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STORIES AT THE SPOT

DESIGNERS LEARNING FROM CAREGIVERS OF CHILDREN WITH AUTISM

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ABSTRACT

Designers need insight into the needs and experiences of the people they are designing for. However, when these people are very different from the designer, it can be challenging for him or her to get an understanding of them. In this paper, designers learned about the needs and experiences of children with autism for their design project by means of direct contact with these children, and their caregivers. In this direct contact, designers and caregivers jointly used an observation tool called 'Tick & Watch'. This tool is especially developed to support and stimulate designers and caregivers in remembering and discussing learning moments from direct contact with children with autism. This paper discusses how this tool optimizes the interaction between designers and caregivers in user observations.

Keywords: empathic design, design tools, Autism Spectrum Disorder (ASD)



Figure 1: A designer and caregiver using Tick & Watch while observing children with autism.

INTRODUCTION

For designers it is important to have insight into the needs and experiences of the people they are designing for in order to design and develop products fitting this user group (Koskinen et al., 2003). Common ways for designers to learn about users are for example observational studies and interviews.

However, children with autism are often unable to communicate or process information. Therefore, designers cannot use language to communicate with them. Directly, they can learn from and about them through observing and/or interacting with children (e.g., van Rijn et al., 2009). Indirectly, designers can learn about them through involving their caregivers (e.g., Cohene et al., 2005, van Rijn and Stappers, 2007). For example, a caregiver, such as teacher, therapist, or parent, can tell a designer stories about the child, explain why he or she is behaving in a certain way, or how he or she is feeling at that moment.

In this paper, designers learned about children with autism for their design project by means of direct contact with these children and their caregivers. In their first contact, designers and caregivers used an observation tool called 'Tick & Watch'. This paper discusses the role of this tool in structuring user observation and bringing out learning points. Special attention goes to the multiple roles that caregivers play during the designers' learning process.

LEARNING ABOUT CHILDREN WITH AUTISM

Autism Spectrum Disorder (ASD) is an inborn developmental disorder that affects around 1% of all people. Much variation exists between children with ASD, and even within one child the diagnosis can change over time. Affected children may display a range of disabilities at many levels, such as impairment in social interaction, communication, and imagination (Wing, 1997). Although the official term is Autism Spectrum Disorder, we refer to autism for short in this paper.

There is a variety of sources available for designers to inform them about user groups, ranging from: reading literature, books and blogs, watching documentaries and movies, involving users in focus groups, consulting experts, conducting observational studies, working intensively with users in everyday situations, to involving them in generative or even co-design sessions (e.g., Sleeswijk Visser & Visser, 2005). Moreover, design outcomes (van Rijn & Stappers, 2007) and guidelines of others (e.g., Dautenhahn, 2000, van Rijn & Stappers, 2008) can inform and inspire designers about the user group. In our experience, guidelines do not inform sufficiently, even though they are developed for designers. Even though designers are not trained as user researchers (Bruseberg & McDonagh-Philip, 2002), we believe designers need direct contact with users. Along with several other authors (e.g., Fulton Suri, 2003; Kouprie & Visser, 2009; Mattelmäki et al., 2002; McDonagh-Philip & Bruseberg, 2000), we believe that if designers see the world of users with their own eyes, they gain an understanding, which cannot be retrieved from other information sources. Experiencing or simulating this world is almost impossible, but a glimpse into their context and behaviour through direct contact supports designers to get a feel for them.

The designers in this project used various sources to learn about children with autism. This paper focuses on the designers' observational studies, and especially the caregivers' involvement in these studies.

THE ROLES OF CAREGIVERS IN AND AFTER OBSERVATIONS

Children with autism are unable to communicate or process information by themselves. Therefore it is appropriate to involve people who are familiar with this user group (Lazar et al., 2009). Caregivers, such as parents, teachers, and therapists, deal with these children on a daily basis and can serve as information source for design (van Rijn & Stappers, 2007; Cohene et al., 2005). At start, we distinguished five roles for caregivers in a design project. In the project, we investigated how we can support these particular roles better.

Caregiver as enabler

Children with autism are dependant on their caregivers. Caregivers enable these children in their daily life. They are needed to support the children in activities, such as playing and eating lunch, and structure these activities for them.

Caregiver as mediator

Designers often have no prior experience in interacting with children with autism. Caregivers can mediate direct contact between designers and these children. They are experienced in interacting and communicating with the children. Caregivers are able to point out particular behaviour, or conduct activities with the child, which designers 'should know about'.

Caregiver as informant

Many young children with autism are unable to communicate or speak in language. Instead of them, caregivers can inform designers about the experiential world of the children. They can explain the children's behaviour and answer questions designers have about them. They can interpret these behaviours for designers and place them in a wider frame. Later in the process, caregivers can evaluate suggestions, ideas, and concept designs of designers.

Caregiver as user

Eventually, caregivers use the product the designer develops for the children. Continuously, they take care of the children. Therefore, they are near when the child uses the product, and most likely use the product too. They typically prepare, control, oversee, or support the children's interaction with the product.

Caregiver as co-designer

Caregivers can co-design the product the designer develops for the children. They have knowledge of the situation, and possibly use the eventual product. Therefore, caregivers may play a role in co-creation methods, and come up with (parts of) solutions themselves.

TICK & WATCH: A TOOL TO STRUCTURE OBSERVATION AND DISCUSSION

These different roles play an important part in the learning process of designers in observational studies. They define how caregivers can support the learning process of designers. A tool was developed to optimize the interaction between designers and caregivers during observational studies. This tool had to fit in (and not disturb) these roles and responsibilities of the caregivers. On the other hand, it also had to fit the needs of the designers. Designers had limited time to meet the children. In addition, observing the children and possible interactions with them can be overwhelming for designers, especially during the first encounters. This led to the following criteria:

- The tool should support designers and caregivers in remembering observed and/or experienced learning moments, containing particular or interesting behaviour of the children.
- The tool should make the designer feel confident in the observation.
- The tool should not disturb children and caregivers in everyday activities.
- The tool should enhance a dialogue between designers and caregivers about learning moments.
- The tool should enable designers to recall learning moments throughout the design process for understanding and ideation.

THE OBSERVATION TOOL: TICK & WATCH

Based on the criteria above, we developed 'Tick & Watch', a tool to help designers in their first observational study of children with autism. It consists of a video camera by 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.

OBSERVATION: REMEMBER THE TICKS

Each designer or caregiver wears a tick-watch around his or her wrist (see figure 2). This watch consists of a button mounted on a wristwatch base. When this button was clicked, a small light on the watch flashes and the laptop registers the moment and ID of the watch. In this way, each designer or caregiver can 'tick' a moment whenever they think they see something of interest. For example, a moment on which a designer does not understand what



Figure 2: Three designers and a teacher wear a tick-watch during a two-hour observation in the classroom.

happened or a teacher has something to explain to the designers, while impossible due to her teaching responsibilities. Annotation cards accompany the watch to support designers in writing down their reason for a 'tick'. Caregivers did not receive annotation cards, as we expected that to interfere too much with their multiple roles described earlier.

DIALOGUE: DISCUSS YOUR TICKS

Immediately after the observation, the video recording can be reviewed on the laptop as depicted in figure 3. Software visualizes the 'ticks' of designers and caregivers on a timeline of markers. By clicking on a tick, the designers and caregivers can look back at the video recording of that moment and discuss what happened.

DESIGN: USE YOUR TICKS

Any time during the process, designers can watch their ticks again.



Figure 3: Three designers and one teacher discuss their ticks together with the Tick & Watch software.

THE PROJECT: "INFORMED BY CAREGIVERS"

In a design project, we evaluated how Tick & Watch structures the interaction between designers and caregivers in observational studies and supports caregivers in the earlier described roles. The project was offered as an elective course to first year M.Sc. design students. As result, nine design students chose to participate in the project. In this paper, we refer to them as 'designers'. These nine designers were divided into three teams. Each team of three designers was linked to one specific class of four to six children, and asked to design a product for them. In total, eleven children with autism participated. They all go to a school for children with communication disorders. In each class were two or more children diagnosed with autism. These children varied in diagnosis, intelligence, and speaking abilities. Their parents, teacher, and therapist, gave permission for cooperation. Two teachers and one therapist were involved. None of the designers had prior knowledge about autism. They were challenged to learn about these children through direct contact with the children and their teacher (phase 1), and later design a product for these children (phase 2). An overview of the whole project is given in figure 4.

Designers kept track of their gained insight in three ways: individually, with their team members, and in plenary class meetings. Individually, they wrote insights in a notebook that served as a reflective diary. As team, they told their expectations and first reactions into the camera right before and after each visit as a video diary. Plenary, they discussed their insights in class meetings. These three different ways of reflecting are illustrated as square boxes in figure 4. The yellow line shows how these reflection moments were scheduled in time.

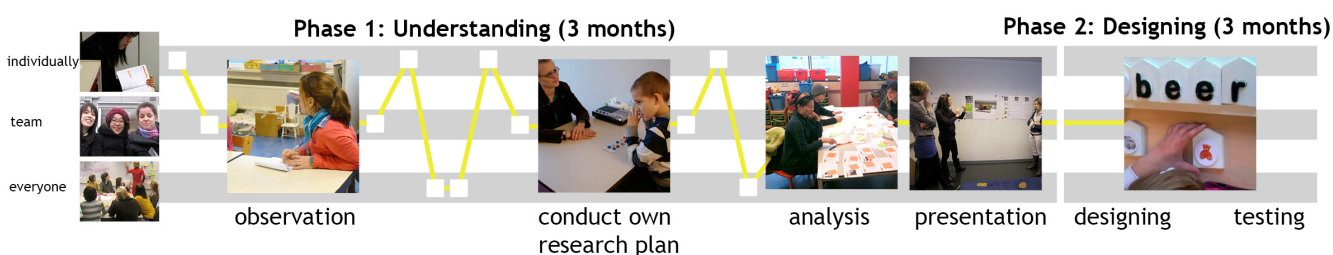


Figure 4: Overview of the design process combined with three ways of reflecting.

PHASE 1: LEARNING ABOUT CHILDREN WITH AUTISM

First, each design team visited their group of children at school to get acquainted with the children and their environment. They could learn about the children and how to interact with them. During this visit, a caregiver (teacher or therapist) and a team of three designers were instructed to observe the children with Tick & Watch. Later, the team visited their group of children more times to gather information for their design assignment. At forehand, they made their own research plan for their following visits. Next, they analysed their data (e.g., observation videos, photos, probes from parents, or interviews with teachers and therapists). Finally, they presented their insights as starting point for the design phase to the other design teams, the course organisers and a researcher on the subject of autism. This researcher gave feedback on their presentations and answered their questions about autism.

PHASE 2: DESIGNING FOR CHILDREN WITH AUTISM

The three teams used the knowledge gained in the first phase for their design project for children with autism. Together, each team designed a product concept, built an experiential prototype of this concept, and tested this prototype with children. The children's reactions were evaluated with the caregiver and used to improve the concept.

EVALUATION OF TICK & WATCH

PROCEDURE

The researchers were present at the school while the designers used the observation tool. After the project, the authors conducted semi-structured interviews with the nine designers about their design process. As preparation, the designers were asked to complete a sheet with open questions about their process, including questions about involving caregivers and the use of Tick & Watch. The answers on these questions were the basis of the interview. The authors transcribed and analysed the interviews. The outcomes are presented in the section below.

DESIGNERS USING TICK & WATCH

The three teams and caregivers used Tick & Watch as instructed during the observation. In the discussion

afterwards, only one team used the tool as instructed. The other two teams deviated from the initial setup. One teacher had only fifteen minutes to discuss with the designers after the observation. Even though the software was running in front of them, they did not use this during their discussion with the teacher. The other team used the video in the discussion, but did not use the provided software. Some ticks were not presented correctly. Therefore, they watched the video in another application. The teacher did not like to work like this. Below, we will provide more details about how the different parts of the tool were used.

Observation: Remember the ticks

Using the ticker-watches during the observation was helpful according to the designers. A 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."* Two designers mentioned that wearing the ticker-watch made them more conscious and focused on the observation. 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."*

The designers and teachers received cards to annotate their ticks. These cards were too much to carry around during the observation. They prefer 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 special annotation cards."*

Dialogue: Discuss your ticks

Tick & Watch prescribed the designers and teachers to discuss learning moments immediately after the observation. Two teams discussed for about an hour, while one team only had fifteen minutes. Both designers as teachers considered this discussion very useful. For the first time in their life, the designers encountered children with autism. The deviant

behaviour of the children raised questions in the designers' minds, 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."* For another designer, the watch served as an icebreaker with the teacher. It made the designer feel at ease. The designers also mentioned that the amount of ticks show the importance of a bit of video. The teachers expressed the value of the discussion afterwards, although they mention the discussion is very time-consuming. 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"*.

Each team used the software differently during the discussion. The team that only had fifteen minutes to discuss with the caregiver did not use the software at all. One team used the software as intended. For them it was helpful. The third team watched bits of the movie, without using the software. The teacher did not like to use it and therefore they did not.

Design: Use your ticks

Three out of nine designers used the software at home to watch the moments again for analysis purposes. Interestingly, this was depending on the designer's personal preferences. From one team, two designers installed it, from another team one. And in the third team no designer installed it, because none saw the benefits. Moreover, it takes some time. The ones that installed the software found it useful to look back at the moments. Watching the whole movie is a lot, and with the software most important moments were quickly selected. 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 did not consider this helpful, 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". He would find it helpful if he could add and remove ticks later, so that the tool could grow along during his process. So, annotations were taken along in the process.

DISCUSSIONS: CAREGIVERS USING THE TOOL IN DIFFERENT ROLES

Tick & Watch supported designers in feeling at ease and focused during the observation. It made the observation efficient, and most importantly, forced the discussion with caregivers afterwards. It structured their visit. Earlier, we described five roles that caregivers take on during their involvement in a design project: (1) enabler, (2) mediator, (3) informant, (4) user, and (5) co-designer. These roles had consequences for designers in using Tick & Watch during their interaction with caregivers.

Caregiver as enabler

Most importantly, the therapist and two teachers are caregivers. The children are depending on them. Their work is to make sure the children feel safe, learn new skills, and get their full attention. Therefore, we learned caregivers stay in their role of 'enabler' during an observation.

The caregivers used a ticker-watch. After the project, they explained they had difficulties focusing on the designer's information need while dealing with the children. The amount of ticks made by the teachers during the observation supports this statement. The tool was developed to help caregivers in switching from 'enabler' to 'informant', but this appeared to be difficult for them.

Caregiver as mediator

As expected, the caregivers mediated direct contact between designers and the children, because designers are inexperienced in this. The teachers often used sign language to communicate with the children, but designers were not able to. A designer explained: *"The first two visits, we didn't know how to approach the children. But the fact that the teacher was in the room, made me more comfortable. When something goes wrong, the teacher controls this. We can try, but maybe that is not allowed or not good for them. We are just*

designers, involved for six months, and cannot do that. We are no teacher". Later in the process, the teachers tested prototypes with the children, and mediated in that way for the designers. While using the ticker-watch, caregivers mediated between the designers and children, depending on the activity. During play, the designers interacted with the children from time to time, already in their first visit. The teacher helped the designers in this. During activities such as lessons, designers took on a more passive observation style. The ticker-watches were mobile and thereby supporting caregivers in their mediating role during interactions. For the designers, it was sometimes difficult to keep the camera focused on something, because during free play the children walk easily outside the frame.

Caregiver as informant

The caregivers informed the designers about the needs and experiences of the children, and themselves. They are used to explain others about autism. They explained the deviant behaviour of the children and understood well which information was necessary for the designers, because the eventual product needs to support their educational sessions with the children. A designer said: *"Most valuable is that teachers can tell you what happened. You can interpret something completely different yourself"*. Caregivers' explanations bring the designers empathy for children with autism. Even though the caregivers were unable to focus on using the ticker-watch while teaching, the designers did while observing them teaching the children. For the first time in their life, the designers encountered children with autism. The deviant behaviour of the children raised questions in the designers' minds. Tick & Watch enabled designers to remember these questions for the discussion afterwards with the teacher. The teacher could not answer these at the spot due to teaching responsibilities.

Caregiver as user

The designers considered the caregivers as users of their product too. Discussions with caregivers made designers aware of their needs and preferences. In each eventual product concept, the teacher or therapist has a role in preparing, supporting, using or finishing the game.

Caregiver as co-designer

Finally, the caregivers could co-design by developing (parts of) ideas and concepts as input for design team. In this project, teachers helped the designers in taking design decisions. They served as a judge, who said whether an idea or direction was good or not. One designer mentioned the teacher's input limited their creativity. According to this designer, the teacher was only thinking in current solutions. However, the others valued the teacher's input. They provided information (as informants), which the designers translated to a concept design.

FURTHER DEVELOPMENTS

From using the observation tool in this project, we learned that both designers as caregivers value the dialogue about the children. However, the tool was too demanding to use for caregivers during teaching. Caregivers appreciate a 'normal' conversation afterwards over spending time on technology, although they enjoyed explaining the video fragments to designers.

In their daily work, teachers are used to work with technology. For example, the teachers in this project had a computer in their classroom and used a digital video and/or photo camera. They often use videos and photos to communicate with the children. Moreover, they make pictures every day to show to parents what the child does and learns during the day. Therefore, using the proposed solution was not that far from the teachers' current practise. The main problem was that the tool asked them too much to step out of the 'enabler' role, which was impossible during teaching. Caregivers are capable of dealing with technology, as long as it does not disturb or keeps them away from their responsibilities for the children.

CONCLUSIONS

In this paper we presented Tick & Watch, a tool especially developed to optimize the interaction between designers and caregivers during observational studies. Results show that Tick & Watch forced a dialogue between designers and caregivers after the observation. Especially the designers considered this dialogue as valuable. Moreover, Tick & Watch structured the visit for

designers, who are not trained as observers. This made the designers feel at ease and focused during the observation and the observation itself more efficient. Caregivers had difficulties with using the tool while taking care of the children. We learned that tools and techniques for learning from direct contact should be offered in a solution close to the caregivers' current practises, fitting the roles they need to fulfil at that moment. In further studies, we want to research how to support designers in learning from direct with children with autism and their caregivers.

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