main findings, and allowed the development of nuances of the framework. They indicated the necessity for designers to (1) familiarize themselves with the new context before entering the learning cycle, (2) observe the children without any instructions to record these observations, and (3) consciously search for moments in which the children give a different meaning to objects and/or interactions than they do themselves. The latter emphasizes the importance of admitting mistakes in interactions, to assist the goal of learning.

In design literature, many researchers give overviews of tools and techniques for learning about users during the fuzzy front end of a design process. However, little is

known about how designers should act, and what processes take place when learning from encounters. In everyday life, people empathize in their social interactions with others. Children with autism have impairments in social interaction, communication, and imagination. This poses an extra challenge for designers when empathizing with them.

Table 1 on the next page provides an overview of the entire framework. For each activity or transition, it describes what designers do, how they do it, and in what way it contributes to creative understanding and concept development. Here, we discuss the three main findings above as they take place in the activities familiarize, observe, and try-out. For these activities, we discuss how designers approach children with autism in encounters and what role the designers’ attitudes play in building creative understanding. Moreover, we discuss how children with autism and caregivers act in these activities, and how their actions contribute to the designers’ learning cycle.

**Creative understanding**  
from encounters with users  
for the design process

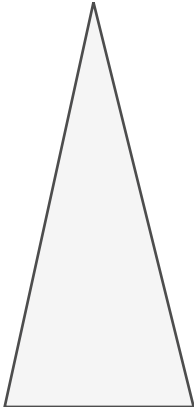
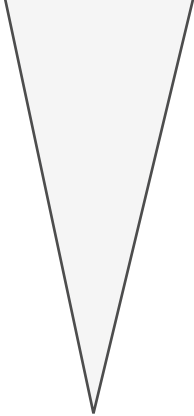



**Figure 1:** The developed framework

**Table 1:** The activities and transitions in the developed framework

Learning cycle	What designers do	How?
1: discover	Amaze themselves	Be open-minded
2: familiarize	Wait to see what happens	Find a comfortable spot in the room and do nothing for a while
3: immerse	Go along with occurring interactions, without any explicit goal	Open up towards the children and come as close to their world as possible
4: observe	Register experiences in the context with eyes wide open	Take a bit more distance in interactions
5: connect	Relate to prior knowledge	Think about situations in their life that relate to how the children experience the world
6: reflect	Interpret data	Think about what the experiences and observations mean for the design assignment
7: detach	Let go of the children and caregivers as individuals	Shift from children as subject to children as object
8: theorize	Make sense of data and achieve an overview	Look for patterns and categories
9: apply	Translate the creative understanding into a design proposal	Develop ideas and concepts into prototypes
10: try-out	Try-out design proposals with the children	Approach the children with the design proposal as prototype



Why?	Contribution to creative understanding	Contribution to concept development
Become curious and interested	Discovery brings a willingness to learn	
Feel at ease	Familiarity provides a solid base for learning, which enables designers to put findings in perspective, prepare for interaction, and conduct activities as planned	
Have concrete experiences with children in the context	The experiences from immersion are the source designers utilize to gain empathy	
Bring home stories about the child in his or her context	The observations are the source designers utilize for information about the child and his/her surroundings	Build on existing solutions
Connection brings the children's experiences closer to designers.	Designers understand the experiences they can relate to, which is necessary to gain empathy	
Reflection helps in understanding the user's experiences and what they mean to them	Interpretation is necessary to utilize observations appropriately	
Distance supports designers in adopting a helpful stance	Detachment is needed to allow empathy to develop into a helpful stance	
A clear overview is needed as preparation to design	This activity brings creative understanding, so results in inspiration, information, and empathy	Generate ideas
Physical interpretations of creative understanding are embodiments of presumptions, that can be tested	New ideas and concepts based on the achieved creative understanding	Build new solutions
Testing the proposal confirms or brings growth to creative understanding	New discoveries about ideas and concepts in use bring growth to this creative understanding	 Improve and create new solutions

### **Refinement: familiarization & discovery**

In the studies, we found that becoming familiar with the new and unknown context is important when learning from encounters. Therefore, we added the activity ‘familiarize’ to further develop the framework. With the new step in place, the developed framework also devotes attention to how designers enter the learning cycle. This is visualized in the framework, with the horizontal line on the left being the starting point for learning (see figure 1). Familiarization automatically takes place when designers immerse themselves in the children’s context (see study 1). It is a natural activity preceding to immersion, because both involve allowing time to freely wander around in the new context. The studies showed that clear goals, or activities such as collecting data according to instructions, hinder both familiarization and immersion. As familiarization fluently turns into immersion, they can be seen as one activity. However, we address them separately, because that brings designers awareness about both activities, and shows the necessity of them. Familiarity with the children is - to some extent - a necessity for the upcoming learning activities. When designers feel familiar with the situation, they have a more solid basis for learning about the children. They can go along with the interactions that are occurring in a more natural way, are more likely to conduct their activities as planned, and can place what they learn in perspective. Familiarity helps designers to feel in control of activities during encounters, so they can fail at what they want to fail at.

In the empathy process described by Kouprie and Sleeswijk Visser (2009) ‘discovery’ is the first step towards gaining empathy with users. In the framework presented earlier, discovery was considered a part of immersion and therefore not explicitly mentioned. The developed framework presents ‘discovery’ as the first transition, because this process occurs in parallel with familiarization. The studies showed that whilst becoming familiar with the children, designers discovered that they interact differently with the objects and people around them compared to what the designers are used to. A first encounter brings many possibilities for discovery, because the context is so new and unknown. In accordance with Kouprie and Sleeswijk (2009), we found that discovery fascinates designers and raises their curiosity and willingness. In addition, we found that the first encounter brings sympathy for the children and caregivers, because designers closely observe the struggles in their daily lives. In the studies, both this discovery and sympathy raised the designers’ willingness to learn about, and design for, children with autism. Willingness is important, because it determines to a large degree the level of creative understanding that is reached by designers. We observed the designers’ willingness was indeed strong after meeting the children. The participating designers wanted to learn more, in order to design products that would improve the lives of these children and caregivers.

### **Observation without tools**

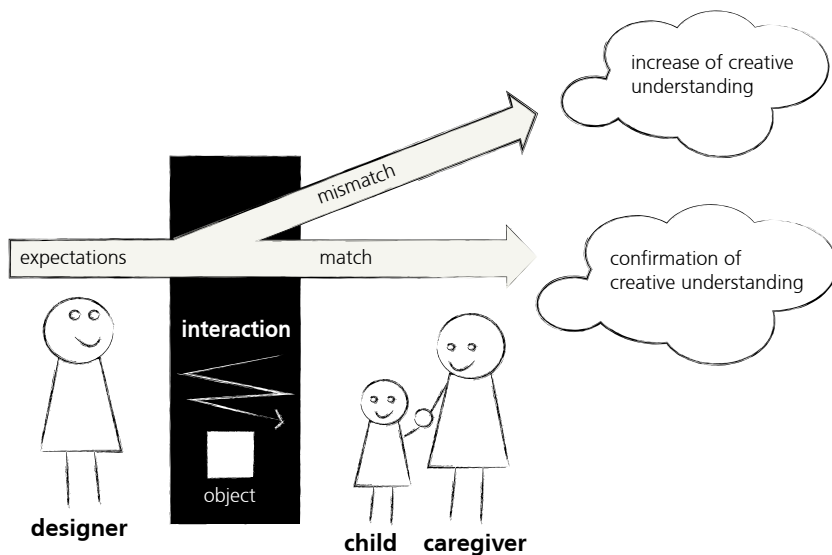
In the studies, we investigated how designers conduct observations during encounters. In these activities, the designers’ own experiences are an important ingredient for building creative understanding. To assist this understanding, it is necessary that

designers register their experiences in order to explicate them. Since experiences are personal, subjective and ephemeral (Sleeswijk Visser, 2009), we expected that recording them for future reference would be helpful as technique for learning from observations. We expected this for a number of reasons. Firstly, recording supports designers in memorizing, explicating, and sharing experiences with others. Secondly, recorded data can be looked at from an outsider's point of view, which helps objectify the experiences. Although recordings are useful for learning, the studies showed a strong side effect. The occupation with recording inhibits empathizing, which is an important part of creative understanding. The proposed framework was intended to assist designers to come close to the children and caregivers. Immersion in the children's context takes place most effectively when designers have no clear goal. Inevitably, recording devices such as cameras and video recorders, implicitly contain a goal; to use the device to record data from the context. In the studies, we found that recording devices stood literally and metaphorically between designers and their target users. Sometimes, the designers' attention went into operating the tool instead of coming close to the children. When instructed to make recordings, designers easily skip familiarization and immersion. Even when we developed a special observation tool that enables recording while immersing, designers still took time and effort to make sure the camera captured everything. They did not trust the camera to work properly in the background and capture relevant data. Surprisingly, the studies showed that the absence of recording tools enables designers to move more freely in the children's context, open up towards the children and caregivers, and thereby gain more empathy with them. Without any recording tools, designers use their empathic skills and memory to take the insights to the designers' table. On the other side, designers have trouble with sharing insights that are not recorded, so explicated. Therefore, the developed framework (see figure 1) shows eyes instead of a camera to illustrate observation. As recording tools inhibit empathizing, but support data collection, the specific needs of a design project will determine how designers can best act during observation.

### **Matches & mismatches in try-out**

In the studies, we investigated how designers utilize objects in their interaction with the children and how they learn from this. The framework proposes that the designers' attempts to interact with the children and caregivers increase creative understanding. The studies indicated that 'try-out' informed and inspired designers the most for idea generation, out of all the activities. Interactions confront designers with their presumptions about the children and caregivers. In interactions, designers face the children with either a match or a mismatch of expectations. This match or mismatch between expectations and actual interaction shows designers whether their presumptions about the children were right or wrong, which contributes to their learning process. We learned that matches bring very little new insight (see figure 2). They confirm the current understanding, but do not bring any growth. Mismatches on the other hand are more informative and inspirational for designers. They reveal something that was unknown until that moment and force the designer to adjust

and thereby construct higher understanding. In the first encounters, mismatches are likely to occur. Designers learn the most when they admit mismatches in interaction. Especially because mismatches cannot always be prevented in interactions, regardless of how much designers know about the impairment. Learning how to minimize, prevent or deal with mismatches brings insight. Along the way, designers learn better what they can expect from the children. As the interactions become more fluent, designers can understand or even foresee the mismatches.



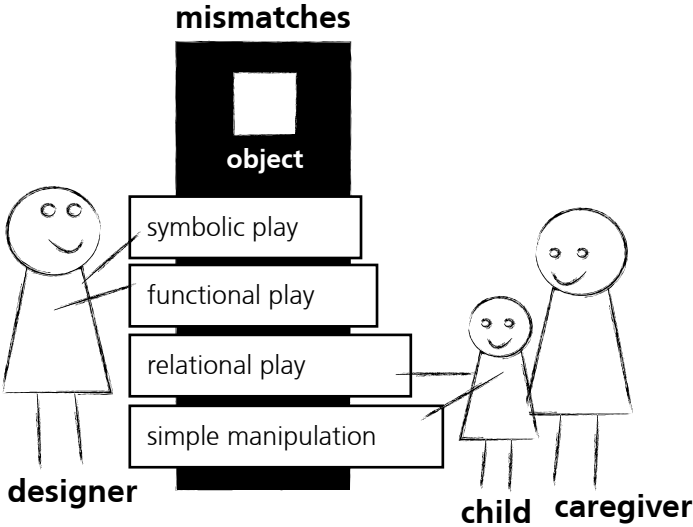
**Figure 2:** Mismatches bring an increase of creative understanding, while matches bring confirmation.

### *Objects as aids for interaction*

The studies showed that objects are useful tools for designers when they attempt to interact with the children. Most importantly, we learned that objects intuitively bring out any presumptions that designers may have based on prior experiences with objects and people. In interactions, designers are literally faced with these presumptions, especially when mismatches occur. Objects are helpful in mediating interaction, both for the designers and for the children. They put designers in a playful mode and force them to the level of communication that the children are comfortable with. Objects intrigue children with autism, who may otherwise be difficult to engage in social interaction. This mediation provides a helping hand to designers. Learning about how children with autism interact with existing objects is relevant for designers as well. This insight helps them to predict future experiences with the new objects that they design for them. The course of the interaction between designers, children, and objects illustrates particular findings for designers. Especially the mismatches described earlier play an important role in learning. The studies showed that the toy play levels of Ungerer and Sigman



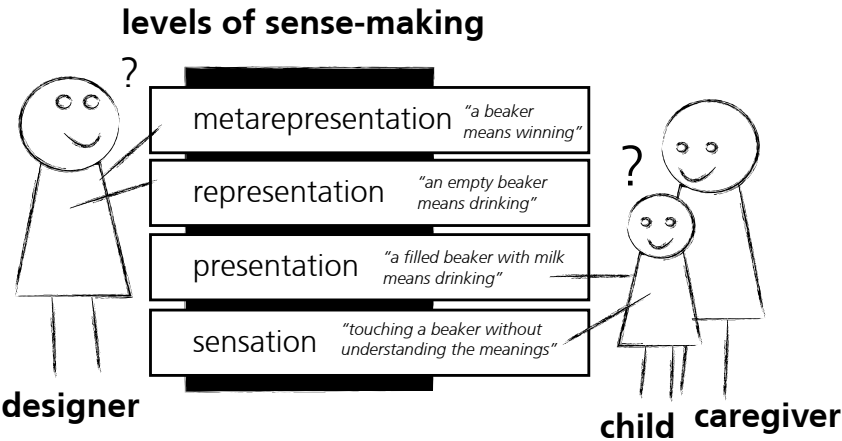
(1981) are useful to explain and predict these mismatches. The figure below illustrates that designers expect children with autism, like other children of the same age, to play at the upper two levels, while in reality they often play at the lower two. Familiar objects such as a dollhouse have a symbolic and functional meaning to designers. Designers expect the children to derive the same meaning from the object, but learn that they do not during interaction.



**Figure 3:** The four levels of play applied to the interaction between designers and children with autism. Designers expect the children to play at the level of symbolic and functional play, while in reality the children often play at the level of simple manipulation and relational play.

When designers develop prototypes, they embed their hypotheses about the upcoming interaction of the children with that object. The designers' expectations about its use determine the choice of aspects like functionality, tactility, and shape. Utilizing these prototypes in early encounters helps to test the designers' expectations and increase their creative understanding. When time is limited, pre-developed tools may offer opportunities to designers. In the studies, we developed a set of toys that addressed the four levels above. The toys had a certain appeal to children with autism, mostly based on the author's experiences in the LINKX project. Each object embodies expectations about how a child will react to it, and how he or she will interact with it. Through utilizing these objects in play with children, designers learn about the differences in their understanding of the world. We learned that objects that only address the lower play levels elicit children to show specific habits (their 'trick'), but provide designers no guidance on what to do with them. Objects that simultaneously address four levels such as the doll house result in the most mismatches.

Designers can also look at the four levels of sense-making to achieve the appropriate way of communication with users (see 4.2). These levels are: sensation, presentation, representation, and metarepresentation (Noens and Van Berckelaer-Onnes, 2004; Verpoorten, 1996). Understanding the level on which communication with the child can take place supports designers in understanding how to connect to children with autism through interaction, and helps them explain the differences in sense-making. These levels can help designers to discover the appropriate level of communication for other user groups with cognitive impairments as well.



**Figure 4:** The four levels of sense-making applied to the interaction between designers and children with autism. Designers are familiar with sense-making at the level of representation and metarepresentation, while the children understand the level of sensation and presentation.

**Attitudes and roles in encounters**

The framework proposed that designers change their physical and emotional distance with the children and caregivers, as a part of the learning cycle. Each transition, from one activity to the next, corresponds with a change in the designers’ relationship with the children and caregivers. We argued that these changes are important to develop empathy with the children. The framework prescribes that during an activity in encounters all parties ideally keep the distance equal. For example, observation prescribes that designers must go along with spontaneous interactions, while ‘try-out’ encourages them to initiate interaction. The personal distance in try-out is smaller than in observation. Designers and caregivers can stick to such an agreement. However, children with autism do not understand, so might not behave in a predictable manner. At some moments they approach other people, while at other moments they neglect them.

During observation this unpredictability has benefits for learning. The spontaneous behaviour of the children forces designers out of their comfort zone and supports them in familiarization and immersion. Their behaviour also reflects strongly how they feel. Children with autism will not pretend that they enjoy an interaction with an object or person if this is not the case. If a person or object does not interest the child, it will be ignored. This purity is helpful for designers, because they can trust their observations. In the studies, the designers' presence rarely distracted the children. Observation could take place without interfering in daily activities. This ignorance has disadvantages for 'try-out', in which designers hope to interact with the children and learn from their reaction to the objects they present. As children with autism are unpredictable in their behaviour, designers can only utilize the proposed learning cycle in a flexible manner. The possibilities for interaction depend greatly on the child's current mood and, more importantly, the support of the present caregiver.

The studies showed four roles in which caregivers can contribute to the designers' learning process (see table 2). These roles are: enabler, user, mediator, and informant. Firstly, the role of enabler relates to the caregiver's relationship with the child. The children's dependency ties caregivers to this role whenever the two are together. Caregivers step in and enable the child to perform their daily activities when needed. This role clarifies the children's capabilities and limitations to designers. Secondly, the role of user relates to the eventual product. The dependency described above also impacts the way these children use products. Caregivers prepare, oversee, support, or finalize the child's interaction with the product. Designers must take this role into account for design, because caregivers are future users too. Thirdly, the role of mediator relates to the interaction between designers and children. This role enables designers to interact with the children, even if they do not have the skills to do so. The intervention of caregivers in the interaction teaches designers important lessons on how to improve their future interaction, so that they are not likely to make the same mistakes again. Finally, the role of informant relates to designers. Caregivers inform designers about the children's experiences, when they are not able to interpret these first-hand.

**Table 2:** The four observed roles of caregivers in encounters

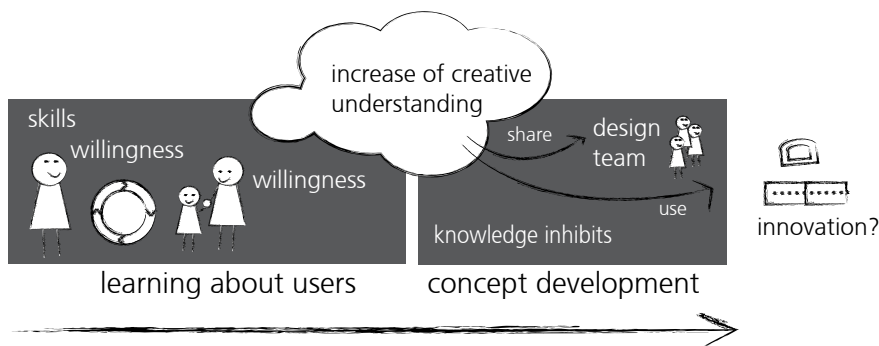
Caregivers' role	In relation to...	Relevance for designers
Enabler	Child	Information about the children's capabilities and limitations
User	Product	Information about the needs and experiences of caregivers
Mediator	Designer + child	Information about interaction with the children (procedural knowledge) Enabling designers to interact with the children
Informant	Designers	Information about the children's experiences that cannot be retrieved directly

## 7.2. Encounters in the design process

The previous section discussed the findings from the studies in relation to the proposed framework. In the studies, designers took the time to follow the proposed learning cycle in their design process. This brought us insight into what processes take place when learning from and about such an extreme user group for the purposes of designing.

But did that result in a higher level of creative understanding and higher quality of product concepts? This is a very difficult question to prove in general. Based on results from the studies, we cannot give an absolute answer. We did observe that designers opened up towards the children, discussed their findings with fellow designers, and used these insights in concept development. We are confident that the observed activities and processes were important for designing. But as creative understanding and concept development are mental processes, they are difficult to measure in such explorative studies. Van Rijn et al. (2011) indicated the value of encounters with children with autism, both for the designers' empathy and for the quality of product concepts that they produced. Based on this study and the LINKX project we presumed that encounters were helpful for designers. The further studies of chapter 6 explored how encounters support designers in learning about, and designing for children with autism and their caregivers.

The studies revealed additional insight into how encounters affect design projects. Figure 5 illustrates these findings within the time frame of a design process. The left block presents findings that apply to learning about users. The middle cloud represents the creative understanding that is built. The right block illustrates those findings that specifically apply to concept development. Below, we discuss these themes from left to right.



**Figure 5:** The findings about encounters within the time frame of a design process

## **The willingness of people**

This dissertation concerns the process of designers learning about children with autism. A condition for any type of learning is willingness to learn (see 2.3). The willingness of designers, but also that of caregivers, and children, influences the designer's quality of learning. We only discuss the willingness of designers and caregivers, because the children do not consciously contribute to the designers' learning.

### *Willingness of designers*

The designers' willingness to learn about users contributes to the level of empathy, and therefore the level of creative understanding that they achieve (Kouprie and Sleeswijk Visser, 2009). Willingness is not a constant, but continuously grows or decreases over time. In the beginning, the intrinsic motivation of a designer determines his or her willingness. In the studies, the designers' intrinsic motivations varied. They included a desire to do good, a wish to design for children, having the chance to embrace a true design challenge, and curiosity about the disorder. Addressing these motivations stimulates the willingness of designers. The studies showed that encounters have a positive effect on willingness as well. They provide designers control over what they learn based on what they consider relevant for design, and demand the full attention of designers. In encounters, designers need to stay alert in order to anticipate and react appropriately to the presence of others. In the studies, designers confirmed that this control and alertness motivated them in learning. The outcome of learning is definite and reliable, because they have experienced it with their own eyes. Moreover, encounters enable designers to discover the world of children with autism, and feel sympathy for them and their caregivers. Both discovery and sympathy also raise willingness (see 7.1). The studies showed that especially observed improvement in the children's skills is motivating for designers. Progress, even small steps, brings grounds for belief that design can make a difference for these children and caregivers. We found a flip-side of the encounters for the willingness of designers as well. Encounters reveal the complex reality that designers are challenged to design for. In the studies, some designers felt a lack of motivation when they realized how little they knew, and that they could never fully understand these children. In time, they built confidence and trust in their skills, which revived their willingness.

### *Willingness of caregivers*

Not only the willingness of designers determines the level of creative understanding that is achieved. The willingness of caregivers plays a crucial role in the learning process of designers as well. Their consent enables encounters to take place at all. They also mediate and participate in encounters, in various roles. In order for caregivers to contribute to the learning process of designers, a relationship of trust and respect is essential. Designers can influence the trust of caregivers by means such as; expressing expertise, acknowledging the importance of consent from caregivers, and working from a trustworthy institute or company. The studies showed that both direct contact and

indirect contact (such as postcards), support the process of building a relationship. When caregivers complied with or participated in the work of designers once, they are likely to remain willing to contribute in the future. This principle, described as the foot-in-the-door technique, can be explained by people's desire to be consistent (e.g., Beaman et al., 1983). In the studies, we observed more elements that motivated caregivers. Concrete benefits and common goals also helped increase their willingness. Moreover, the way in which a caregiver is involved in the process affects willingness. Acknowledgment of their expertise stimulates willingness. For instance, the author did an extensive job of keeping caregivers informed about the LINKX project. Caregivers received reports and ideas that often literally reflected their contributions in the form of photos, videos, anecdotes, and quotes. These caregivers felt ownership about the project when they saw that the results reflected their contributions and were correctly used (van Rijn and Stappers, 2008b). In the studies, designers explicitly thanked caregivers for the possibility to interact with the children by means of a postcard (see figure below). This indirect contact made them more willing to contribute to future encounters. Evidently, pleasant interactions during encounters are important. Caregivers lose interest in participation when the designers' presence repeatedly disturbs or upsets the children.

### **Skills for creative understanding**

The skills of designers also determine the eventual level of creative understanding that is reached. Creative understanding requires analytic, empathic, and creative skills. In the studies, designers intuitively collected information about the context that was relevant for their design assignment. We found nuances in the empathic and analytic skills of designers, which are described below.

The designer's empathic skills determine the level of empathy that is reached after an encounter. People naturally have these skills, so training is not required. However, awareness of the empathic processes and the amount of time they take are helpful for increasing empathy with users. Therefore, the developed framework includes discovery, immersion, and detachment, which are part of the empathic process. In the studies, we orchestrated the learning process in such a way that designers had sufficient time for immersion. We learned that an open-minded attitude, courage, and time to actually meet children stimulate designers in gaining empathy with the children they met. Some designers develop products based on one single user that they meet (e.g., Vollens and De Pauw, 2011). They develop the product with the needs and experiences of this one person in mind. After realisation, the product might indeed be useful, and be developed for other users as well. This is a rather unique approach to new product development. A more common approach is to learn about and design for a group of users (e.g., target groups, segmentations, or lifestyles). For this, analytical skills are necessary to detach from and generalize these individual needs and experiences for design. In the studies, inspiration for ideas came after generalisation. We observed three main elements that allowed the designers to generalize beyond the particular users they have met.

Firstly, in a user group with impairments the impairment itself is a common factor. Information about this impairment and its corresponding behaviours supported

designers in making sense of and generalizing the observed needs and experiences in the context. When variation within the user group is large, it is often narrowed down, or (parts of) the eventual product are adaptable or customizable (De Couvreur and Goossens, 2011; Hengeveld, 2011).

Sources of information such as literature and movies, both scientific and fiction, can explain the motivations behind the children's behaviour, and provide insight into what is dependant on the disorder and what on the child's personality or preferences. We expected that designers would use literature for generalisation. However, many designers in the studies were not interested, or did not have the skills to extensively read scientific literature. Only a few designers took the effort to read the literature that was given for optional background study. Others complained that the text was too theoretical for their liking. Most designers preferred a hands-on approach.

Secondly, the involvement of at least three users supports the process of generalisation. Comparing the behaviours and experiences of at least three children also brings insight into what observations are related to the disorder, and what to the child's personality. From learning about one child or comparing two children designers cannot be sure. Still, observing one or comparing two children is less informative than comparing three children, but more informative than observing none.

Finally, discussing observations and insights from encounters with fellow designers and caregivers supports generalisation. Each designer involved in the encounter registers and interprets observations and experiences differently. Comparing these observations and interpretations helps to get a grip on what has been observed and what it means. Moreover, caregivers have a deeper understanding of the children. Discussion with caregivers can verify and offer interpretations of observations.

### **Creative understanding in concept development**

The creative understanding designers achieve from encounters serves as a starting point for concept development. This understanding is accessible and actionable for designers because they built it up themselves. Still, the studies showed that designers struggled with three main difficulties at the beginning of idea generation.

Firstly, creative processes were inhibited when designers were still in the process of making sense of user experience. In the studies, the design process included a planned analysis activity of one afternoon. After that, idea generation should start. Although designers completed their analysis, we observed that this transition from learning to designing was too abrupt and difficult. Theorisation, the interim activity between these two phases, includes detachment and incubation. These processes take more time than a single afternoon. Especially when learning about children with autism, designers need to make sense of a large amount of entirely new information, which they themselves are personally involved with. It seems that creative processes are unable to take place, because learning is still using the designers' working memory. In the studies, some designers said that drawing quick conclusions and staying close to the existing solutions in the context was the easiest path forward.

Secondly, the observed impairments and/or difficulties of the children blinded designers at first. They were initially confronted by the limited capabilities of the children and their struggles in daily life, and the large variety within their needs and experiences. The solution space for design seems limited in some cases because of the children's limitations. Designers realized that they could only know a little about their user group, and never fully understand their thoughts and behaviour. The user group feels too complex to understand, and thus to design for. In order to overcome this struggle, we found that designers needed to consciously search for similarities instead of differences, and abilities instead of impairments.

Finally, the achieved creative understanding built from personal experience was difficult to share within design teams. Individual designers were able to gain relevant insights for design. They could access the understanding in its completeness, because they comprehend what they learned from close contact with the children and have anchored this in their memory. However, creative understanding is difficult to put into words and share with others. The studies revealed that designers struggled in collaboration when they were differently informed, but given the task to design together. It inhibited the group process. In this case, designers should make an effort to communicate the rich experience data to their other team members (Sleeswijk Visser, 2009). We observed that shared experiences of designers in the encounter have positive effects. In the studies, designers mostly visited the children's context as a team. We observed that they helped each other out in encounters and understood each other more quickly afterwards.

Even though knowledge can inhibit creativity in the beginning, it is necessary when designing for children with autism. Uninformed design does not lead to better products for these children (van Rijn et al., 2011). It results in a high quantity of low quality ideas; ideas that do not fit the user group. In this case, the skills of individual designers are the main factor that determines the quality of the products and services that are developed. Methods, tools, and techniques can enhance design activities, but do not guarantee successful design. Some researchers argue that technology instead of user needs feeds new product development (Norman, 2010). Inventors create new technologies for general use and people who see some worth in it pick it up. These technology-driven processes aim for radical innovations, innovations that bring a major shift in the entire world of products and how people interact with them and give meaning to them. This dissertation did not aim for a major shift in the world. Our work focused at the world of a specific group of people, not the entire world population. When affordable products and services are developed that fit the experiential world of children with autism, the result can be a radical change in their lives. That's where we're aiming for.



### 7.3. Methodological issues

The studies used the context of design education as research setting in which arranged encounters took place between M.Sc. design students, children with autism and their caregivers. Below, we discuss the validity of the setting and research approach, generalizability of children with autism to other user groups, and ethical issues concerning this user group.

#### **The research setting**

The studies in this dissertation took place in the context of design education. This setting provided the opportunity to control conditions such as the design process, and the tools and techniques designers utilize in this. In design practice, projects for children with autism are rarely conducted, and constraints such as time and low budgets determine the course of the design process. Professional designers often have no time to meet users in person (Sleeswijk Visser, 2009). The educational setting enabled us to investigate encounters in the design process in a systematic way. Although the conditions to realize encounters in education are different than in design practice, the developed framework nonetheless describes the generic learning process from encounters. This process itself applies both to design students and professional designers. Differences such as age, skills, and expertise might change the designers' starting point and the final level of creative understanding that is reached, but not the described activities and processes in the cycle itself. In this setting the author was a teacher of the M.Sc. design students who took part in the project. This role may have influenced the behaviour, feelings, and thoughts of the students. For example, students are more likely to follow and appreciate a process because 'the teacher says so'. As described in the setup of the studies in chapter 6, we tried to reduce this effect by including multiple researchers, and various methods of documentation such as reflective notebooks, video observations and class meetings.

#### **Extreme users as a basis for the framework**

The participating users in the studies were 'real' children with autism and caregivers. The children were from different schools and families, and represented the user group 'non-verbal children with autism'. Looking back, the developed framework can be applied to any user group that is largely dependent on caregivers. The course of interaction and ways of supporting it differ for each specific user group. For example, children with autism might lack reciprocity in interaction, whilst people with dementia use inappropriate content in reciprocal communication.

The encounters with this extreme user group framed our thinking about how to learn from encounters with users in general. The level of empathy that designers reach depends on how easy it is for the designer to imagine the experiences and intentions of the other. Two opposite forces operate here: increased similarity makes it easier to empathize, but also makes it easier to overlook differences. The learning process is easier when the people involved have needs and experiences in common. However, the presence

of commonalities may make designers expect the other has needs and experiences that are similar to their own. In that sense, the closer people are to each other's experiences, the more information remains below the surface. Because they assume they know, they do not ask the expected/obvious. Designers and children with autism have little in common, and therefore the empathic understanding between them is low. Designers cannot imagine the significance of the experience of these users, and therefore cannot relate to their experiences (Battarbee, 2004). The extreme challenge in designing for such a different user group in this research brought the learning process of designers to the surface. It served as a magnifying glass, and much that we learned about how designers can learn from encounters not only holds for learning about such different user groups, but can be applied to learning about any user group.

### **Ethical issues**

The teachers and caregivers of the school and daycare, involved in this study have selected the children for participating. Thereupon the parents of these children are approached to give permission for participating, filming and taking pictures. None of the parents refused, they all were very interested in the study and very helpful in giving additional information.

### **Developed tools and techniques**

As described in the setup of the studies, the author took on the role of 'tool-designer' of tools and techniques for 'product-designers' to use in the studies. In this role, the author designed specific tools and techniques because she considered them a good way to support designers in learning from encounters. The proposed tools and techniques are not the only way to support these designers in learning from encounters. A different researcher, or tool-designer, may have developed (slightly) different tools and techniques to instantiate similar principles. However, we do not expect that others reveal complete different principles e.g., than the ones embodied in the dollhouse. In the context of this research, the tools are used as a research vehicle to assist in developing the framework. Other tools could light the framework from another perspective, but would result in similar principles for the framework. The guidelines that will be presented in chapter 8 are related to the developed framework. They provide hands-on support on how to involve people with cognitive impairments and their caregivers in design. Thereby, these guidelines are a tool for both designer and caregivers in practice.

## 7.4. Future work

The presented research has introduced the phenomenon of learning from encounters with children with autism and their caregivers, in the context of a design project. This revealed many aspects about encounters with users in the design process. But rather than providing any definite answers it raised new questions.

The studies took an explorative approach, because so little was known about the processes that take place in designers learning from encounters. In future research, elements in the developed framework should be further investigated in a more experimental manner. This may help to achieve more definite answers. Moreover, this framework has been developed based on encounters between design students, children with autism and caregivers. In future work, we would further investigate the use of the developed framework as a technique in professional design practice, to learn about and from any user group. In this way, the validity and usefulness of the developed framework increases. The guidelines for practice (see next chapter) enable practitioners to use the gained knowledge in this dissertation.

The studies focused on tools and techniques for direct contact during encounters. In learning from encounters, half of the activities (reflection and theorisation) take place outside the encounter. Also the maintenance of a relationship with caregivers and collaboration with fellow designers are an essential part of the process. Further research could investigate how tools and techniques support designers after actual encounters. It can investigate how designers making sense of and utilize their creative understanding from encounters in the design process. Especially how designers can use insights from encounters in ideation deserves extra attention in further research. For keeping experiences from encounters alive in the design process, video seems a helpful tool. However, we learned that the activity of recording may inhibit the process of empathy during encounters. The relation between learning and design activities needs to be further investigated. This future work would result in designers obtaining a deep understanding of any type of users, and especially those with cognitive impairments. They would be able to design and develop products and services that truly meet the needs and experiences of these users. This could result in a higher quality of life for both users and their caregivers.



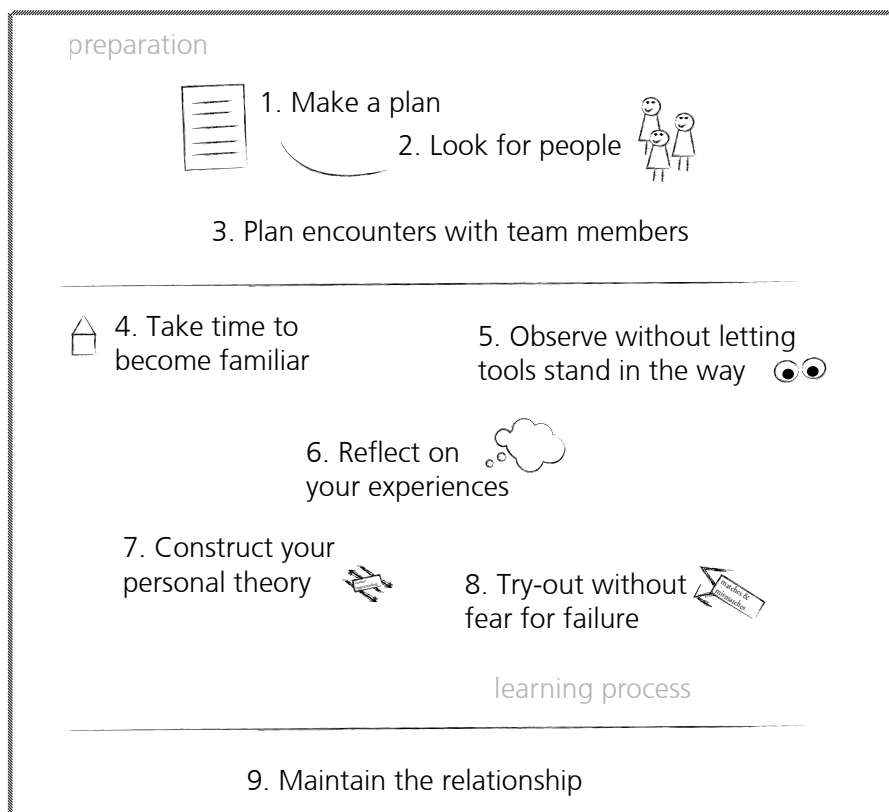
# Guidelines for practice

*Encounters with users are a valuable source of information and inspiration for design. From their personal experiences and observations in encounters, designers have a solid foundation on which to build creative understanding. Creative understanding includes information about the user and his/her surroundings, empathy with the user, and inspiration for idea generation (see chapter 2). These three ingredients enable designers to develop products and services that fit the experiences and needs of future users. Parallel with developing the framework that is the subject of this dissertation, we formulated a set of practical guidelines. These guidelines are extracted from the research, in which designers were the key topic of interest. The guidelines are presented in a general way, because many of them can be applied to other users that are dependent on caregivers such as children in general. The developed framework describes a learning cycle for designers, and explains how caregivers can contribute to this cycle (see chapter 7). This chapter presents practical guidelines in relation to this cycle, as the two are closely connected. The guidelines are divided into 'guidelines for designers' and 'guidelines for caregivers'. They are presented together, because mutual understanding is important for collaboration.*

This chapter presents a set of nine guidelines for practitioners who are involved in a design project. For each of the guidelines, we give practical tips and tricks both for designers and caregivers. The nine guidelines discuss how we would organize the learning process if the goal is that designers optimally learn from encounters for design activities. Of course, other sources of information can inform and inspire designers in this process, especially in theorisation (see guideline 7). However, these guidelines focus on encounters, as this is the topic of this dissertation.

They are based on evidence from the five studies and two design projects presented in this dissertation and formulated parallel with developing the framework. In addition, we used literature on empathy in design as source.

The figure below presents an overview of all guidelines. They are divided into three main parts. The upper part includes guidelines 1 to 3, which are related to the preparation of encounters. The middle part contains guidelines 4 to 8, which are related to the activities in the learning process. In reality these activities occur as a gradual transition with many overlaps. We present them as separate activities to assist with explaining the designers' different tasks and attitudes towards users. The lower part contains the last guideline, which addresses the relationship between designers and users.



# Guideline 1: Make a plan, but do not plan too much

This first guideline may seem obvious, but a plan about who to involve, when to involve them, and why they should be involved is important for successful user research. Encounters involve a certain level of planning since they take place between a number of people and are time-consuming. A rough plan supports designers and caregivers in collaborating with one another. It includes the type of people designers intend to involve in their project, the moments at which they will need these people, and most importantly for which purposes they will be needed. The plan should be an initial proposal, that is open for changes in consultation with users.

## Designers: determine who your users are

The primary users in this dissertation were children with Autism Spectrum Disorder. There is a large amount of variety within these children's needs and experiences. For instance, a non-speaking child with classic autism has a different understanding of the world than a verbally capable child with Asperger's syndrome. Defining a set of user specifications such as calendar age, developmental age, gender, interests, or specific type of impairment ensures that you involve and learn about the correct people for their design task. And don't forget about secondary users when designing for people with cognitive impairments. People with cognitive impairments are dependant on caregivers such as family, therapists, and teachers. Determining both the primary and secondary users will assist you in gaining a complete overview.

## Designers: define when you need users and explain why

The project aim, time-span, and budget determines how to shape the design process. Encounters can take place in different phases. In the fuzzy front end, encounters can help to bring creative understanding for concept development. During concept development and product detailing, they can inform and inspire you. To choose the right moments, specify the needed input for each phase and the available time and budget. Encounters early on in the process result in a feasible user involvement plan. After you have experienced the capabilities of users, you are likely to propose more suitable ways for users to express themselves.

## Designers: determine how many users you need

Your needs, available time, budget, and research plan determine the amount of users that can be involved. An in-depth investigation of the needs and experiences of at least three users brings optimal results for a reasonable amount of effort. Comparison of three users can reveal common behaviours that are part of the impairment, but also highlight individual preferences and personality traits. A comparison of two users is insufficient to show the distinction between personality and impairment (see page 158). However, note that involving one user always brings more insight than involving none.

1

2

3

*Designers: be open to a change of plans*

The plan can best be seen as a proposal to be discussed with the involved users. In this dissertation, caregivers had the power to change the plan, because it was performed in their context and required their cooperation. As the plan may change anyway, do not spend too much time on perfectly defining it. Instead, involve users as early as possible, discuss the plan with them if possible, expect to be surprised and think together about appropriate ways to let users express themselves.

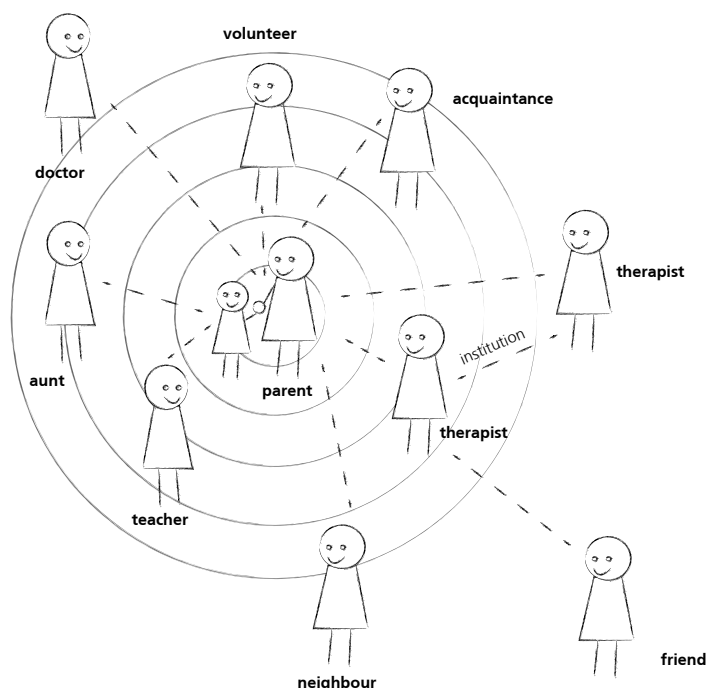
## Guideline 2: Look for people!

The second guideline involves the users that are necessary to execute the plan. Possibly, the client can provide access to users. If not, designers need to take the time and effort to find people that are willing to participate. First, they must search and find them. Next they must convince them to participate.

*Designers: search for someone who knows someone...*

Searching via connections in your social/professional network increases your chances of finding caregivers who are willing to participate. When you know (a friend who knows) a caregiver, you are more likely to be able to convince this caregiver to participate. A network of caregivers surrounds people with cognitive impairments. Try to visualize which people, institutions and organisations may be involved in this network. Most people with impairments have a support group or organisation behind them. Looking more broadly at the network of people around the users increases the chance that designers actually know someone (who knows someone who knows someone...). Be sure to get introduced to the manager of the care institution, because this gives this person initial trust in you. Moreover, the institutions and organisations in the network contain locations where people who have experience with the user group meet. They are therefore useful to help find and access people. It might even be possible to partner with such organisations, if they are interested in attaching their name to an innovative design project.





## Designers: make the first move

For a first move, face-to-face contact is usually preferred over an email or phone call. You can peek into the context, informally speak to caregivers, and take a step towards achieving consent from caregivers. First encounters give a feeling for the project, as well as ideas to improve the feasibility of the plan (see guideline 1). You might not feel up to visiting the context because they feel they do not know enough yet. But simply said, an encounter is the best means for discovery. Caregivers will understand that you do not immediately know everything at the start, but will not mind as long as you act respectfully and are interested in their work.

## Designers: Communicate your plan

The plan is useful not only for time planning, but also for convincing caregivers to participate. Caregivers may be hesitant, because their primary responsibility is towards the people they care for. Before they can make a decision they need to know the project goal, what is expected from them and the children and when, and what they might personally gain. Explain, in person, what you would like to do. Give them a written plan in addition to this. When you are absent, caregivers can read this over, give it more thought, and come up with questions or suggestions for improvement for you.

4

Caregivers: Listen to the plan

Designers communicated their plan with you. It most likely contains a project aim, time-span, and contact moments where they require input from users, so you! First, listen carefully to this plan.

5

Caregivers: provide your input

Determine if this plan sounds feasible to you. Explain to the designers how you and the people you take care of can contribute to encounters. Is there something the designer may have forgotten to add?

6

Designers: arrange consent

At a certain point designers need to ‘officially’ commit people to the project. In projects for people with cognitive impairments, caregivers decide on their behalf whether they will participate. In this delicate matter, trust and trustworthiness is important. Trust could be obtained by sharing prior experiences, or conducting your research via a well-known institution. Take small steps. When caregivers have contributed once before, they are more likely to give consent a second time, if this was a positive experience. Again, face-to-face contact has positive effects on commitment, because it is more difficult to say no to someone’s face. After compliance has been verbally agreed, arrange written consent through a permission form. This form should explain the type of data that will be collected (e.g., photo, video, audio recordings, notes) and how it will be used (e.g., internal use, presentations, internet, media). Only ask for what is really needed, because too many checkboxes can scare people off. Arrange consent as early as possible to make sure it does not inhibit the design process. Professional caregivers need to forward the request to families. In case of rejection, designers will need time to look for other users.

7

Caregivers: give consent

Participate in the project if you feel confident about the designer’s intentions. Are you authorized to give consent for the user or does someone else need to give consent? Think about what designers may gather from encounters (e.g., pictures, video recordings) and how they may utilize it (e.g., internal use only, scientific purposes, media).

## Guideline 3: Plan encounters with team members

Creative understanding is difficult to share with others. When designers work in a team, they should plan encounters together with fellow designers. This provides shared experiences, which binds the team together and makes sharing and discussing easier. This third guideline only applies when designers work in teams on a design assignment.

### Designers: support each other

Some designers in the team might have never met users with cognitive impairments before. Support each other during the encounter, because a first encounter can be exciting and unfamiliar.

### Designers: use more eyes

Often, the only way you can learn about people with cognitive impairments directly is through observation. Caregivers can assist by giving their interpretations of the users' behaviour. Since this is always your personal interpretation or that of someone else, it is helpful to compare interpretations with those of other people who were present in the encounter. Therefore, the more eyes that are observing, the better.

## Guideline 4: Take time to become familiar

This fourth guideline refers to the activity of familiarisation in the framework. It is extra important in situations where designers are unfamiliar with the users and context. This is often the case when designing for people with cognitive impairments. An unfamiliar context contains unknown objects, and people that follow different rules and have different ways of interacting. Do not underestimate the value of becoming familiar with these aspects before taking action. Only when designers feel familiar and at ease can they perform their tasks with full attention and as planned.

1

2

1

*Designers: be open to discovery*

In familiarisation, you should be receptive to new discoveries. Especially an unknown context brings many opportunities for discovery, which is in turn important for achieving empathy. It brings curiosity and willingness to learn about people. Be surprised by the people's different ways of interacting with the world around them. Be present without any clear goal in mind. Forget about your future plans for a moment and take the time to wait and see what happens next.

2

*Designers: Make yourself at home*

You may feel strange when entering a new context for the first time, but that feeling quickly vanishes. Feeling welcome has a positive effect on familiarisation. Ask the caregiver to tell you the best position to observe from, so as not to disturb them or the people they take care for. Ask for a tour of the building or permission to look around by yourself. Knowing your way around in the building helps in becoming familiar with the context.

3

*Caregivers: welcome designers*

Designers are unfamiliar in the user's environment. Explain to them when, where, and how they may act around the user. These boundaries give designers a hand-hold and certainty. This stimulates the familiarisation of designers with the context, which is important for their learning process. When designers are at ease, they are more open to learning.

## Guideline 5: Observe without letting tools stand in the way

The fifth guideline refers to the activity of observation in the framework. When they are familiar with the context, designers are more able to register their experiences and observations about users. Observation is frequently associated with cameras and notebooks, however the studies showed that they inhibit the process of empathy.

1

*Designers: immerse in the context for empathy*

Immersion in the users' context is important for enhancing empathy with users (see chapter 2). Participate in the interactions that are occurring with users, without any clear goal in mind. Forget about your planned activities. Be open-minded and aware of your own biases, beliefs and judgements. Don't focus on idea generation. Shelve or suspend ideas possible. Learn the users' basic interaction rules by being close to them.

### Designers: take home evidence

Data collection is useful in the situation that experiences and observations from the context need to be shared with others. In this case, take some time to capture observations and experiences with users - if permitted. Data collection supports memorizing, sharing with team members, and utilizing the experiences in design activities. Be aware that tools such as photo cameras, video cameras and notebooks can inhibit immersion (see study 2). When using such a tool, designers pay attention to operating it instead of interacting with people. Moreover, objects that are brought into the context might distract users. For example, in the studies some children with autism were attracted to objects such as the video camera.

### Designers: ask caregivers for explanations

In daily life, caregivers often explain to laymen about the special needs and behaviour of the users. They won't mind explaining this to designers. Use the caregivers' expertise and ask for explanations about what you observe. When preoccupied with taking care of users themselves, caregivers do not always have the full attention needed to give explanations. Play-breaks, the end of the day, or the evenings are good moments for private discussions with caregivers.

### Caregivers: inform designers

You know best what goes on in the users' mind. Make time to explain to designers the users' behaviour, needs, preferences and experiences so the designers do relevant work. Explanations on the spot are insightful, because the subject of the explanation is present. If the moment is unsuitable, talk to them in the absence of users. Designers might feel that little is possible when designing for users with cognitive impairments. At first, designers might not be sensitive enough to observe the small things that matter, or notice small steps of progress. Help designers to see this, because it motivates them in their work. If possible, test if the designers have understood what you said.

### Caregivers: be aware that you are a user

Not only the people you take care of are users. You, as caregiver, are user as well. The future design may help you in your daily life to interact with people with cognitive impairments. Make sure the designer sees what is important for you as well.

# Guideline 6: Reflect on your experiences

The sixth guideline refers to the activity of reflection in the framework. People, including designers, learn unconsciously and automatically from experiences during encounters. In reflecting, designers interpret these experiences. Reflection is about posing the right questions. Dedicate a notebook as a reflective diary for the project, in which you can write down and keep track of your thoughts and ideas.

1

## Designers: analyze in detail what you know as preparation

Before the actual encounter, analyze what you know. A mindmap can be a helpful tool to do so. It can help you to frame the right questions and bring to light what you learned from the encounter. Sometimes, the findings might seem obvious and nothing new. Next, think of what you don't know yet, and what you would like to learn from the coming encounter; e.g., about yourself, the users, or the location. Determine when you would be satisfied. Contact moments themselves can be so overwhelming that you forget what you came for. Make sure you think about this too.

2

## Designers: Reflect on what happened

During the encounter, designers can be overwhelmed by new experiences, which inhibits reflection in-action. If possible, annotate the interesting observations and experiences you want to think about later. Afterwards, designers can reflect upon their observations and experiences in their personal time. Explicate the data as much as possible. For instance, write down experiences, annotate observations, and transcribe conversations. Next, interpret the data and ask help from caregivers with this activity if needed.

3

## Designers: connect to the users' experiences

Designers should connect to the experiences of the users, in order to understand their feelings and the meaningfulness of their experiences. To do this, it is helpful to explicitly recall personal memories of experiences that relate to the observed user experiences. In this way, designers connect with users on an emotional level, which is needed for developing empathy. For instance, in the studies a foreign designer compared the children's experiences of not being able to read words to his first experiences in a Dutch supermarket. He could not make sense of many groceries either.

4

## Designers: state what you would do differently next time

The encounter brought understanding, but probably also raised new questions. Determine if the findings from the encounter are satisfying. Did they bring enough information about the users' context, empathy with the users, or inspiration for ideas? Or did they reveal missing knowledge? Designers might have performed interactions with users that did not go as fluently as they expected. Think of what you could do differently next time to improve your interactions and



Start time  
00:12:22

End time  
00:13:50

Scene of event

Project duration

with a comment!

At first hand Esther refuses to play with the toys. Suddenly she takes one toy and laughs about the sound.

Why do you find it interesting?

It was surprising for everybody that Esther for a moment took the toys. And laughter started it.

54



# Guideline 7: Build your personal theory

In learning from encounters, designers take a bottom-up approach. They collect data from the field and use this to build their own theories. In addition to experiences and observations, other sources such as documentaries, books, articles, and movies can bring insight. By searching for the relationship between findings from the research, and constructing theories based on this, designers can gain a better overview of the information. This process aids their understanding and offers inspiration for ideas.

1

## Designers: let go of the people you met

Designers make sense of the data they collected, and utilize this in design activities. Try to detach from the people you met by seeing your users as objects of your research. When designers are too emotionally involved with users, they cannot take enough of a step back to design for them.

2

## Designers: Select relevant data

Browse through your data (e.g., notes, photos, video recordings) and select the data that is relevant for the project. Selection infers elimination; isolating the most important findings from the mass of data helps to create a clear working space. People can work only with so much information.

3

## Designers: interpret data

In the process of reflection, designers interpret their experiences and observations. To do this, describe for each selected piece of data what happened. State what that implies for the user or product. If you find aspects for which you do not yet have an answer, you might consider asking a caregiver or expert for help. In the studies we developed analysis cards to support the process of theorisation. Additional sources such as literature and movies about the user group can also help in making the right interpretations.

4

## Designers: Search for similarities, relations and patterns

When a user group has a large variety in their needs and experiences, the search for similarities, relations, and patterns demands extra attention. Generalization is necessary for design activities, but similarities can be difficult to reveal. When they connect different chunks of data, designers reduce the pile of information that they have to take into account. This brings overview, and makes the data comprehensible and usable. In order to do so, first categorize the insights. What data fits in the same category, and what does not? What makes you wonder, or surprises you? Can you explain this or do you need help from caregivers or experts? Next, search for relations between the categories and patterns. Does taking a step backwards to a higher abstraction level help to explain the data?



### Designers: formulate your design vision

A personal point of view on the matter is important for the design activities that come later on. The interpretations that are coupled to the data ensure that the resulting theory is personal. State how objects should act in relation to the users, and explain why. What founding principles explain and support this?

### Designers: look for possibilities and challenges in design activities

Designers need empathy with users in order to design a product or service that fits their needs and experiences. During encounters, designers observe the limited abilities of users. This might inhibit their ability to think creatively about the problem. Try to see a problem as a challenge, and look for possibilities instead of difficulties. What objects and interactions work well with the user group? Can you utilize these principles in your design?

### Caregivers: stimulate and trust the designers' creativity

Designers are used to thinking of solutions that do not exist yet. Not knowing yet what the solution will become is what they enjoy about their job. They first investigate the current situation and identify the problem. Although it might be difficult for you to commit to something you do not yet know the outcome of, have faith. Show the solutions that you came up with for the users' and their daily challenges. That stimulates the designer's creativity. From your solutions designers can distract principles and new ideas.

## Guideline 8: Aim to fail

Designers develop ideas during and after their analysis phase. These ideas can be evaluated during encounters. For instance, designers can discuss sketches and storyboards with users, or build and explore early prototypes with them. These interactions confront designers with their presumptions about the children and caregivers. Designers experience a match or a mismatch between their expectations and the actual interaction. This contributes to creative understanding for the future product or service.

### Designers: determine how users communicate with others

Users with cognitive impairments express themselves in different ways than we are used to. Communication can take place on four levels: sensation, presentation, representation, and meta-representation (see chapter 4). Determination of the level of sense-making provides designers a helping hand in connecting to these users through interaction. Moreover, it helps designers to discover the way that users express their feelings about an interaction. Discuss this with caregivers, because they are used to interpreting the behaviour of users. Also during the encounter itself, caregivers can explain how the users feel.

## 2

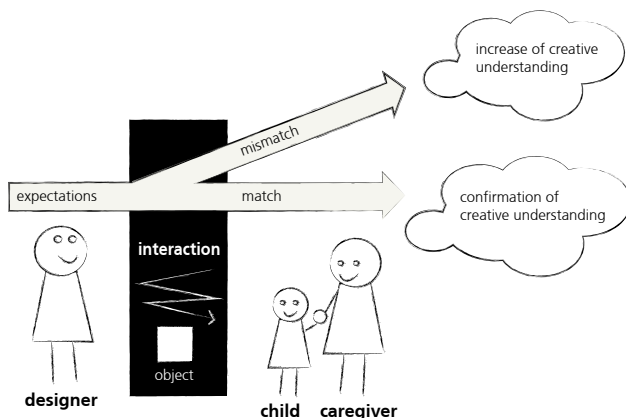
*Designers: bring objects that address multiple meanings*

Objects serve as useful tools when designers attempt to interact with users who have cognitive impairments. Objects intuitively bring out your expectations and mediate in interaction. They force you to the users' level of communication and intrigue users. Moreover, learning about how users interact with objects is relevant for you. This insight helps you to predict the user's future experiences with the new objects they are designing for them.

## 3

*Designers: admit mismatches*

The course of the interaction between designers, users, and objects brings out particular insights for you. Especially objects that address many levels of play, such as: having interesting sensory qualities, enabling relational play, and having functional and symbolic meaning, are likely to cause many mismatches (see chapter 4). Mismatches between expected and observed behaviour play an important role in learning. A match gives you confidence that you understand the users. However, a mismatch reveals something that was unknown until then. It feels uncomfortable, but teaches you what could be done differently next time. Have an open mindset and admit when mismatches are occurring. Realize that regardless of how much you know about the impairment, mismatches cannot always be prevented in interactions. Learning how to minimize, prevent or deal with mismatches brings you creative understanding.



## 4

*Caregivers: Mediate the contact with designers*

Designers have little experience in interacting with the user group. Especially in the beginning, they might feel hesitant just being around the users. Help both designers and users by mediating interactions. Give basic instructions. In this way, the designers can learn from close interactions, and users will feel more at ease around the designer.

## Guideline 9: Maintain the relationship

User involvement implies a relationship with users. This includes the caregivers who have committed to the project. Keep users content, and updated about the process. In that way, the relationship is maintained, and they can help you by delivering input in several stages of the design process.

### Designers: send updates

Update users about the progress you are making. When users are informed of the latest developments, they are able to quickly provide an answer to any questions you may have. The better users are informed, the more satisfied and co-operative they are. This stimulates their willingness to help you throughout the process.

### Designers: be clear on your demands and wishes

Most people are not aware of exactly what you do as designer. They are not used to the uncertain aspects of a design project, and might not understand what information you need. Mention explicitly what you require from users, and how you think users can best provide it.

### Caregivers: ask for and provide feedback

Designers feel that their efforts are being acknowledged if they notice that you are interested. Ask about the project status, or how your input will be used. Your interest and feedback on the designers' ideas stimulates them to inform and include you in their design process. In that way, you can ensure that designers choose the correct design direction.

### Designers: compliment and thank people for valuable input

People know that they are helping out and feel useful when they are told so. Let users know when their input is valuable and appreciated. You can explicitly tell users this, but they can also implicitly let them know that they are valued by keeping them informed of results during the project. Buy or make a little gift to thank users for their participation.

### Designers: keep your deadlines

Appointments with users are deadlines. When an encounter is planned and promised, make sure it is ready in time. Not keeping promises has a negative effect on the willingness of users to participate. Next time, they will go to less effort for you. This seems obvious and applicable to many cases, but we cannot emphasise enough the importance of maintaining a good relationship with users.

1

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3

4

5



# Acknowledgements

Writing this dissertation was possible thanks to the support of many people. I would like to say thanks to ...

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# Exhibitions

LINKX at *Made in Brunel*, exhibition at Brunel University in London (June 2008)

LINKX at *the Dutch Design Week* (November 2008)

De Klessebessers at *the Dutch Design Week* (November 2008)

LINKX at *Made in Holland*, an exposition in de Kunsthal in Rotterdam (December 2009)

PhD-research at *the Dutch Design Week* (November 2010)



**De Klessebessers at the Dutch Design Week (november 2008)**



# The author's publications

Rijn, H. van, Sleeswijk Visser, F., Stappers, P.J. (2011). *Stories at the spot: Designers learning from caregivers of children with autism*. Proceedings of IASDR 2011. Delft, The Netherlands.

Rijn, H. van, Sleeswijk Visser, F., Stappers, P. J., & Ozakar, D. A. (2011). Achieving empathy with users: the effects of different sources of information. *Codesign*, 7(2), 65-77.

Rijn, H. van, Sleeswijk Visser, F., Stappers, P.J., Ozakar, A.D., (2010). *Understanding users: A comparative study about informing designers by different sources of information*. Proceedings of the 7th International conference on Design and Emotion. Chicago, USA.

Nijhof, N., van Gemert-Pijnen, J.E.W.C., Rijn, H. van, Hoof, J. van, Seydel, E. (2010, May). *The Chitchatters: a leisure activity for people with dementia to stimulate social interaction*. Poster presented at ISG2010, Vancouver, Canada.

Rijn, H. van, Hoof, J. van, Stappers, P.J. (2010). Designing Leisure products for people with dementia: developing 'the chitcatters' game. *American Journal of Alzheimer's Disease & other dementias*, 25(1), 74-89.

Rijn, H. van, Sleeswijk Visser, F., Stappers, P.J. (2009). *Connecting through interacting: Toys that help designers learn from children with autism by playing with them*. IASDR 2009. Seoul, South Korea.

Rijn, H. van, & Stappers, P. (2008a). The puzzling life of autistic toddlers: design guidelines from the LINKX project. *Advances in Human-Computer Interaction, Special issue: Child and play*.

Rijn, H. van, & Stappers, P. J. (2008b). *Expressions of ownership: Motivating users in a co-design process*. Proceedings of the Tenth Anniversary Conference on Participatory Design 2008. Indiana University Indianapolis, IN: ACM.

Stappers, P.J., Rijn, H. van, Kistemaker, S., Hennink, A., Sleeswijk Visser, F. (2008). Designing for other people's strengths and motivations: Three cases using context, visions, and experiential prototypes. *Advanced Engineering Informatics*, 23, 174-183.

van Rijn, H., van Hoof, J., Stappers, P.J. (2008). *Designing De Klessebessers: a Leisure Game for People with Dementia*. ISG08: Smart technology for active longevity. Pisa, Italy.

Rijn, H. van, & Stappers, P. J. (2007). 'Codesigning LINKX': A case of gaining insight in a 'difficult-to-reach' user group. Proceedings of IASDR 2007. Hong Kong.

Rijn, H. van, Stappers, P.J. (2007). *Getting the shy to talk: scripts and staging for contextmapping*. Proceedings of Include 2007. London, UK.

Rijn, H. van (2007). *LINKX a language toy for autistic toddlers, developed in co-creation with parents and pedagogues*, Unpublished Master's thesis, Delft University of Technology, Delft.

Rijn, H. van, Bahk, Y.N., Stappers, P.J., Lee, K.P. (2006). Three factors for contextmapping in East Asia: Trust, control and nunchi. *CoDesign*, 2(3), 157-177.

# Valorisation



Elsevier thema **STUDEREN**  
(October 2007)



**"IK WIL HET LEVEN VAN MENSEN VERBETEREN DOOR TECHNIEK"**

Mijn ambities moeten het leven van mensen verbeteren. Voor autistische kinderen heb ik een speciale rekenaar ontwikkeld op wielen kunnen rijden. In feite het LISAQ genoemd. Het bestaat uit een klein kunstmatig jasje dat je op een speciale manier draagt. Het jasje heeft twee wielen achter en twee voor. Het jasje is gemaakt van een lichtgewicht materiaal. Het jasje is gemaakt van een lichtgewicht materiaal. Het jasje is gemaakt van een lichtgewicht materiaal.

## De vissenkom spreekt autisten toe





**DESIGN**

## Sociaal spel

Dutch Design Week toont ontwerpen die demente bejaarden weer even een vrolijk moment bezorgen

Emilie Escher

**G**rote kans dat *De Klessebessers* een rage wordt onder demente bejaarden. Het komende week op de Eindhovense Dutch Design Week gepresenteerde product valt bij de doelgroep in de smaak. De proefpersonen in een Rotterdamse dagopvang voor demente bejaarden konden er maar geen genoeg van krijgen. Er was een uur voor de presentatie uitgetrokken, maar het werden er meer.

Grote kracht van het spel, bedacht door de industrieel ontwerpers Helma van Rijn en Mariet Schreurs, is dat het direct prettige herinneringen oproept. Uit de tv, radio en telefoon (*De Klessebessers*), met opzet vormgegeven in de stijl van de jaren vijftig, komen bekende beelden en liedjes uit het verleden. Wim Sonnevelds *Op de step*, het versje *In Den Haag daar woont een graaf*, beelden van de Rotterdamse haven. Brandt er naast een Klessebesser een schemerlampje, dan is hij klaar voor gebruik. Eén druk op de knop en daar is het verleden. De ouderen bloeden ervan op.

Mooier kan design eigenlijk niet zijn. *De Klessebessers* ([www.klessebessers.nl](http://www.klessebessers.nl)) is winnaar van de door de provincie



Wie de telefoon opneemt hoort een kinderliedje



Vertrouwd serves op de cover van het tijdschrift *Nostalgiemedia*

Een van de 'Klessebessers' is een tv met Wim Sonneveld-conference

Noord-Brabant uitgelooft ontwerpwedstrijd om een product te maken voor dementerende ouderen, die nogal eens worden afgescheept met teddyberen. Er reageerden opvallend veel jonge ontwerpers, niet alleen van technische opleidingen, maar ook van de Design Academy Eindhoven.

Daar richt de steeds populairdere masteropleiding man and humanity zich op 'sociaal design' voor kwetsbare groepen als gehandicapten, artistieke kinderen en dementerenden.

De andere finalisten van de ontwerpwedstrijd, het duo Wendy van Zon en Marianne

Maas, bedachten hét cadeau voor familieleden op leeftijd. Het kwartaalblad *NOSTALGIEmedia* ([www.nostalgiemedia.nl](http://www.nostalgiemedia.nl)) doet net als *De Klessebessers* een direct appèl op de zintuigen. Wie de pagina met grootmoeders appeltaart omslaat, ruikt de geur.



Industrieel ontwerpers Helma van Rijn en Mariet Schreurs



*De Klessebessers* vallen bij de doelgroep in de smaak

# References

- Ackoff, R. L. (1989). From Data to Wisdom. *Journal of Applied Systems Analysis*, 16, 3-9.
- Amabile, T. M. (1996). *Creativity In Context: Update To The Social Psychology Of Creativity*. Boulder, CO: Westview Press.
- Asperger, H. (1944). Die 'Autistischen Psychopathen' im Kindesalter. *European Archives of Psychiatry and Clinical Neuroscience*, 117(1), 76-136.
- Bakhtin, M. (1986). *Speech Genres and Other Late Essays*. Austin, TX: University of Texas Press.
- Barakova, E., & Lourens, T. (2010). Expressing and interpreting emotional movements in social games with robots. *Personal and ubiquitous computing*, 14(5), 457-467.
- Baron-Cohen, S. (1993). From attention-goal psychology to belief-desire psychology: The development of theory of mind, and its dysfunction. In S. Baron-Cohen, H. Tager-Flusberg & D. J. Cohen (Eds.), *Understanding other minds: Perspectives from autism*. Oxford: Oxford University Press.
- Baron-Cohen, S. (1995). *Mind Blindness*. Cambridge, MA: MIT Press.
- Baron-Cohen, S. (2009). Autism: The Empathizing-Systemizing (E-S) Theory. *Annals of the New York Academy of Sciences*, 1156(1), 68-80.
- Baron-Cohen, S., & Wheelwright, S. (2004). The Empathy Quotient: An Investigation of Adults with Asperger Syndrome or High Functioning Autism, and Normal Sex Differences. *Journal of Autism and Developmental Disorders*, 34(2), 163-175.
- Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement. The concepts, methods, and practices of experience-based design*. Oxon, UK: Radcliffe Publishing Ltd.
- Battarbee, K. (2004). *Co-experience: Understanding user experiences in social interaction*. Unpublished doctoral dissertation, University of Art and Design, Helsinki, Finland.
- Beaman, A. L., Cole, M., Preston, M., Klentz, B., & Steblay, N. M. (1983). Fifteen years of the foot-in-the-door research: A meta-analysis. *Personality and Social Psychology Bulletin*, 9, 181-186.
- Berkelaer-Onnes, I. A. van (1991). Autistisch... en toch spelen. In J. Hellendoorn & I. A. van Berkelaer-Onnes (Eds.), *Speciaal spel voor speciale kinderen*. Groningen: Wolters-Noordhoff.
- Berkelaer-Onnes, I. A. van (2003). Promoting early play. *Autism*, 7(4), 415-423.
- Bird, G., & Buckley, S. (1999). Meeting the Educational Needs of Pupils with Down Syndrome in Mainstream Secondary Schools. *Down Syndrome Needs and Update*, 1(4), 159-174.
- Black, M., Freeman, B., & Montgomery, J. (1975). Systematic observation of play behavior in autistic children. *Journal of Autism and Developmental Disorders*, 5(4), 363-371.

- Bryan, L. C., & Gast, D. L. (2000). Teaching on-task and on-schedule behaviors to high-functioning children with autism via picture activity schedules. *Journal of Autism and Developmental Disorders*, 30(6), 553–567.
- Buchenau, M., & Fulton Suri, J. (2000). Experience Prototyping. *Proceedings of the 3rd conference on Designing interactive systems: processes, practices, methods, and techniques* (pp 424-433). New York: ACM.
- Buxton, B. (2007). *Sketching user experiences. Getting the design right and the right design*. San Francisco: Morgan Kaufmann.
- Charman, T., Baron-Cohen, S., Swettenham, J., Baird, G., Cox, A., & Drew, A. (2000). Testing joint attention, imitation, and play as infancy precursors to language and theory of mind. *Cognitive Development*, 15(4), 481-498.
- Clarkson, J., Coleman, R., Keates, S., & Lebbon, C. (2003). *Inclusive design. Design for the whole population*. London: Springer-Verlag.
- Cohen, D. J., & Volkmar, F. R. (1997). *Handbook of Autism and Pervasive Developmental Disorders*. Volume 2. New York: John Wiley & Sons.
- Couvreur, L. de, & Goossens, R. (2011). Design for (every)one: co-creation as a bridge between universal design and rehabilitation engineering. *Codesign*, 7(2), 107-121.
- Csikszentmihalyi, M. (1998). *Creativiteit: over 'flow', schepping en ontdekking*. Amsterdam: Boom.
- Dalen, J. G. T. van (1994). Autisme van binnenuit bekeken. *Engagement*, 21, 29-30.
- Damasio, A. (1994). *Descartes' error: emotion, reason, and the human brain*. New York: Gosset/ Putnam Press.
- Dawe, M. (2007). *Reflective design-in-use: co-designing an assistive remote communication system with individuals with cognitive disabilities and their families*. Unpublished doctoral dissertation, University of Colorado-Boulder.
- Dawson, G., Meltzoff, A., Osterling, J., Rinaldi, J., & Brown, E. (1998). Children with autism fail to orient to naturally occurring social stimuli. *Journal of Autism and Developmental Disorders*, 28(6), 479-485.
- Dawson, G., Webb, S., Schellenberg, G., Dager, S., Friedman, S., Aylward, E., et al. (2002). Defining the broader phenotype of autism: Genetic, brain, and behavioral perspectives. *Development and Psychopathology*, 14(03), 581-611.
- De Couvreur, L., & Goosens, R. (2011). Design for (every)one: Co-creation as bridge between universal design and rehabilitation engineering. *CoDesign*, 7(2), 107-121.
- Demeyer, M. K., Mann, N. A., Tilton, J. R., & Loew, L. H. (1967). Toy-play behavior and use of body by autistic and normal children as reported by mothers. *Psychological Reports*, 21(3), 975–981.
- Dr. Leo Kannerhuis (2012). *How's*. Retrieved October 26, 2012, from <http://www.autismeplein.nl/serious-games>.

- Duck, S., Ruti, D., Hurst, M., & Strejc, H. (1991). Some evident truths about conversations in everyday relationships. *Human Communication Research*, 18(2), 228-267.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, 33(4), 365-382.
- Francis, P., Balbo, S., & Firth, L. (2009). Towards co-design with users who have autism spectrum disorders. *Universal access in the information society : international journal*, 8(3), 123-135.
- Frith, U. (1989). *Autism: Explaining the Enigma*. Oxford, UK: Blackwell Publishing.
- Fulton Suri, J. (2003). Empathic design: informed and inspired by other people's experience. In I. Koskinen, K. Battarbee & T. Mattelmäki (Eds.), *Empathic design, user experience in product design* (pp. 51-57). Helsinki: IT Press.
- Gabrielli, S., Mirabella, V., Teso, M., & Catarci, T. (2005). The design of an authoring interface to make eLearning. In M. Costabile & F. Paterno (Eds.), *Human-Computer Interaction - INTERACT 2005* (Vol. 3585, pp. 1100-1103): Springer Berlin / Heidelberg.
- Gaver, W., Dunne, T., & Pacenti, E. (1999). Cultural probes. *ACM Interactions*, 6(21), 21-29.
- Gaver, W. W., Beaver, J., & Benford, S. (2003). *Designing design: Ambiguity as a resource for design*. Proceedings of the SIGCHI conference on Human factors in computing systems (pp 233-240). New York: ACM.
- Gershensfeld, N. (2007). *Fab: The Coming Revolution on Your Desktop--from Personal Computers to Personal Fabrication*. New York: Basic books.
- Gladstein, G. A. (1983). Understanding empathy: integrating counseling, developmental, and social psychology perspectives. *Journal of Counseling Psychology*, 30(4), 467-482.
- Goodwin, M. (2008). Enhancing and Accelerating the Pace of Autism Research and Treatment. *Focus on Autism and Other Developmental Disabilities*, 23(2), 125-128.
- Gould, J., Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis: girls and women on the autism spectrum. *Good Autism Practice*, 12(1), 34-41.
- Grandin, T. (1996). *Thinking in Pictures*. New York: Vintage.
- Grayling, A. C. (2003). "Epistemology" In N. Bunnin & E. P. Tsui-James (Eds.), *In The Blackwell Companion to Philosophy*. (pp. 37-60 ). Oxford, UK: Blackwell Publishing.
- Gudykunst, W., & Shapiro, R. (1996). Communication in everyday interpersonal and intergroup encounters. *International Journal of Intercultural Relations*, 20(1), 19-45.
- Haddon, M. (2004). *The curious incident of the dog in the night-time*. New York: Vintage.
- Happé, F. (1994). *Autism: An Introduction to Psychological Theory*. London: UCL Press.
- Happé, F., & Frith, U. (1996). The neuropsychology of autism. *Brain*, 119(4), 1377-1400.
- Happé, F. G. E., & Booth, R. D. L. (2008). The power of the positive: Revisiting weak coherence in autism spectrum disorders. *The Quarterly Journal of Experimental Psychology*, 61(1), 50-63.

Health Council of the Netherlands (2009). *Autism spectrum disorders: a lifetime of difference*. The Hague: Health Council of the Netherlands, 2009; publication no. 2009/09E. Retrieved May 1, 2012, from <http://www.gr.nl>

Hecht, M. (1978). Toward a conceptualization of communication satisfaction. *Quarterly Journal of Speech*, 64(1), 47-62.

Hengeveld, B. J. (2011). *Designing LinguaBytes: a tangible language learning system for non- or hardly speaking toddlers*. Unpublished doctoral dissertation, Technische Universiteit Eindhoven-Eindhoven.

Hogan, K. (1997). Nonverbal thinking, communication, imitation and play skills from a developmental perspective. Chapel Hill: North Carolina University.

Holtmann, M., Bölte, S. and Poustka, F. (2007). Autism spectrum disorders: sex differences in autistic behaviour domains and coexisting psychopathology. *Developmental Medicine & Child Neurology*, 49, 361–366.

Hornby, A.S. (Ed.). (2005). *Oxford Advanced Learner's Dictionary* (7th ed.,). Oxford: University Press.

Horvath, I. (2007). *Comparison of three methodological approaches of design research*. Proceedings of the 16th International Conference on Engineering Design (pp 361-362), Paris, France.

Hospers, J. (1990). *An Introduction to Philosophical Analysis*. London: Taylor & Francis.

Itin, C. M. (1999). Reasserting the Philosophy of Experiential Education as a Vehicle for Change in the 21st Century. . *The Journal of Experiential Education*, 22(2), 91-98.

Kanner, L. (1943). Autistic Disturbances of Affective Contact. *Nervous Child*, 2(2), 217-250.

Karthus, P. (2009). *Snapje*. Retrieved May 1, 2012, from <http://www.emotiondiary.com>

Keay-Bright, W. (2009). ReacTickles: playful interaction with information communication technologies. *International Journal of Arts and Technology*, 2(1-2), 133-151.

Klin, A. (1991). Young autistic children's listening preferences in regard to speech: A possible characterization of the symptom of social withdrawal. *Journal of Autism and Developmental Disorders*, 21(1), 29-42.

Klin, A., Jones, W., Schultz, R., & Volkmar, F. (2003). The enactive mind, or from actions to cognition: lessons from autism. *Philosophical Transactions of the Royal Society Biological Sciences*, 358(1430), 345-360.

Kolb, D. A. (1984). *Experiential Learning: experience as the source of learning and development*. New Jersey: Prentice-Hall.

Koskinen, I., Battarbee, K., & Mattelmäki, T. (2003). *Empathic Design, User experience in Product Design*. Helsinki: IT Press.

- Kouprie, M., & Sleeswijk Visser, F. (2009). A framework for empathy in design: stepping into and out of the user's life. *Journal of Engineering Design*, 20(5), 437-448.
- Lelie, C. van der (2006). The value of storyboards in the product design process. *Journal Personal and Ubiquitous Computing*, 10(2-3), 159-162.
- Leonard, D., & Rayport, J. F. (1997). Spark Innovation through Empathic Design. *Harvard Business Review*, 75(6), 102-113.
- Levinger, G. (1983). Development and change. In H. H. Kelley, E. Berscheid, A. Christensen, J. H. Harvey, T. L. Huston, G. Levinger, E. McClintock, L. A. Peplau & D. R. Peterson (Eds.), *Close relationships* (pp. 315-359). New York: W. H. Freeman and Company.
- Levinson, B. (Writer), Johnson, M. (producer) & Rich, L. (producer). (1988). *Rainman* [Motion picture]. United States: MGM/United Artists.
- Lugt, R. van der, & Sleeswijk Visser, F. (2007). *Creative workshops for interpreting and communicating rich user information*. Proceedings of the Include conference, London, UK.
- Mattelmäki, T. (2006). *Design Probes*. Unpublished doctoral dissertation, University of art and design, Helsinki, Finland.
- Mattelmäki, T., & Battarbee, K. (2002). *Empathy probes*. Proceedings of the Participation Design Conference, Malmö, Sweden.
- McCune-Nicolich, L. (1980). *Manual for Analyzing Free Play*. New Brunswick, NJ: Rutgers University Press.
- McDonagh-Philip, D., & Bruseberg, A. (2000). Using focus groups to support new product development. *Institution of Engineering Designers Journal*, 26(5), 4-9.
- McDonagh-Philip, D., & Denton, H. (1999). Using focus groups to support the designer in the evaluation of existing products: a case study. *The Design Journal*, 2(2), 20-31.
- Mead, G. H. (1934). *Mind, self and society*. Chicago, IL: University of Chicago Press.
- Millen, L., Cob, S. V. G., & Patel, H. (2011). Participatory design with children with autism. *International Journal on Disability and Human Development*, 10(4), 289-294.
- Mundy, P. (2003). Annotation: the neural basis of social impairments in autism: the role of the dorsal medial-frontal cortex and anterior cingulate system. *Journal of Child Psychology and Psychiatry*, 44(6), 793-809.
- Mundy, P., & Neal, R. (2001). Neural Plasticity, Joint Attention, and a Transactional Social-Orienting Model of Autism. In L. M. Glidden (Ed.), *International Review of Research in Mental Retardation* (Vol. 23, pp. 139-168). San Diego, CA: Academic Press.
- Nécs, P. (Writer). (2006). *Mozart and the whale* [Motion picture]. United States: Millennium Films.
- Niedderer, K. (2007). Mapping the meaning of knowledge in design research. *DesignResearchQuarterly*, 2(2), 1-13.

- Nielsen, L., & Madsen, S. (2006). *Storytelling as Method for Sharing Knowledge across IT Projects*. Proceedings of the 39th Annual Hawaii International Conference on System Sciences, (vol.8, pp 191a). Kauai, Hawaii.
- Noens, I., & Van Berckelaer-Onnes, I. A. (2002). Communicatie bij mensen met autisme en verstandelijke beperking: Van inzicht naar interventie. *Nederlands Tijdschrift voor de Zorg aan Mensen met een Verstandelijke Handicap*, 4, 212–225.
- Noens, I., & Van Berckelaer-Onnes, I. A. (2004). Making Sense in a Fragmentary World: Communication in People with Autism and Learning Disability. *Autism*, 8(2), 197-218.
- Noens, I., Van Berckelaer-Onnes, I. A., Verpoorten, R., & Van Duijn, G. (2006). The ComFor: An instrument for the indication of augmentative communication. *Journal of Intellectual Disability Research*, 50(9), 621-632.
- Norman, D. (2010). Technology first, needs last: the research-product gulf. *Interactions*, 17(2), 38-42.
- Oxendine, C., Robinson, J., & Willson, G. (2004). Experiential learning. In M. Orey (Ed.), *Emerging perspectives on learning, teaching, and technology*. Retrieved May 1, 2012, from <http://projects.coe.uga.edu/epltt/>
- Ozonoff, S. (1997). Components of executive function deficits in autism and other disorders. In J. Russel (Ed.), *Autism as an executive disorder* (pp. 179-211). Oxford: Oxford University Press.
- Pares, N., Carreras, A., Durany, J., Ferrer, J., Freixa, P., Gomez, D., et al. (2005). *Promotion of creative activity in children with severe autism through visuals in an interactive multisensory environment*. Proceedings of the 2005 conference on Interaction design and children (pp 110-116). New York: ACM.
- Pasman, G. (2003). *Designing with precedents*. Unpublished doctoral dissertation, Delft University of Technology, Delft.
- Pennington, B. F., & Ozonoff, S. (1996). Executive functions and developmental psychopathology. *Journal of Child Psychology and Psychiatry*, 37(1), 51-87.
- Piaget, J. (1952). *The Origins of Intelligence in Children*. New York: International University Press.
- Pierce, K. L., & Schreibman, L. (1994). Teaching daily living skills to children with autism in unsupervised settings through pictorial self-management. *Journal of Applied Behavior Analysis*, 27(3), 471–481.
- Piper, A. M., O'Brien, E., Morris, M.R., & Winograd, T. (2006). *SIDES: A Cooperative Tabletop Computer Game for Social Skills Development*. CSCW '06 Proceedings of the 2006 20th anniversary conference on Computer supported cooperative work (pp 1-10). New York: ACM.
- Postma, C. E., Lauche, K., & Stappers, P. J. (2009). *Dialogues: A framework for bridging the gap between people research and design*. Proceedings of Designing Pleasurable Products and Interfaces. Compiègne, France.
- Potter, C., & Whittaker, C. (2001). *Enabling Communication in Children with Autism*. London: Jessica Kingsley Publishers.

- Preece, J., Rogers, Y., & Sharp, H. (2002). *Interaction design: beyond human-computer interaction*. Chichester: John Wiley & Sons Ltd.
- Pruitt, J., & Adlin, T. (2006). *The persona lifecycle*. San Fransisco: Morgan Kaufmann Publishers.
- Raijmakers, B., Gaver, W., & Bishay, J. (2006). *Design documentaries: Inspiring design research through documentary film*. DIS '06 Proceedings of the 6th conference on Designing Interactive systems (pp 229 - 238). New York: ACM.
- Rijksoverheid. (2012). Speciaal Onderwijs. Retrieved May 1, 2012, from <http://www.rijksoverheid.nl/onderwerpen/passend-onderwijs/speciaal-onderwijs>
- Rijn, H. van (2007). *LINKX a language toy for autistic toddlers, developed in co-creation with parents and pedagogues*, Unpublished Master's thesis, Delft University of Technology, Delft.
- Rijn, H. van, & Schreurs, M. S. (2007). *De Klessebessers*. Retrieved May 1, 2012, from <http://www.klessebessers.nl>
- Rijn, H. van, Sleswijk Visser, F., Stappers, P. J., & Ozakar, D. A. (2011). Achieving empathy with users: the effects of different sources of information. *Codesign*, 7(2), 65-77.
- Rijn, H. van, & Stappers, P. J. (2007). 'Codesigning LINKX': A case of gaining insight in a 'difficult-to-reach' user group. Proceedings of IASDR'07. Hong Kong.
- Rijn, H. van, & Stappers, P. (2008a). The puzzling life of autistic toddlers: design guidelines from the LINKX project. *Advances in Human-Computer Interaction, Special issue: Child and play*.
- Rijn, H. van, & Stappers, P. J. (2008b). *Expressions of ownership: Motivating users in a co-design process*. Proceedings of the Tenth Anniversary Conference on Participatory Design 2008. Indiana University Indianapolis, IN: ACM.
- Robins, B., Dautenhahn, K., Boekhorst, T., & Billard, A. (2005). Robotic assistants in therapy and education of children with autism: can a small humanoid robot help encourage social interaction skills?, *Universal Access in the Information Society*, 4(2), 105-120.
- Roeyers, H. (1997). Subclassification of Children with a Pervasive Developmental Disorder: Assignment to Social Subtypes. *Journal of Developmental and Physical Disabilities*, 9(4), 347-357.
- Roeyers, H. (2008). *Autisme: alles op een rijtje*. Leuven: Acco uitgeverij.
- Rogers, C. R., & Dawson, G. (2010). *Early Start Denver Model for Young Children with Autism: Promoting Language, Learning, and Engagement*. New York: The Guilford Press.
- Rogers, S. (1999). An examination of the imitation deficit in autism. In J. Nadel & G. Butterworth (Eds.), *Imitation in infancy: Cambridge studies in cognitive perceptual development* (pp. 254-283). New York: Cambridge University Press.
- Rozenburg, N. F. M., & Eekels, J. (1995). *Product Design, Fundamentals and Methods*. Chichester: John Wiley & Sons Ltd.
- Sanders, E. B.-N. (2001). *Virtuoses of the Experience Domain*. Proceedings of the 2001 IDSA Education Conference. Boston, MA, USA.



- Sanders, E. B.-N., & Dandavate, U. (1999). *Design for experiencing: new tools*. Proceedings of The First International Conference on Design and Emotion. Delft, The Netherlands.
- Sanders, E. B.-N., & Stappers, P. J. (2012). *Convivial Toolbox: Generative research for the front end of design*. Amsterdam: BIS.
- Schon, D. A. (1983). *The Reflective Practitioner*. New York: Basic Books.
- Scott, M. O. (Writer). (2009). *The horse boy* [motion picture]. United States: Zeitgeist Films.
- Seach, D. (2007). *Interactive Play for Children with Autism*. Abingdon: Routledge.
- Sleeswijk Visser, F. (2009). *Bringing the everyday life of people into design*. Unpublished doctoral dissertation, Delft University of Technology, Delft.
- Sleeswijk Visser, F., Stappers, P. J., van der Lugt, R., & Sanders, E.-N. (2005). Contextmapping: experiences from practice. *CoDesign*, 1(2), 119-149.
- TED. (2010). Temple Grandin: The world needs all kinds of minds. Retrieved February 2, 2012, from [http://www.ted.com/talks/temple\\_grandin\\_the\\_world\\_needs\\_all\\_kinds\\_of\\_minds.html](http://www.ted.com/talks/temple_grandin_the_world_needs_all_kinds_of_minds.html)
- Thieme, J.C., & van Boeijen, A. G. C. (2011). Some students are more different than others. *Journal of Design Research* 2011, 9(2), 119-130.
- Ungerer, J. M., & Sigman, M. (1981). Symbolic Play and Language Comprehension in Autistic Children. *Journal of the American Academy of Child Psychiatry*, 20(3), 7-14.
- Veldhuizen, H. G. (2008). *Market intelligence for product intelligence*. Unpublished doctoral dissertation, Delft University of Technology, Delft.
- Verpoorten, R. A. W. (1996). Communicatie met verstandelijk gehandicapte autisten: Een multidimensioneel model. *Nederlands Tijdschrift voor Zorg aan Verstandelijk Gehandicapten*, 22, 106-120.
- Velt-Simon Thomas, J.M. in 't, & Mol, A.J.J. (2005). Normaal tot hoogbegaafde vrouwen met een autismespectrumstoornis: Niet begrepen? Niet herkend! *WTA*, 3, 104-112.
- Volkmar, F. R., Lord, C., Bailey, A., Schultz, R. T., & Klin, A. (2004). Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry*, 45(1), 135-170.
- Vollens, M., & De Pauw, F. (2011). *Thea*. Retrieved April 4, 2011, from <http://www.theaschommelt.be>.
- Waag Society (2012). *Bodyguard*. Retrieved October 26, 2012, from <http://waag.org/nl/project/bodyguard>.
- Wallas. G. (1926). *The art of thought*. New York: Harcourt Brace.
- Warren, W. H., Jr., & Shaw, R. (1985). *Events and Encounters as Units of Analysis for Ecological Psychology*. Paper presented at the Persistence and Change: Proceedings of the First International Conference on Event Perception (pp. 1-27). Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.
- Werner, H., & Kaplan, B. (1963). *Symbol Formation: An Organismic-Developmental Approach to*

*Language and Expression of Thought*. New York: John Wiley & Sons.

Wing, L. (1988). The continuum of autistic characteristics. In E. Schopler & G. B. Mesibov (Eds.), *Diagnosis and Assessment in Autism* (pp. 91-110). New York: Plenum Press.

Wing, L. (1997). The autistic spectrum. *Lancet*, 350, 1761-1766.

Wing, L. (2001). *The Autistic Spectrum: A Parents' Guide to Understanding and Helping Your Child*. Berkely, CA: Ulysses Press.

Wing, L. (2006). *What's so special about autism?* London: National Autistic Society.

Wing, L., Gould, J., Yeates, S., & Brierly, L. (1977). Symbolic play in severely mentally retarded and in autistic children. *Journal of child psychology and psychiatry*, 18(2), 167-178.

Wright, P., & McCarthy, J. (2005). The value of the novel in designing for experience. In A. Pirhonen, P. Saariluoma, H. Isomäki & C. Roast (Eds.), *Future Interaction Design* (pp. 9-30). London: Springer-Verlag.

Wright, P., McCarthy, J., & Meekison, L. (2003). Making sense of experience. In M. A. Blythe, A. F. Monk, K. Overbeeke & P. C. Wright (Eds.), *Funology* (pp. 43-53). Norwell, MA, USA: Kluwer Academic Publishers.

Yanagisawa, H., Kozuka, Y., Matsunaga, M., & Murakami, T. (2009). *Observation support system for recording, reviewing and sharing observed design problems*. Proceedings of IASDR'09. Seoul, South Korea.

# About the author

Helma van Rijn was born on the 18th of April, 1982 in Delft, The Netherlands. She studied Industrial Design Engineering at Delft University of Technology. During her master Design for Interaction, she obtained her propaedeutics in psychology at Leiden University. In 2007 she graduated with honors on an interactive language learning toy for children with autism. With this work, she was awarded as best graduate of Delft University of Technology 2006-2007 by rector magnificus prof. dr. ir. Jacob Fokkema.

Helma is a designer and a researcher. During her PhD research at the ID-StudioLab of the Delft University of Technology she designed and developed 'de Klessebessers' for people with dementia. This design won the first prize in design competition 'Vergeethenniet'. Currently, two nursing homes in the Netherlands utilize de Klessebessers to provide leisure to their clients.

Helma's research interests are in developing tools and techniques to optimize the design process for user-centred design. She continues her work as user researcher at a user research consultancy company in Rotterdam.

Helma lives in Delft with her boyfriend, who is an interaction designer, and her one-and-a-half year old son.

