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Trans-Create - Co-Design with Persons with Severe Disabilities

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Abstract. Technology has potential for improving the lives of persons with severe disabilities. But it's a challenge to create technology that improves lives from a person's own perspective. Co-design methods have therefore been used in the design of Assistive Technology, to include users in the design process. But it's a challenge to ensure the quality of participation with persons with significantly different prerequisites for communication than ourselves. It's hard to know if what we design is good for them in the way they themselves define it, in a communication situation, which has to be significantly different than traditional co-design. In this paper, we present a new approach to co-design with persons with severe disabilities. We call this process "trans-create", based on the creative translation we use when translating between cultures. We found that by using familiar artifacts that could be added and removed in the co-design process, we had a language for communication. By adding a personalisable digital layer to the artifacts, we could adapt, scale and redesign both tangible, visual and sound qualities in the situation dynamically. For example, by making it possible for the user to choose and activate a pink music cover card (RFID) that turns the lighting of the entire room pink and changes the music. This implies changing the distinction between designer and user, between the design process and the use process, and the view of what we create during a co-design process. That is why we have chosen to call this process "trans-create", instead of co-create, what we create for "living works", instead of design, a hybridisation between design and use, process and result.

Keywords. co-design, co-create, trans-create, assistive technology, children with special needs, severe disability

1. Introduction – Co-Designing Health Promoting Assistive Technology

Technology has great potential for improving the lives of persons with special needs, persons with different abilities on many levels. "Assistive Technology" intends to enable persons to live healthy, productive, independent, and dignified lives, and to participate in education, the labour market and civic life[1]. But it's a challenge to create technology that really improves persons' lives from their own perspectives. Participatory and co-design methods have therefore been increasingly used in the design of health and Assistive Technology to improve the design by including the user in the design process.

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However, it is difficult to stage a fruitful participation situation. Both because it is difficult to understand each other, and communicate the goal and program for the actual co-design session, with persons with very different lifeworlds and abilities then ourselves. It is hard to ensure that the design actually gets the qualities that the persons want[2]. It is therefore important to develop methods and techniques that include the persons with disabilities into the design process. To become empowered creators of their own situation and lifeworld, instead of passive and frustrated receivers of technology, created by others based on their assumptions, prejudice and will, which most often is the case. There is a risk that the Assistive Technology is abandoned, due to the lack of quality and ownership, when users don't have a say in the design process[3].

Co-design setups and tools such as Post-it notes, pen and paper to brainstorm words, make simple idea-sketches and maps on paper, are not usable for children with severe disabilities, because it is not sufficiently motivating for the children, and they don't understand the goal and process. Not because they don't want to affect and create their lifeworld. The tools and programs are simply not suitable to communicate and inspire the co-design session to happen and develop. We need a more suitable language and situation to succeed in co-designing with children with severe disabilities. In line with the 7 Universal Design principles[4] we co-design situations that are more simple, intuitive and perceptible for the user to understand[3,4]. More flexible and equitable in use[1,2], and more tolerant for detours and other paths because the emotions and focus level can change fast[5]. And a space that is designed and[6,7] with things and tools suitable to structure the co-design sessions. This paper is our contribution to this challenge.

The paper is structured as follows: First, in the "Framework" section, we present our background, framework and relevant perspectives from others' work. Then we present the methods we have used and the background and setup for research. In the "Research" section we further present our findings and discussion. Lastly, we conclude with our view on the value of our contribution.

2. Framework – Co-Design and Universal Design

2.1. Participatory Design in Time

Participatory Design (PD) includes theories, practices and studies involving end-users as participants in designing products and services, both computer-based activities and other[5]. PD came out of the 1960-1970ies democratic reaction against dominant management approaches[6-9]. The Human-Computer Interaction (HCI) field first built their understanding of how users think and use technology on functionalistic and cognitive models[10-12]. With more awareness of interaction in different situations as processes of situated cognition[12], HCI moved away from closed-off usability labs. HCI opened up for enquiries made where people worked and lived[13] and on actions for solving social problems[14].

2.2. From Participatory Design to Co-Design

Core principles in Participatory Design is 1. "Have a say" as a right to voice your opinion, 2. "Mutual learning", a two-way communication between co-equal participants, and 3. "Co-realization", where participants are able to make and co-design things, giving

practice presence in the world[15,16]. PD therefore seeks a balance between the participants practice-based, tacit knowledge and an academic more abstract and analytical knowledge[8]. The artifact is viewed as a mediated form of knowledge, residing in the co-construction of the artifact[17].

PD is a broad term, balancing processes of academic analysis and practical making. Co-design concentrates on methods for engaging users in making.

2.3. Co-Design with Children

Instead of seeing children as passive participants in a common culture among adults, it is recognised that children have their own child cultures with the right and need to be understood[18,19]. Researchers in the Child Computer Interaction community (CCI) address the unequal power relationships between children and adults, as the reason why children's participation in the design processes is limited. The group dynamics are challenging, as children are physically and cognitively different from adults and often without power[13,20]. One main issue is that the CCI community "...lacks robust methods to integrate visual and tangible dimensions of co-design artifacts, and their verbal explanations into a coherent analysis"[7]. The lack of methods integrating different sensorial and tangible dimensions, in combination with unequal power relations between child and adult, limits the possibilities for participation[13].

2.4. Co-Design with Children with Special Needs

The lack of sensorial and tangible dimensions for children is even more limiting in co-design with and for children with special needs, such as physical, cognitive, verbal, social needs. It is destructive since children, due to their special needs, often are left out of the traditional decision-making processes[21]. The designer/researcher therefore has tried to adapt and change the process, materials and tools, towards using fictional characters, narratives, competitive strategies and rich sensory qualities to inspire participation in co-designing[21-23].

PD-researchers have tried out particular methods to strengthen an individual child's personal abilities to build up confidence and select activities that makes the child able to participate[23]. With the familiar object one can give the child with disabilities expectations based on their experience with the object, which may help balance between the need for flexibility and structure in the co-design session[24]. On the topic of collaboration some researchers have tried to mix children with and without disabilities in the co-design activities, or sequentially let children without disabilities co-design for the children with disabilities[22].

2.4.1. Tools

There are a wide variety of tools within co-design, in the form of games, hands-on building blocks, mockup and prototyping techniques. Further, there are more abstract design method tool kits for concept development. The rationale behind these tools is the belief that it is necessary to give structure and scaffold childrens' creative abilities. Over the years designers have developed collaborative Design Thinking processes in order to simplify and facilitate creating choices and making choices for persons with layman expertise and children[7]. For children with and without special needs the ideal of

openness, with possibilities to redesign the tools[25], can sometimes in practice limit the ability for those groups to participate[13].

2.5. Cultural Probing

Cultural probes are artifacts, such as kits of things and tools that designers and researchers hand out to people to inspire ideas and gather data about how people pursue and engage in explorative design, based on their values and thoughts. A goal is to understand local cultures, inviting emotional and ambiguous responses of the use of the probes to gather ideas[26]. Another goal is to lead the local groups towards unexpected ideas without dominating them.

2.6. Lacks and Challenges

Participatory Design and co-design are not automatically adaptable for people with disabilities, since it requires a verbal language and a higher degree of idea and concept understanding. A naive and unquestioned faith and focus on verbal communication[7], can end up with environments that exclude several groups, persons with disabilities and children from participating in the design process. There is a lack of knowledge about tactile and multi-sensory media, and of how they can be used in communication and co-creation with children with disabilities. Further there are little knowledge about the possibilities technology and software (IoT, AI) offer to co-design processes for this group. The existing co-design tools such as cultural probing[26], toolkits, collaborative Design Thinking, co-design methods and dynamically challenging group processes, are poorly adapted for persons with special needs.

We therefore need another way of communicating and creating together, suitable for their strengths, needs and abilities.

2.7. Our Ambition

In exploring how other researchers have utilized co-design methods in design of technologies for children with special needs, we think the field lacks knowledge about persons with severe disabilities and their lifeworlds. It lacks knowledge about what it demands of the environments, resources, communication and relations to people around them. For instance, we cannot speak directly in verbal language with many of the children we have met and co-designed with. Some can use rudimentary sign language, others have sensory disorders and complex and multiple diagnoses, such as movement disorders like cerebral palsy, autistic spectrum disorders and multi-functional disabilities. It was therefore our ambition, research question how to develop ways to co-design with persons with severe disabilities. Therefore, we had to find complex and multi-layered languages to communicate, that altered the conditions for the design process. In contrast with earlier research on co-design with children without disabilities for children with disabilities[22], we have tried to do the opposite. We have instead co-designed with children with disabilities for children without disabilities, in order to try to break the imbalance, empowering the children with disabilities (see User stories below). We use music, rhythm, lighting, tangible artifacts and new programmable possibilities in order to facilitate communication and co-creation, as an alternative to verbal language.

3. Method – Participatory Action Research and Video Observation

3.1. 5 generations of PAR

The basis for this paper is the use of the interactive installation "Polly World" through the Cultural Schoolbag Accessible Program in Norway[27]. Polly World is the 5th generation of tangible technology developed in the research project RHYME [28-30], where the goal was to create health promoting musical tangibles for children with severe disabilities, by using Participatory Action Research (PAR) and Research-by Design methodology[31,32].

The Polly World installation consists of many parts. Polly World is a complex hybrid between the physical and virtual, between a cultural artifact like a musical instrument, a furniture or a toy, and an interactive, net-based media and service, that enables to co-create musical and visual experiences over the Internet. The Polly World consists of one wired (Polly Land see Figure 1), three wireless interactive objects (Polly Ocean, Polly Planet and Polly Fire, see Figure 1-4) and two APPs. One APP, Polly Compose, enables distributed interaction over the Internet with the physical objects using a Smartphone/Tablet with a graphical and/or text-based (high-levelTwitter language) user interface.

When traveling with Polly World as part of the Cultural Schoolbag program Polly World was a co-creative workshop. For the Cultural Schoolbag Tour we brought with us the 3 body sized wireless interactive objects (Polly Ocean, Polly Planet and Polly Fire see Figure 2-4): A soft "ball", a "banana shaped cushion" (Figure 2) and a "hybrid blanket". They have touch, bend (Figure 6), microphone (Figure 7) and RFID-reader (Figure 8) as input sensors and light and sound as output. In addition, there are many RFID-tagged familiar artifacts and music-tunes, that play when the tag is close to the RFID-reader on the interactive object. An interactive dynamic video projection on the whole wall, and a flossy white carpet made the familiar school environment into a wondrous magical world.

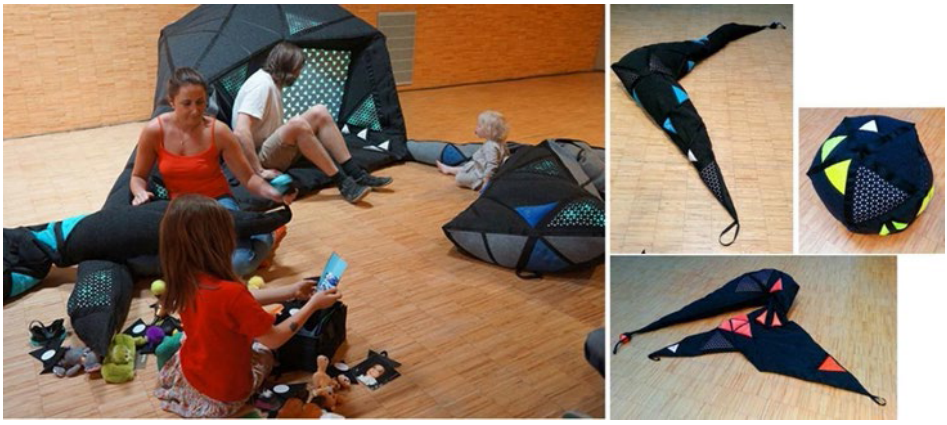

Figure 1-4. Polly World with Polly Land 1, Polly Ocean 2, Polly Fire 3 and the ball Polly Planet.

3.2. Participatory Observation

We were a team of three that travelled with Polly World, and invited the school pupils to co-creative sessions. The sessions usually were from 45 to 60 minutes. In order to build comfort and good communicative relations initially, we usually had groups of 2 to 3 so that we in the touring team could concentrate on one pupil at the time in the beginning. The teachers, who knew the pupils had in advance put together fruitful constellations according to our directions. We videotaped all user sessions, in total 12 schools and 178 children with multi-functional disabilities (physical, cognitive, social), from the age of 7 to 18 co-creating in the installation. We did additional interviews with the teachers afterwards.

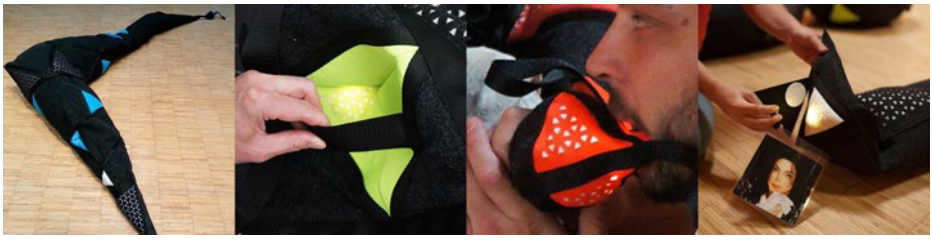

Figure 5-8. Parts of Polly World: 5. Banana shaped Interactive object Polly Ocean, 6. Bend sensor, 7. Microphone, 8. RFID-reader and music-tune RFID-tagged cover (Michael Jackson).

4. Research, Findings and Discussion

A central starting point and motivation for co-design is everyone's right and value to influence and be part of creating their own life and situation. Since we all are experts of our own life, we should be part of the process of designing our environment, situation and lifeworld. Similarly, Polly World, as part of the Cultural Schoolbag Program, was a place where children with severe and multiple disabilities was able to experience to create their own music and multi-sensory environment and experience, not as usual, be a passive receiver and an audience of others performances of music and design, or good will. Polly World was in the program presented as a creative imaginative space where one could question, "what things are, can be and what we create and do" with it, in order to open up for creativity, self-confidence and empowerment. In that sense, Polly World as a place and event functioned similarly to a co-design workshop.

4.1. Adapting for Comfort and Creativity

Since we travelled from school to school and set up our installation in rooms where children had experience of doing other things, we had to stage the installation and workshop sessions as suitable as possible to create a safe, equal and creative session.

In the 12 schools we visited we most often used the gym, but sometimes we used the music room, theatre room and sometimes an ordinary classroom. The pupils' earlier experience of the room was an important backdrop to build from, in order to stage the installation, and meet the Universal Design[4] principles and our own demands[33] when setting up and designing the sessions.

As presented in earlier papers we suggest that universal designs should offer the user: "Many positive experiences to make in every situation, where there are no wrong actions or failing possibilities, to share, relate, participate and create meaning over time... Many ways to act and build competence and mastering in every situation, with few dependencies or closed paths… Many ways to share, relate, participate and create meaning over time."[33]

Therefore, we had to adapt the installation from place to place, to create a both safe, inspiring and creative environment. By using familiar objects from the school, such as furniture, and things such as toys and instruments and well-known music, we created a suitable space for creating comfort and feeling of safety. With the dynamic lighting and musical possibilities, we opened their minds to be creative and inspired in the Polly World co-creative sessions. We therefore set up the space differently in every session depending on the pupils' weaknesses, abilities and interests to create. To create a bridge between the familiar and the new, we set up the light, sound and organized the space and time to design as fruitful a session as possible. The many Polly World parts offered an opportunity to add and subtract things from the situation and set up light, sound and planning the session to truly embrace each pupil's fragile and strong abilities.

In line with the Universal Design principles, we staged and improvised co-design sessions that are more simple, intuitive and perceptible for the actual pupil to grasp and understand, embracing their weaknesses and acknowledging their interest and abilities. Make them initially comfortable and secure to co-create with us and their teachers and personal assistants. Evoke their positive feelings, inspire them to interact, experience self-efficacy and co-create by making them understand what they could utter (have a say), do (mutual learning) and change (co-realization)[7,15]. Experience participation on equal terms and the joy of creating together. Since everything was programmed software and could be edited and logged, the actual session could be saved and replayed as a finished design, a hybrid between design and use. This hybrid we choose to call a "living work", referring to the process of creating works through the joyful experience of living.

4.1.1. Lighting

Colourful dynamic light projection is an essential part of Polly World that the pupils could affect and create with and in, which has strong visual impact. Many of the pupils had visual sensitivity or disorders, which we had to take into account when preparing each session.

To bridge the gap between the Polly World and the rooms outside, which generally had standard ceiling lighting, we put a spotlight right inside the door, while the ceiling light was turned off. This allowed people outside to get used to the different lighting in Polly World. At the same time, the different light inside Polly World attracted the interest of the outside and passers-by every time the door opened. We often started with gentle music (Alina by Arvo Pärt) that had a white and light-yellow graphics to make the room as bright and similar to the other rooms as possible. After the pupil got used to the new situation, we often chose music with related lighting/graphics that we had been told in advance that the pupil liked or knew. This in order to build on existing knowledge and competence and boost their self-confidence while teaching them how to change music, lighting and graphics with the triangular RFID-tags. We always started with things the teachers thought the pupils liked and knew or had a positive relationship to from before. Again to build confidence in the communication situation.

4.1.2. Furnishing

Most rooms we came to were full of furniture and appliances adapted to their usual use of the room. In the gym there were bumps, balls and low benches. The music rooms had chairs and musical instruments, while the classrooms had desks and chairs in rows. We needed to empty the rooms in order to fill them with new meaning, but also build bridges, between the space outside, what the room used to be, and the situation Polly World opened up for.

We placed the projector so that you could not see the projection through the door, only when you were in the room. We tried to make the projection as wide and large as possible. Always along the floor edge close to the white carpet we laid on the floor to create a common, comfortable social place where we all could co-create on equal terms. This also gave the room direction, since we naturally directed us towards the projection. Polly World offered many possibilities to arrange the co-creative sessions according to what was best and most fruitful for the pupils.

4.1.3. Sound and Music

In connection with the declaration of consent, we asked for input on music that was popular and well-liked by the pupils. It could be music that was popular at the time, songs they sang together at each school in common and in music lessons, or songs that single kids liked to sing with their close ones. This became an important resource for communication and building a relation to each pupil. We had more than 50 different music tunes the pupils could choose from. All with their own colour which they could clearly see on the Scene-card. The Scene-card is also a hybrid between an Assistive and Augmented Communication (AAC) card, which most of the pupils where familiar with and a music cover to point toward the world of music. Attached to the card there was also a RFID-tag so the user could easily put on the favourite tune, create interactive music and change the colour of the room.

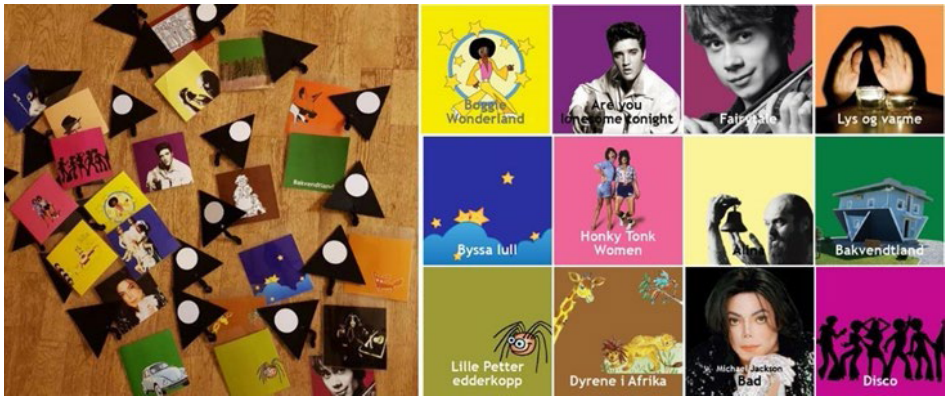

Figure 9. A few of the Scene-cards with RFID-tag on the floor. One control the music tune and colour graphics with the Scene-cards. By interacting, you can change the music and visuals dynamically.

4.2. Customization for different users

Polly World includes about 100 different common artifacts with an RFID-tag (see Figure 10). You can use the artifacts to communicate with, through and by, by building on the relationship to the common artifact as a mediator of communication. Some know, like and have interest and experience and relate to musical instruments. Others relate to toys, sport gear, kitchenware or more dramatical objects such as hats and microphones to dress up for a performance.

We inquired before the Polly World sessions about the pupils' preferences regarding things and music so we could use this in order to get a relation to the pupils through the artifacts. For many of our children in our user group, familiar objects are comforting and they often carry them around as comforting things. By having a pinch with a RFID-tag we could include the pupils' favourite things into Polly World and they could explore new dimensions with their favourite things by interacting with the RFID-tag.

Since none of the things had wires, we could select and arrange the big and small things to best suite the abilities and dispositions of the pupils to make them feel safe and inspired to co-create.

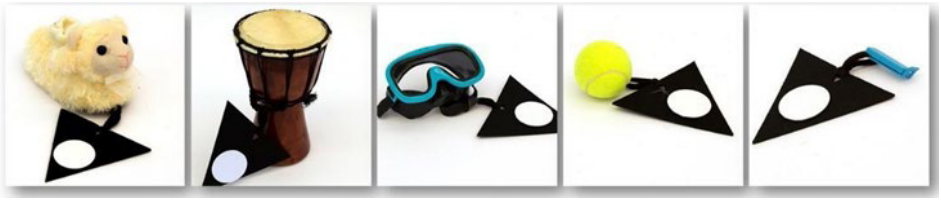

Figure 10. Familiar Common Arifacts with RFID-tag with virtual layer to change sound and graphics.

4.3. User stories – Express, Co-create and Trans-create

Since the children have so different preconditions, abilities and communicated in such different ways, we have a large number of collaborative user-stories. We have selected 2 relevant cases as the basis for our discussion here.

4.3.1. Mila on the bench

The door opened to the hallway. Mila, a little 10 year old girl came hand-in-hand with her teacher into the room. She hesitated. We sat as usual on the soft white carpet, with the big and small things that Polly World consists of around us. We asked her to sit down with us in different ways, with voice and gestures. But Mila was clearly unsure of the situation and sat on the low bench just inside the door. The dark room, the strong projection, all the new things were clearly too new for Mila to feel safe enough to sit on the floor. I tried to say her name into the microphone at the end of the big banana-shaped "pillow", Polly Ocean (Figure 5). And then I replayed and varied her name, by interacting with the pillow by activating bend and motion sensors. She looked up in amazement. I had her attention. I showed her the tagged soft white sheep. Asked if she knew what it said. But she just sat next to her teacher on the bench. After activating the tag on the sheep, Polly replied with "baa, baa, baa" and then started playing the children song "Baa, baa little lamb" for a few seconds. She looked up again. I put the sheep 20 cm in front of her so she just couldn't reach it from the bench she was sitting on. Then I did the same

with the soft brown dog. The dog barked. Mila looked at her teacher in amazement again, trying to reach for the sheep without removing herself from the bench. I put the dog 30 cm off the bench and played further "Baa, baa little lamb" using the Scene-card. Mila went down on her knees for the sheep and the dog. She was down on the carpet! I stretched the corner of the pillow, the white RFID-reader towards her. And showed her how to activate the tag, get the sheep to baa and the dog to bark and play the song "Baa, baa little lamb". Like breadcrumbs on a road, I let out the interactive things in succession. After 12-15 minutes she was down on the carpet and playing herself. She was clearly unsure of me, so I took the blanket Polly Fire and played on it, one thing at a time. After each thing, I put it on "her side". She took the things, activated the tag on her Polly Ocean and we could play against each other here and there (mutual learning). Bark here bark there. Bobble here and bobble there. Then we took it a step further and created rhythms in repetitive sequences against each other. I then showed her the Scene-cards, how the colour of the card matched the colour of the projection and the whole room. She was wearing a pink sweater and I tried the pink disco card. The disco music filled the room. I took the blue "Mamma Mia card". Abba sang. The room turned blue and Mila smiled recognisingly. We both danced with our arms and sang. Mila had become safe in the room. She had learned what she could do. She sat on the carpet and looked around. She grabbed the various things she recognised, a pot, a flower, a diving mask. She heard the sound they played as she touched them against the white triangle, saw the colours, the dynamic graphics and heard the music as she interacted (co-realization). And she became more and more active in the creation of the situation. When her hour was over, she would not leave at all. Several times later during the day, she peeked in through the door, though it was not her turn. At the end of the day she came back again.

4.3.2. Creating the room Pink

At another school we met Frida. She entered Polly World alone. She had great difficulty moving due to cerebral palsy and was visually impaired. We put the banana-shaped Polly Ocean around her so she could sit comfortably on the soft white carpet. She soon discovered that she could make shadows with her hands against the projection wall. She had done this before! I could see she felt safer and freer to express herself (have a say), through the familiar "shadow language", in an otherwise new and unfamiliar environment. I tried to arouse her interest in creating from the shadows on the wall, as she knew from before, to creating dynamic graphics that she never had done before. She grabbed hold of the handle I was showing her and pulled even though she didn't have the power to squeeze the sensor. Pulling was equally suitable and had the same effect. In Polly World, there are many ways to do the same so that everyone can manage and master. Full of surprise, Frida saw how the graphics changed. I asked what kind of music she liked, but no verbal conversation came out of it, since she could hardly formulate any words. But she wore both a pink sweater and pants, so it told me that this girl likes pink! We learned from each other. I brought out the pink disco card and put on the disco music. Frida howled with delight as the entire room changed from white to pink. She had learned and been inspired to create further (mutual learning). She looked for all the pink stuff, and all the pink and purple Scene-cards. Elvis, Prince and Stones. She heard immortal music covers in a long line, took part in our cultural heritage and certainly got musical experiences she never had before. She collected pink flowers, pink cars and pink trains. She tested and listened motivated by the colour pink. For each time more puzzled. After identifying and trying all the pink and purple things, she sat down quietly again, but her

world of pink and purple things lay around her (co-realization). She tried the things again. Listened, watched and created further variations of pink, purple, fast rhythms to more tranquil Fauré variations. She experienced being able to control and master, excitedly motivate herself to use her whole body to change the pink patterns on the wall and calm more romantic moods. All in a pink light.

It was clear that this was how she wanted it (co-realization). After an hour and a half, she was picked up by her teacher for the next school lecture. She strongly opposed it. She wanted to be left in the world of things, lights, colours, patterns and music she herself had created. At the end of the day, when we were shutting down, she came back with two non-disabled girlfriends. It was clear that she wanted to show them what she had created and experienced here. She resolutely presented the pink disco card. And everything turned pink. The friends were totally amazed. She drew another card she knew and showed her friends. Everything turned purple and Elvis sang impassioned "Are you lonesome tonight". The friends didn't even realize what was happening, although they seemed to recognize Elvis's voice. Frida showed them how to put the white dot on the black triangle against the white triangle (RFID-reader) in her body language. This was perhaps the first time Frida could teach them and not vice versa. She was clearly proud. The girls were clearly excited and understood the point (mutual learning). Suddenly they saw that there were lots of things with Black Triangles with white dots. They ran around, gathered things they wanted to try. The three girls each took their big object in Polly World, each with its own white triangle (RFID-reader). They took turns, listened and listened again, so they could understand what was happening, what they were creating in the complex multimedia experience. We showed them that they could use a microphone and sensors to vary the graphics, the music. And then we withdrew from the carpet, observantly. Frida had taught her friends something that everyone was completely seduced by. She was the one who mastered, who had invited them in. This changed the power relation between them. Together, they added things, removed things, transformed the environment, and added self-created and pre-created music and rhythms, colours and patterns that they had never experienced before (co-realization). They danced and felt rejoiced until we had to ask them to go. They had experienced co-designing the space in their school.

When we had packed everything in the car, Frida joined us with her mother who had picked her up for the After-School program. She wanted to tell us that Frida had never been so excited about something in school before. We had again experienced how much Polly World could enable communication through colour and body movements on equal terms. Between people with such different strengths, weaknesses and abilities.

On our tour we consistently experienced that the pupils would and could participate, create and co-create. Only one single pupil did not want to be in Polly World. After two short attempts he just quickly rolled out of the room, while the teacher excused him for having a bad day. Generally, there were 2 to 3 pupils in the room with us at the same time, which we found optimal, so that the 3 of us were able to give one child our full attention until they felt safe in the new situation. Only in 2 cases the children were so disturbed by each other that they had to be alone, without any fellow pupils in Polly World.

For most pupils, it only took about 5 minutes for them to feel safe in the room, and were able to control light and sound with the triangular RFID-tags. Mila was the pupil who spent the longest time before feeling safe on the carpet in Polly World. A sense of security and confidence is an essential feeling to establish in any co-design session, regardless of user group.

Since Polly World is a good mix of known and unknown, the known territory was safe to walk on until they felt comfortable and inspired to express their opinions and ideas about the co-design workshops within the theme and goals. By saying or singing something in the microphone, repeating it by interacting with the sensors, choosing things, music and room colour, gave the pupils many ways to express themselves. This diverse way of "having a say" is essential to this target group, and here it breaks with the usual co-design directive that usually follows a program where everyone at the workshop must do the same at the same time. Through the large amount of pupils we have met, we had to develop a *programme* and phases on a general level. We had to establish a feeling of safety, show and teach some of the functionality, invite and motivate to communicate and interact with us, give them an experience of control and mastery, encourage them to co-create with classmates, and calming down before ending the session. But the way we were able to achieve the phases varied enormously depending on the pupils' personal parameters such as diagnosis, weaknesses, interests, gender, emotional state, daily condition, personality and communication skills. Because Polly World offered so many things to communicate through, so many ways to communicate and so much to communicate about, we could, in almost every situation, find ways to establish security, evoke positive emotions and will to co-create and themes to communicate about. Often, as with Mila, we could begin with a familiar song such as "Baa baa little lamb", a well-known song that in itself created safety and confidence. Other times we could use textile structures, shapes and textures such as the soft fur of the sheep to create safety and community. Other times it could be the rhythm and the colour, as in pink with Mila, that became the common starting point.

Since the pupils felt that they immediately could influence through the use of the RFID-tags, they felt that they practically "had a say" and created (co-realization) immediately. The room turned pink immediately. The patterns danced with their movements. The music played the choices in the rhythm they created, but were also influenced by others when they collaborated. Our joint experience of Polly World was negotiated dynamically on equal terms (mutual learning) where we all sat or danced together on the white carpet in front of the big projection.

In regular co-design sessions, words, opinions and ideas are expressed on Post-it notes and paper in the form of words, maps or simple abstract 2D or 3D sketches, often small-scale depending on the theme. Rarely the result of a workshop are others than notes or sketches to memorise, not a finished usable result in itself. But in Polly World it was just that.

4.3.3. Trans-creating together

Together we co-created the experience. The theme, the visuals and the sound. And since everything could be logged on a computer, lighting tracks and set-design choices could also be saved as a unique movie, song or multimedia programme, for precise playback later. The pupils, but also us, precisely because we were so different and had such different backgrounds and abilities, created and gained experiences we had never had before. The pupils had the experience of being able to express, influence and create with media such as lighting, interactive graphics, music and rhythm. It broke the boundary of what they had experienced to be able to influence and create before. The combination of the concrete and familiar things with the virtual and new possibilities, gave the pupils a feeling of self-confidence and empowerment. In cases where we returned to schools and

pupils we met on an earlier tour, we clearly saw that they recognised us and Polly World, and immediately showed clear expectations and mastery skills. We were very surprised.

The flat structure of the sessions, where we all could choose the range and order of things, Scene-cards (music, lighting), the degree of interaction and negotiation, strengthened the pupils feeling to be able to express, influence and create high-quality experiences and things. Not only some sketchy notes that easily, become rubbish like in most traditional co-design sessions. The Polly World session gave opportunity to create together with persons with very different abilities and lifeworlds. Therefore we call this not only co-design such as in traditional sessions, but *trans-create* because it becomes a high level communication which transcend the division between diverse users, and between design and use. The solid physical things combined with the virtual high-quality visual, musical and dynamic graphics make this possible.

But of course, this also has weaknesses. After all, some of the limitations are what we actually created together, the room. We didn't stay but toured on to the next school, but you could also imagine that this was a way to design the environment in the school, in a future "smart school". On the other hand. Through this process, pupils gained experience with lots of music history such as jazz music and classical music that they never had accessed before, due to the preconditions inherent in parents and teachers. This musical experience expanded their repertoire dramatically and became a resource in the life of a group that greatly enjoy music, but is often limited by not being able to access it.

5. Conclusion – Familiar Artifacts and Dynamic Software has potential

In this paper we have discussed the importance, challenges and possibilities of co-designing with children with severe disabilities. Former research within co-design has shown the value of using tools and tangible objects when co-designing with children and layman persons to communicate through the design process. But to communicate with children with severe and multiple disabilities, the communication challenges increases dramatically. One must communicate and design through, and for this group in less abstract and more understandable ways. To co-design with users with special needs, we need a high-level and concrete form of communication, instead of ordinary abstract co-design tools such as words, paper, pen and Post-it notes. In this paper we have shown and discussed how we used familiar artifacts with digital personalisable layers to facilitate the co-design process by using a less abstract and understandable language for this target group.

We found that by using familiar objects/artifacts that could be added and removed in the co-design process, we had a language for communication. By adding a personalisable digital layer to the artifacts, we could adapt, scale and redesign the situation dynamically. This implies blurring the boundaries between designer and user, between the design process and the use process and the view of what we create during a co-design process. That is why we have chosen to call this process "trans-create", instead of co-create, what we create for "living works", instead of design.

By using familiar things/artifacts with IoT and AI functionality, we have a suitable tool that allows us to communicate and co-create with persons with severe disabilities in a tangible and bodily way, not only through AAC-signs, normally used in communication with this user group.

This tangible and physically situated form of communication is not just a communication tool. It becomes the design itself, not in a final form, but a work in dynamic transformation, that transcends the distinction between design and use.

The persons with special needs interacting are not only users and experts in their own lives, but creators that trans-create their living works, with their unique voices and insights, that showed us something we never could see without it. They become important creative resources for design and innovation where we mutually learned from each other.

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