Design your life: user-initiated design of technology to empower autistic young adults

Thijs Waardenburg, Niels van Huizen, Jelle van Dijk, Koen Dortmans, Maurice Magnée, Wouter Staal, Jan-Pieter Teunisse and Mascha van der Voort

Abstract

Purpose – *This article describes the development and initial experiences of Design Your Life, a new design approach implementing user-initiated design of technological environments that support autistic young adults to live independently.*

Design/methodology/approach – *This article makes use of a phenomenological Research-through-Design approach. Investigation of possible ways in which a set of four guiding principles could be applied into a design toolkit for autistic young adults and their caregivers by means of three design case studies was conducted. Promising methods from the design practice and literature were applied and contrasted with the lived experiences and practical contexts of autistic young adults and their caregivers.*

Findings – *This exploratory research yielded several important insights for the design direction of Design Your Life. Reflecting on how the guiding principles played out in practice it was noted that: the case studies showed that stakeholders appreciate the approach. The design principles applied cannot be used without the help of a sparring partner. This suggests that caregivers may be trained in design-thinking to fulfil this role. The Design Your Life method will be iteratively developed, refined and validated in practice.*

Originality/value – *The presented approach puts design tools in the hands of the people who will use the technology. Furthermore, the approach sees technologies as empowering interventions by which a person can strengthen their own living environment. According to this article, this approach is new for this application. It provides valuable perspectives and considerations for autistic people, caregivers, researchers and policy makers.*

Keywords *Autism, User-initiated design, Co-design, Phenomenology, Assistive technology, Independent living*

Paper type *Research paper*

(Information about the authors can be found at the end of this article.)

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1. Introduction

An estimated 1% of people in the Western world have been diagnosed with autism (Idring *et al.*, 2012). Autism is also called "autism spectrum condition" (ASC) or "autism spectrum disorder" (ASD), where "spectrum" refers to a high degree of heterogeneity among people with autism. Autism is a lifelong neurodevelopmental condition, meaning that the brain is developed differently from neurotypical brains. This results in differences in communication, behaviour and/or sensory integration (American Psychiatric Association, 2013).

Like every human being, autistic people have potential and aspirations, regarding independence. However, this group also faces higher school dropout rates, unemployment and other difficulties with independent living (Burleson *et al.*, 2012). To anticipate these difficulties, a variety of apps, wearables, internet-of-things, robots and other technologies are being developed (Kientz *et al.*, 2013). Stakeholders are positive about the role of technology in gaining more independence

(Parsons *et al.*, 2020). But the uptake of assistive technology is often limited and the effectiveness unknown (Zervogianni *et al.*, 2020). Developing assistive technology using co-design methodologies can have a positive impact on its success.

1.1 Co-design

Co-design refers to "the creativity of designers and people not trained in design working together in the design development process" (Sanders and Stappers, 2008). In recent years, co-design has gained the interest of researchers in the context of (mainly digital) technologies that can support autistic people in daily life. For example, Benton *et al.* developed IDEAS, a co-design method for the interface development of ICT for autistic children (Benton *et al.*, 2012), Aslam *et al.* developed a toolkit specifically for co-designing social robots for and with autistic adults (Aslam *et al.*, 2019), and Frauenberger *et al.* involved autistic children in the design of a technology enhanced learning environment (Frauenberger *et al.*, 2011). Motivations for adopting a co-design approach range from "addressing a pragmatic need to increase the fit between features and users' requirements" to "idealistic agendas related to empower people, democratise innovation and designing alternative futures" (Frauenberger *et al.*, 2017). Morally, a call for empowerment through participation has been more widely advocated within what is referred to as the "neurodiversity movement" (Fletcher-Watson *et al.*, 2019).

The epistemic value of co-design is also invoked: without a proper understanding of autistic experiences, designers may be at risk to end up creating technologies that are both stigmatising and ineffective (Fletcher-Watson and Happé, 2019; Zervogianni *et al.*, 2020). Another reason may be that it is inherently difficult for (non-autistic) designers to empathise with the lived experience of autistic people. Incorporating one's lived, subjective experiences into the design process is already difficult, but in the context of autism, it is extra complex because of the differences in perception between autistic and non-autistic people. The difficulties for mutual understanding are referred to by Milton as the "double empathy problem" (Milton, 2012). An additional reason may be that the autistic population is itself highly heterogeneous, with each person having both individual support needs and sometimes quite specific interests and capabilities. Estimates of intellectual capacities are highly variable in the autism spectrum as well, varying from intellectual disability in about 40% of the autistic population to average and (very) high IQ ranges (Idring *et al.*, 2012).

1.2 User-initiated design

In this research, we want to go a step further than traditional co-design. We want to put the initiative and the design tools in the hands of the users themselves and leave out the professional designer entirely. In the context of healthcare, Sarmiento refers to this as user-initiated design (UID): "the existence and recognition of alterations to the environment enacted by PWD [persons with disabilities], becoming a tool of empowerment for these individuals" (Sarmiento, 2017). This is in contrast with most co-design (or participatory) methods that do involve stakeholders during the design of a product or service to a certain degree, but do not equip them with the tools to design their own, specific solutions without any involvement of designers. Designing your own environment means that the design process starts from your own lived experience, which also means that the double empathy problem is largely bypassed. This can be considered the ultimate form of participatory design. UID also moves away from the concept of "one-size-fits-all" assistive technologies designed for a broad target group. It embraces the concept of self-designed, adapted or selected solutions that better fit individual needs and requirements.

In this study the following research question is answered: "How can user-initiated design for autistic young people and their caregivers be developed into a concrete method?" The rest of this article is organised as follows: First, we introduce our approach, called Design Your Life. Then the methodology is described. The findings and conclusions are presented at the end of the article.

2. Design your life

Here we present the "Design Your Life" approach (DYL): a co-design process used by autistic young adults (AYA [1]) and their caregivers to design a personalised, supportive, technological environment that contributes to independent living. Its purpose is not only to bring creative forms of shared sense-making to the care practice. Its purpose is also to bring the next step in reaching autistic empowerment by providing autistic individuals not just participation in a designer's project, but to instead provide them with tools to design and implement their own solutions. DYL aims to stimulate the autonomy of the AYA. They work on their own competences by taking control of their own lives and connect better to their own living environment. This is hoped to stimulate the three basic needs according to the self-determination theory, namely intrinsic motivation, self-regulation and well-being (Deci and Ryan, 2012).

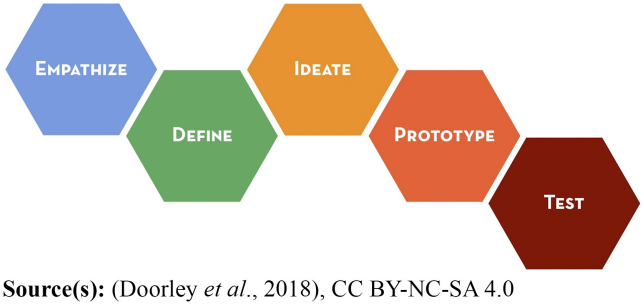
2.1 Guiding principles

To practice the philosophy of UID, four guiding principles were identified. These principles provided an initial direction for the research, while keeping an open mind about what the co-design method itself would look like. We will return to these principles when we discuss our findings.

2.1.1 Design process. The basic idea for the DYL toolkit is that autistic participants and their caregivers are supported in creating their own personal supportive solutions. This means some form of design process to guide the users is needed. Various generic design processes have been proposed, such as the Basic Design Cycle (Roozenburg and Eekels, 1995), the IDEO design process (IDEO, 2015) and the Double Diamond by the British Design Council (Design Council, 2015). These kinds of processes are not unique to co-design projects: both in the digital and the tangible sphere, iterative processes with similar stages have become conventional to include stakeholders and make effective use of their expertise–also in the context of autism (Fabri *et al.*, 2016; Zervogianni *et al.*, 2020). Following the work of Fabri and colleagues, the well-established design thinking process from the Stanford University's Hasso Plattner Institute of Design (Doorley *et al.*, 2018) was selected as a basis for DYL. This process assumes five "modes", which can be repeated and used in various orders: Empathize (i.e. observing, engaging, immersing), Define (i.e. understanding a useful challenge), Ideate (i.e. exploring solutions), Prototype (i.e. realising ideas) and Test (i.e. gathering feedback, refining solutions) (Figure 1).

2.1.2 Personalisation. Design challenges in the context of autism are often described in terms of functional and psycho-social limitations. Frauenberger *et al.* explain that such "reductionist models of disability" ignore the importance of the experience that autistic individuals have with technologies (Frauenberger *et al.*, 2016). This leads to a mismatch in which autistic people abandon technologies that they find ineffective. By describing autism in terms of "technical limitations" one

Figure 1 Design thinking process from Stanford University's Hasso Plattner Institute of Design



Source(s): (Doorley *et al.*, 2018), CC BY-NC-SA 4.0

can expect many technologies associated with autism to take the form of a "technological fix". Therefore, in terms of abandoning technology, personalisation is considered an important principle. To this end, DYL builds on phenomenology as the philosophical study of experience to understand and articulate autistic experiences as core inputs into the design process. To use phenomenological terminology: the technology must be properly "embodied" (Brosnan *et al.*, 2019; Van Dijk, 2018).

2.1.3 Existing technologies. To achieve self-developed solutions, it may be necessary to look beyond existing *assistive* technologies. The reason for this is twofold. On the one hand, generating design ideas is challenging because AYA have may have difficulties conceptualising a concrete, technological intervention "out of nothing". By also allowing all kinds of technologies that are not explicitly labelled as "assistive" to be used in the design process, it may be easier to oversee the design possibilities. A more practical consideration is that already available technologies (not explicitly labelled as assistive) are relatively inexpensive and "present opportunities for applications that can be individualised at lower costs than using the more traditional custom hardware solutions" (Hayes *et al.*, 2013).

2.1.4 Tinkering. DYL recognises the added value of tinkering, an explorative and iterative learning-by-doing strategy that makes the technology being appropriated by experimentation (Resnick and Rosenbaum, 2013). Ethnographic research from Science and Technology Studies shows how existing technologies are "tamed", made suitable for the specific user context, in a constant process of tinkering. "Technologies, in their turn, are not as shiny, smooth, and instrumental as they may be designed to look. Neither are they either straightforwardly effective on the one hand, or abject failures on the other. Instead, they tend to have a variety of effects. Some of these are predictable, while others are surprising. Technologies, what is more, do not work or fail in and of themselves. Rather, they depend on care work. On people willing to adapt their tools to a specific situation while adapting the situation to the tools, on and on, endlessly tinkering" (Mol *et al.*, 2010, pp. 14-15). This underscores its importance to UID.

3. Methodology

To develop DYL, Research-through-Design was applied, which means that the situated process of designing for a concrete practice context was used as a basis for a reflection process leading to insights (Schön, 2017; Zimmerman *et al.*, 2007). In this study, a reflection on three such case studies is presented and their results are integrated into the principles that will underpin the DYL approach and its toolkit, which will be developed subsequently. In each case study, a graduating design student (hereafter: designer), professionally trained in (co-)design methods, began a design process in close contact with an autistic participant and a caregiver (the aim of the toolkit is to leave out professional designers. However, designers are involved in the development of the toolkit itself).

Each designer was asked to freely explore and tailor the design process described in Chapter 2.1 to fit DYL. This process can be repeated over several iterations, noting that the main design challenge (deeper understanding of what the problem is) evolves together with the design proposal (what the solution could be). Although this basic structure of a human-centred design process is well -escribed in the academic design literature and underlies most design methodologies, several specific challenges had to be addressed, for which this case-based Research-through-Design approach was used.

The designer would initiate the design process, build up a relation with the participants and engage with the daily life and their (autistic) experiences. The designer would do a review of existing methods and come up with creative ideas themselves for methods and activities that might apply to the case in question, not starting from a set knowledge base but pragmatically looking for things that might work – as designers do. This allowed for an open-ended, creative process that enabled the designer to weave together their own skilled designerly intuition, existing methods and theoretical principles in the co-design literature and their evolving insights coming from engaging at

a personal level with the participants and their own ways, interests and skills/capabilities, for doing things.

It is important to emphasise that the focus was mainly on the design process, rather than on the technological results created by the participants. It was assumed from the start that technologies would probably not be developed. Based on the case studies, important insights were gained to arrive at a concrete method for UID.

3.1 Participants

Three pairs of AYA and caregivers were recruited. Two pairs were recruited within the partnering healthcare organisations and one pair was recruited in the personal network of one of the involved researchers. The following criteria were used for selection of the AYA: Autism spectrum condition; No intellectual disability (i.e. no IQ < 70 or referred to as "severe autism"); Age: 14–35 years [2]. The caregiver could be chosen by the AYA. This could be a professional or someone the AYA considers knowing them well.

4. Case studies

4.1 Case study one

This case study involved 23-year-old AYA Vincent [3] and his caregiver Bianca. He receives assisted living from one of the mental health institutions involved. Bianca is a 49-year-old. She has been Vincent's carer for three years now.

4.1.1 Focus. Stimulating a better sleep schedule (this is a common challenge for autistic people).

4.1.2 DYL toolkit. The designer considered three different concepts for a toolkit: a board game, a Lego build concept and a large dice. The designer compared the toolkits with a SWOT analysis and the game board emerged as the most promising. Not least because Vincent has a preference for board games. The game board (Figure 2) consists of six islands, five of which relate to the design thinking phases: understand, define, ideate, prototype and test. The final island includes the goal of the AYA. The design process was translated to better fit the user-initiated and iterative nature. This means that for instance the "Empathize" phase is translated to "Understand yourself and each other", because with UID it is illogical to empathise with yourself. Also, the process is depicted in a circular (i.e. iterative) way (Figure 3). Several activities in the form of canvases were developed, such as "This Is Me" (Figure 4), "My Day" and "Finding Products".

4.1.3 Design process. Vincent and Bianca were largely able to go through the design process themselves. However, at various times they needed help from the designer involved. This was the case, for example, in converting ideas into possible solutions. It also proved difficult to think *outside the box*. Vincent expressed that without that help they "[. . .] wouldn't be able to continue with the game".

4.1.4 Result. Already at the first meeting, Bianca expressed her idea to buy a specific care robot called Tessa for this. However, in a next session, Bianca realised that they "[. . .] had been thinking too big". During the same session, Vincent came up with the idea to set up "[. . .] two alarm clocks on his phone, one for waking up and one for going to bed". After testing, Vincent expressed that he has a clear preference for non-auditory modalities. So, during the final evaluation session they ended up with an alternative solution: a wake-up light.

4.2 Case study two

In this case study, 14-year-old adolescent Tim and his mother Sandra were involved (Tim lives at home).

Figure 2 The translated design process from case study one

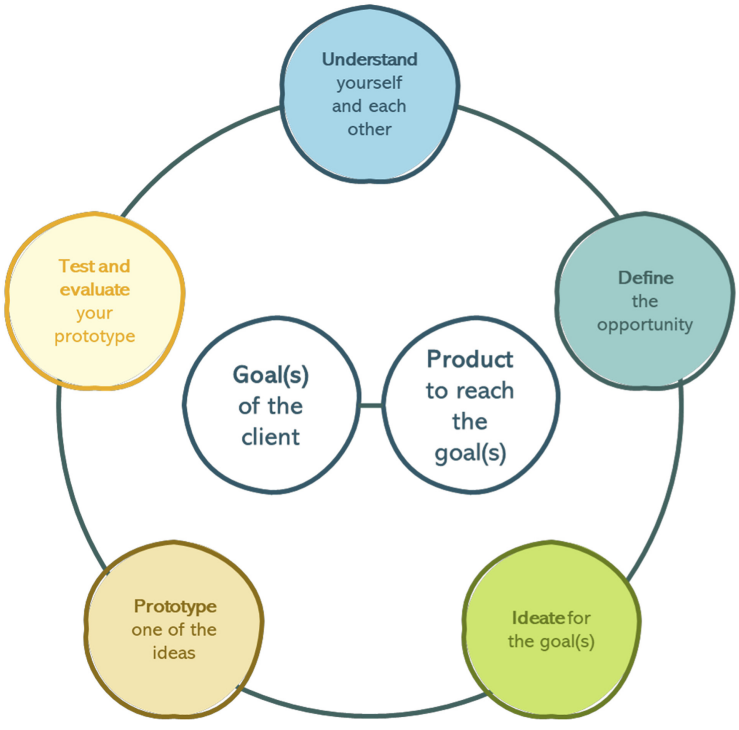


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Figure 3 A game-based prototype called "Good Trip!"

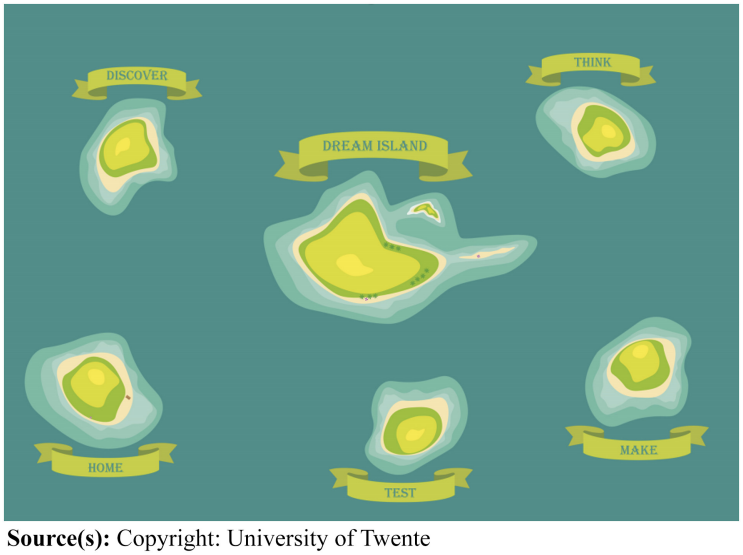

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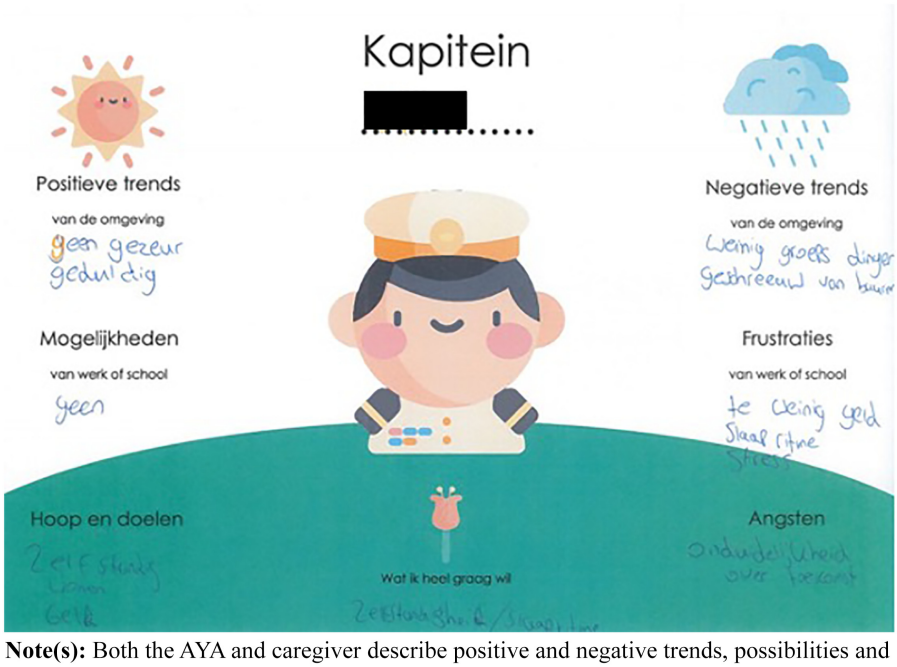
Figure 4 The "This Is Me" canvas for case study one



Note(s): Both the AYA and caregiver describe positive and negative trends, possibilities and frustrations and hopes and fears

Source(s): Copyright: University of Twente

4.2.1 Focus. Sandra feels responsible for the development in independence of her son. However, Tim seems to find that less urgent. For instance, at one moment he remarked something along the lines of "Why should I learn to tie my laces? My mother is much better at it than I am". Also, "[i]f he wants to do something, he wants someone to be with him". In the end, Tim chose to improve his school experience. He experiences this as negative because the other children make a lot of noise. He found out that the core problem is that he cannot work with a lot of noise.

4.2.2 DYL toolkit. The proposed design process includes the same number of modes, but they have all been translated to better fit the life world of Tim and his mother (Figure 5). For example, the mode "Define" has been translated into "Discover the problem" and "Prototype" into "Make your tool". It has also been made more explicit in this process that you can take steps back if you wish. At each phase there is a choice of activities, such as mapping your dreams (Figure 6), a "How can we . . ." activity and an activity that stimulates using available objects.

Different toolkit forms were explored with the participants: tangible, digital and a tangible-digital combination. Tangible co-design tools have been argued to provide a shared space for sense making and open a rich freedom of expression for co-design participants. But in this case Tim preferred the digital form, due to his affinity with ICT and his reluctance to write with a pen. Eventually an interactive PowerPoint prototype was developed and tested (Figure 7). It offers a step-by-step guidance in designing a solution.

4.2.3 Design process. Only a small part of the design process was completed. It turned out to be too textual and took too much time and effort for Tim. His mother said the following about this "To let someone make it on his own is quite much to ask, but I think it stimulates to think and it helps you through the process, to get somewhere together and it does that very well".

4.2.4 Result. Although Tim seemed motivated to improve his school situation, the dedication declined. No technological solution was designed.

Figure 5 The translated design process from case study two

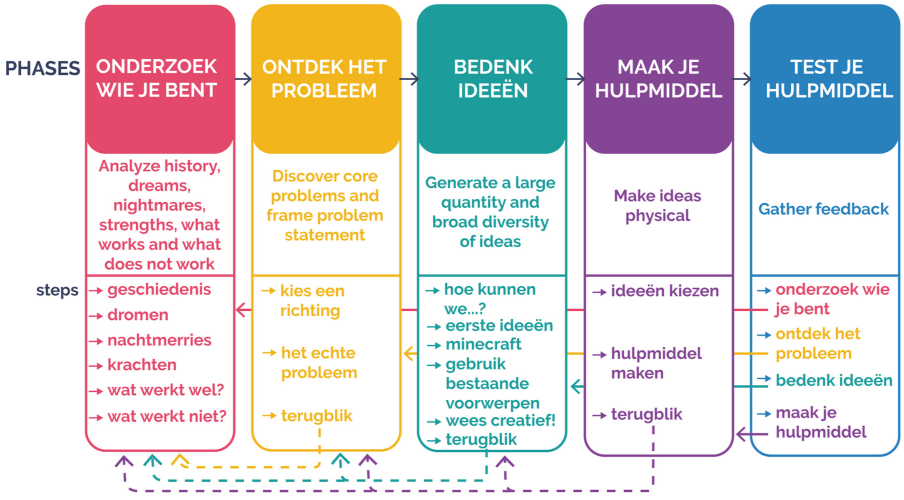


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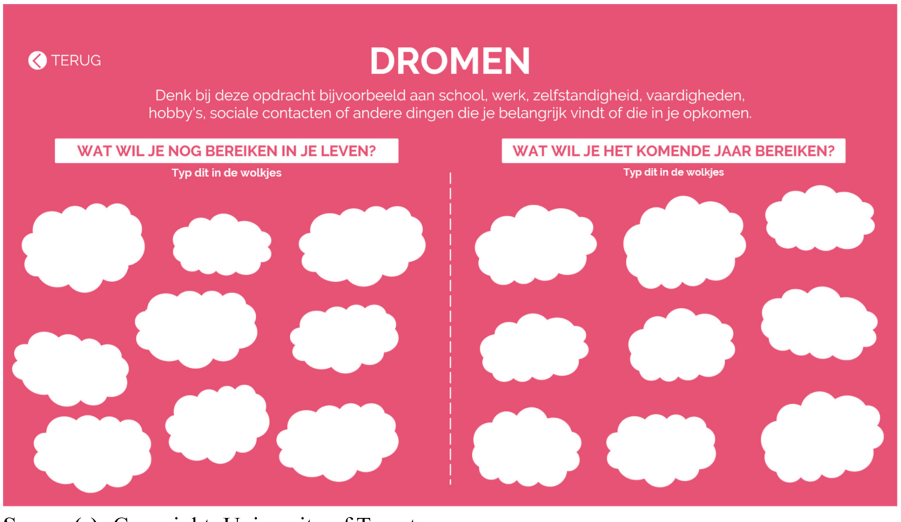
Figure 6 An activity of case study two where dreams of the future can be written down



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4.3 Case study three

This case study involved Paul, a 33-year-old AYA, and his caregiver Irene. Paul lives at a mental healthcare institution that is involved in this research project.

4.3.1 Focus. Slowly but steadily, he is working towards more independence. His goal was to better perform daily cleaning activities, without the help of others.

4.3.2 DYL toolkit. The design process was extended with several additional steps, including an introductory phase ("Introduction") and a phase in which specific consideration is given to existing solutions ("Market analysis", Figure 8). Several activities were proposed for each phase,

Figure 7 One of the phases of an interactive prototype for case study two, made with PowerPoint

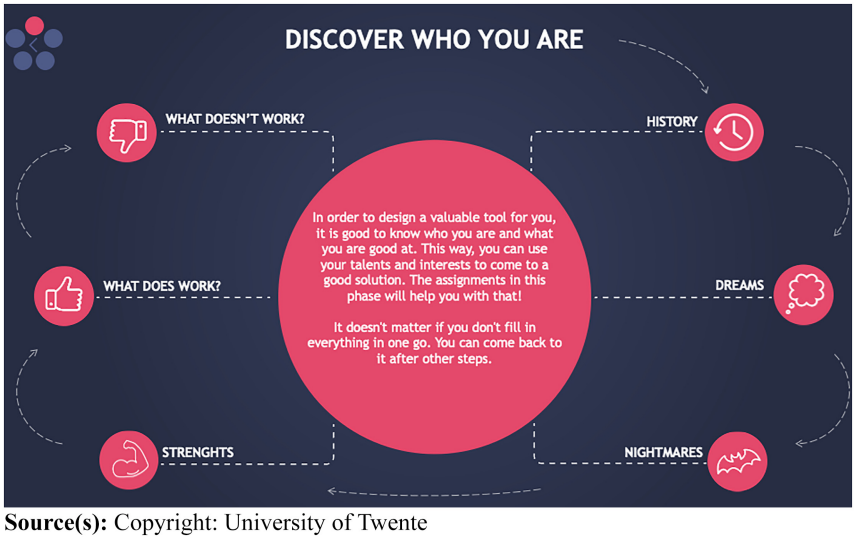

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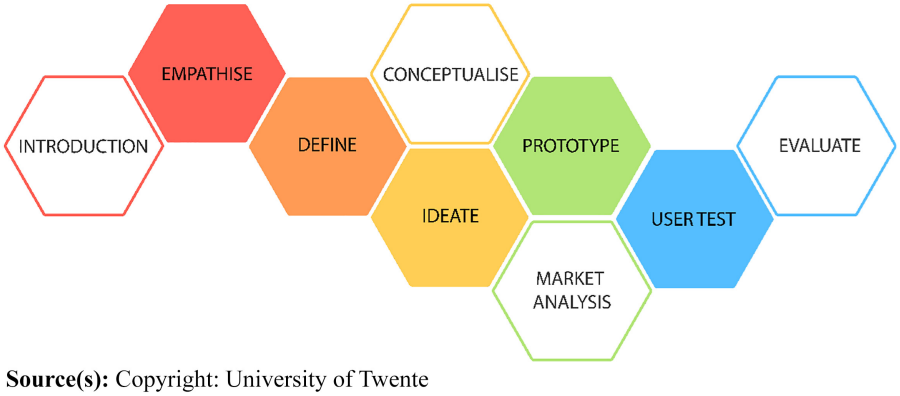
Figure 8 Expanded design thinking process



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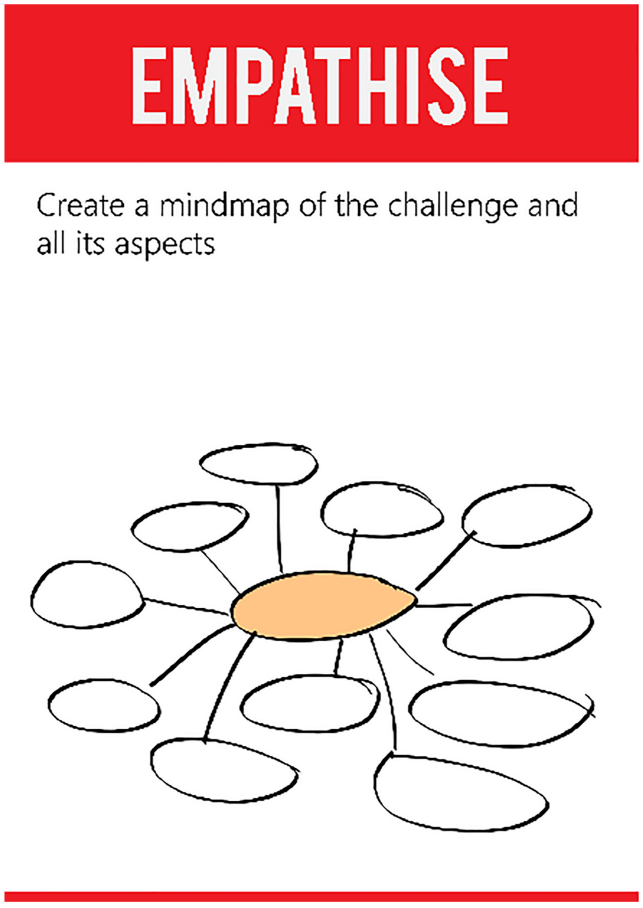
such as making a mind map (Figure 9), generating unconventional ideas and consulting experts. Three different forms were explored: A game board, an adaptable online guide and a physical toolkit. Low-fi prototypes were used as probes for a co-design session with Paul and his caregiver. During this session, they interacted with the prototypes to discover preferences and difficulties in the designs. It resulted in a new prototype design that consists of a set of physical "prompt cards" that is aimed at stimulating, inspiring and guiding the design process. The cards spark creativity or provide the users with new prompts to follow when they stagnate in the design process (Figure 10).

4.3.3 Design process. Although Paul had not yet found a concrete solution at the end of the design process, both he and Irene were positive about the design. According to them, it provided "[. . .] a new way of thinking, which activated them to delve deeper into the problem".

Figure 9 An example of a prompt card that suggests creating a mind map



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4.3.4 Result. Useful insights were gained that could possibly be translated into a workable solution. For example, Paul and Irene thought it would be useful if Paul could have a "little voice on his shoulder" to help him every now and then. Recording, sending (by Irene) and playback of messages can provide such functionality (Bouck *et al.*, 2021).

5. Findings

The case studies led to the following insights. These are linked back to the formulated proposition of UID and the four guiding principles, as described in Chapter 2.1.

5.1 User-initiated design

The participants appreciated the approach of taking more initiative, compared to the usual support they receive. Especially Vincent and Paul experienced being more central to the process and felt being taken seriously as a person who has ideas and experiential knowledge to offer. In addition, the process also impacted the relationship between AYA and caregiver, in favour of reciprocity. For example, Vincent said that during the collaboration he got to know his caregiver in a different and better way, such as when he found out through the context-mapping exercises that his caregiver had been experiencing more stress due to Covid-19 conditions. On the other hand, we saw Tim's

Figure 10 A set of physical prompt cards to guide the design process for case study three

Source(s): Copyright: University of Twente

involvement decrease during the design process. This can perhaps be explained by the influence his mother had on the process, as illustrated by the anecdote about lacing. This may have reduced the initiative and intrinsic motivation of Tim himself.

5.2 Design process

In each case study, the collaboration between the AYA, the caregiver and the design researcher lasted about two months. Initially, all steps of the design thinking process were distributed more or less evenly over time: a week was scheduled for each phase. At the beginning of the week, a meeting of about an hour was held, during which the assignment(s) were given and explained. Then it was up to the AYA and the caregiver to complete the assignments that week. One thing that became clear is that the creative tasks, such as coming up with different potential ideas, were difficult to perform for both the AYA and caregiver. Envisioning future scenarios proved challenging, which is in line with known challenges in autism (Lind and Bowler, 2010). Also, creative tasks like tinkering with materials or technologies were tricky. This required a great deal of guidance from the design researcher involved. This confirmed the added value of a sparring partner in the process, but it also emphasised that knowledge and training of design processes may be required if this task is to be executed by the caregiver.

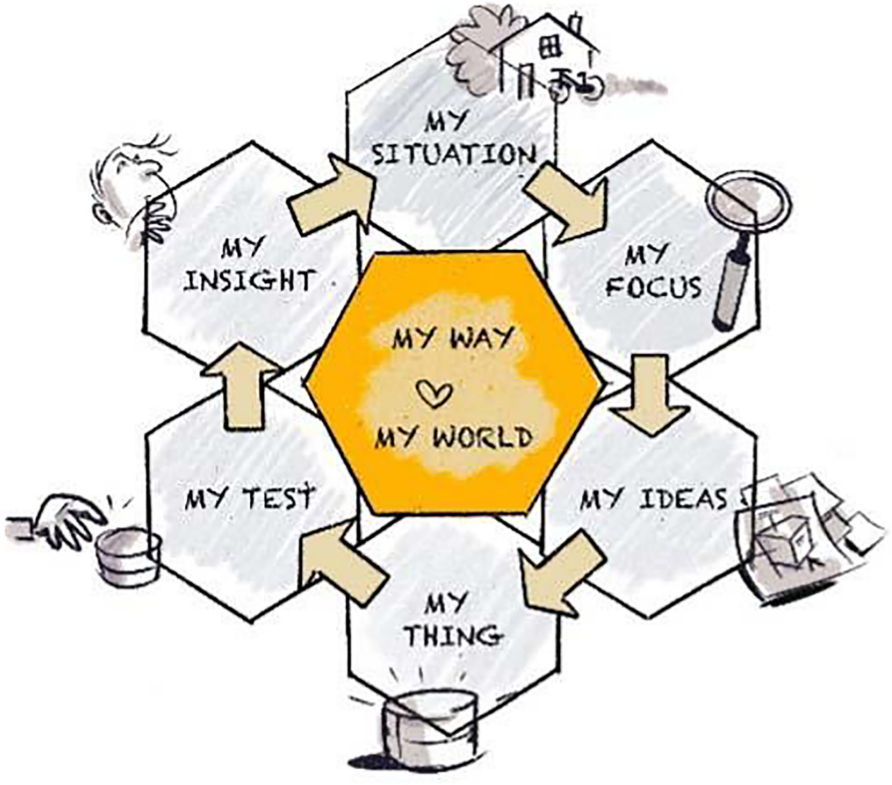
The development of the three case studies has led to development of a new design process, that we call the DYL-Cycle (Figure 11). It encompasses six design stages:

My Situation: The focus here is on establishing a self-understanding ("Who am I?", "What is the world that I live in?"), starting from the fact that a AYA and a caregiver already know each other, at least to a certain degree. So, the goal is to make the insights into one-self and one's world more explicit. Not for a designer or researcher, but for oneself, to unlock design ideas and make them actionable.

My Focus: This phase focuses on determining a specific purpose for which the solution is intended ("What should the technology support?") as relative to a larger life goal that a AYA and caregiver may define as well.

My Ideas: The idea phase begins by broadening the solution space. It is aimed at stimulating creativity to come up with possible (not obvious) solution directions. Then a choice for a specific solution is made.

Figure 11 The design your life cycle



Source(s): Designed by Nathalie Overdevest and Jelle van Dijk

My Thing: Depending on available (financial) resources, capabilities and affinity with technologies, choices are made about how to purchase or realise product(s). These circumstances influence the extent to which technology can be adapted to one's own application. Most people will be able to use technology, but fewer will (be able to) configure, adapt or create technologies themselves.

My Test: Here, products are being used in everyday life. It will be determined if and how it works and to what extent it contributes to the independence of the AYA.

My Insight: As DYL is not only focused on the development of artefacts, but also on personal development, this phase was added to reflect on the process as a whole and how it led to personal development. It is aimed at gaining insights to refine self-understanding.

My Way and My World: The DYL cycle is about developing the AYAs' experience and way of doing things. The design process results not only in personalised technology that supports independence. It also aims to contribute to personal development.

5.3 Personalisation and existing technologies

Our case studies provide a proof of principle that in thinking about technological support needs, it may be valuable to centre, and start from, the autistic experience, and how autistic people themselves make sense of their own situation, and not start from the available technologies and what they were designed for [4]. This is reflected in the design processes of the three cases, which start from the experiences of AYAs (see Figures 5, 8, and 10). Even though resulting solutions can be existing "off-the-shelf" technologies, this still means that the way one arrives at this technology and how the technology is framed (made sense of) and how it will subsequently be appropriated

(used in practice) by the person, rests on a deep understanding of the autistic experience. This should be contrasted with a more traditional "therapeutic" model whereby a professional caregiver determines based on a diagnosis "the problem" and then searches in the available offer of technological tools a fitting "solution".

On the other hand, the execution of the exercises presented several challenges that also relate to the autistic experience. First, the process at times seemed to create too much pressure. In addition, steps such as "Ideate" and "Prototype" required more time than a week. Finally, AYA sometimes forgot to complete assignments or were unable to take initiative, as was especially the case with Tim and Paul (this could be related to disrupted executive functioning (Hume *et al.*, 2009)). We suggest that the toolkit, in timing and order of steps, should be made flexible. For example, by offering a breakdown of assignments in smaller steps (if desired) and stimulating the process with regular prompts, as was suggested in case study two.

5.4 Tinkering

Although it was not a primary purpose of these studies, lessons can be learned from the fact that in two of the three case studies (Tim and Paul) no concrete technological solution had been developed. This was due in part to the insights just described. Another reason could be that there were not enough design iterations. That is, repeated cycles that allow the participants to build on earlier ideas and insights in a gradual, step by step fashion. In design thinking, it is common first to experiment and tinker and not to expect a direct result but to take initial insights produced in one cycle to the next round of design. In these cases, however, the absence of concrete results (and time limitations) after the first cycle led to disappointment and demotivation among the participants. This means the logic of gradual evolution of a design was not yet clear yet to the participants. In case one, a technology did eventually emerge. Here a new question occurred: how could the implementation of this design in practice be financed? Flexibility in financing or a personal budget may prove to be crucial (as opposed to top-down introduction of a predefined range of assistive technologies with preferred suppliers) to successfully embed DYL within professional care organisations.

6. Conclusion

This article describes the initial developments of the Design Your Life: a new approach aimed at increasing the effectiveness of technological solutions that support autistic young adults to live more independently. The added value lies not so much in the designerly approach, but mainly in putting the design tools in the hands of autistic young adults and their caregivers, called UID. This contrasts with the traditional co-design or participatory processes, where designers are still always involved. For this, the existing design tools need to be carefully selected and adapted. Ideally, this would have been done in a participatory way. But this was not decided because then the participants had to think on a meta-level (i.e. co-designing a co-design toolkit), whereas explaining the purpose of the (DYL) co-design method proved already difficult.

Furthermore, the extent to which the findings are generic or unique will be investigated. For example, it will be necessary to examine the extent to which the method itself should be customisable to users' preferences (i.e. personalising a toolkit to create personalised technologies). In any case, when successful, this approach may also have broader implications for the design and engineering practice. Because the role of designers and engineers will change when people can design and realise their own solutions. On the other hand, the vast majority will not be able to develop high-tech technology such as smartphones or robots themselves. However, realising simple technological "one-size-fits-one" solutions may be feasible. Here, the initiative lies with the users themselves. Designers and engineers will at most have a supporting role.

As described in the last section of this paper, users of the method will only be able to adapt the technology to their own needs to a certain extent. So, the effectiveness of the method will likely

depend on the willingness and capabilities of the users. Another important factor is that the application of the proposed method will have an impact on the professional caregivers and organisations that provide care to AYA. Some of the adoption facilitators and barriers well known from implementation research will also apply to the DYL method. To anticipate a better collective understanding and support within the organisation, three multi-stakeholder co-reflection sessions will be organised, in which the results of the design case studies, including the implementation conditions will be studied and interpreted from the different perspectives (Tomico *et al.*, 2011). This provides a more robust reflection of the insights: it identifies the challenges and provides the starting point for the co-design case studies that will follow.

7. Future work

At this point, we cannot conclude that our approach has positive effects on independence and empowerment. Effectiveness will be defined and made measurable so that the final method can be properly validated. In addition to multi-stakeholder meetings, seven more case studies will be carried out, which will be structurally analysed and synthesised using grounded theory (Chun Tie *et al.*, 2019). This will then be used to develop a single Design Your Life toolkit that shall be evaluated.

The case studies presented were conducted between March and November 2020. Thus, Covid-19 conditions had to be anticipated. Shorter and far fewer face-to-face co-design meetings could be organised. This may have had an impact on the outcome of the case studies. On the other hand, it also provided inspiration to explore other forms of collaboration. For example, it will be explored whether the final method can also be used remotely through creative, online collaboration platforms such as Mural or Miro.

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Notes

1. There appears to be no clear consensus on the naming of "a person with autism" (Kenny *et al.*, 2016). There are several variations, for example: "autistic person", "person with autism", "person on the spectrum", etc. In this study, the term "autistic young adult" (abbr. as "AYA", also in plural form) is used, with no intention of disregarding different conceptions of the designation.
2. In this research, we use a broader than usual definition of "young adult".
3. To protect the identity of case study participants, pseudonyms are used.
4. The findings of Personalisation and Existing technologies are discussed together.

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Further reading

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