A Study of the Challenges Related to DIY Assistive Technology in the Context of Children with Disabilities

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ABSTRACT

The term Do It Yourself Assistive Technology (DIY-AT) refers to the creation and adaptation of AT by non-professionals, including people with disabilities and their families, friends and caregivers. Previous research has argued that the development of technologies and services that enable people to make their own DIY-AT will lead to the rapid and low cost development of assistive devices that are tailored to meet the complex needs of individual people with disabilities. We present the results of a qualitative study that explored challenges related to the process of making DIY-AT for children with disabilities. A series of eleven semi-structured interviews with a broad range of stakeholders involved in the current use, provision and adaptation of AT for children with disabilities revealed a number of challenges relating to the prevalence and scope of ongoing DIY-AT practice, barriers to participation, and the challenges faced by makers and users of DIY-AT.

Author Keywords

Accessibility; assistive technology; children; DIY; disability; do it yourself; interviews; rapid prototyping.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; K.4.2. Computers and society: Social issues – Assistive technologies for persons with disabilities.

INTRODUCTION

Assistive Technology (AT) has been defined as "any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed" [6]. Many children with disabilities rely on a wide variety of AT for help and support when undertaking activities of daily living. Such AT can range from simple aids such as specialist cutlery for children with weak grip or a limited

range of motion, to more complex and expensive devices like electronic wheelchairs and augmentative and alternative communication (AAC) systems.

Despite the demand for, and potential utility of, AT for people with disabilities, its design and provision is problematic. The generic designs that are characteristic of commercially produced (i.e. *off the shelf*) AT, in many cases, fail to meet the specific, complex and often-changing needs of individuals [8, 10, 14, 18, 25, 29]. Furthermore, the procurement of AT is often an expensive and lengthy process, which fails to take full account of the needs of individuals with disabilities due to a lack of consultation and involvement of users and their caregivers [5, 7, 25, 28]. One consequence of these shortcomings is readily apparent in the results of adoption studies that have shown that around a third of AT is abandoned by its users [25, 27, 32].

Previous research [9, 10, 15, 16] has argued that the development of technologies and services that enable people to design, make and adapt their own Do It Yourself Assistive Technology (DIY-AT) has the potential to address a number of these challenges. Researchers have contended that supporting amateurs in creating such DIY-AT will lead to the development of devices tailored to meet the specific needs of individuals' with disabilities, while avoiding the lengthy and expensive process of professional-led needs assessment and procurement. While this overriding vision is profoundly engaging, the social and technical barriers that people designing and making DIY-AT may face are as yet underexplored. We describe a study that sought to uncover and explore these challenges, in the context of AT use by children with disabilities.

We conducted a series of eleven semi-structured interviews with a range of different stakeholders involved in the current use, provision and adaptation of AT for children with disabilities. Our participants included: three occupational therapists, one medical physics practitioner, two charity workers, two teachers at an additional needs school; the parents of two children with disabilities (aged 11 and 16) and a person with disabilities who makes DIY-AT as a hobby and runs a website to share his designs. These interviews sought to explore the challenges that children with disabilities face when using AT; if parents, teachers, caregivers and even children with disabilities are already making DIY-AT and what kinds of devices are

being made; and the challenges that are, or might be, faced by non-professionals when making DIY-AT. We chose to interview a varied sample of stakeholders because we wanted to develop a contextual and holistic understanding of DIY-AT practice, which would be informed by the variety of people involved in the daily living, medical care and provision of AT for children with disabilities.

Our findings suggest that only relatively small numbers of non-professionals are currently involved in the creation and adaptation of AT for children with disabilities. Self confidence in practical ability, apprehension to invest time without the guarantee of a useful outcome and factors relating to the aesthetics, practicality, robustness and safety of DIY-AT were found to be key barriers to participation. The results of our study reinforce previous work that has argued for the use of rapid prototyping technologies as the basis of future DIY-AT practice. However, our findings suggest that the impact that such technologies and emergent online resources can have on the lives of the majority of children with disabilities will depend on the development of practical services and communities that support and encourage larger numbers of non-professionals to become involved in making and adapting AT.

RESEARCH CONTEXT

The term DIY-AT refers to the development of AT by non-professionals. A number of cases where the parents, friends and caregivers of people with disabilities have made useful and functional AT have been reported. These include: a head mounted pointer for painting, a drinks holder for a wheelchair [16] and physical guides and screen protectors for touchscreens [1]. Previous research has argued that the development of such DIY-AT could, in certain situations, mitigate many of the problems that exist with the current design and provision of AT for people with disabilities.

The impairment experienced by people with the same *category* of disability can vary considerably and people with disabilities can often have multiple conditions that combine to create a unique set of individual needs [18]. Consequently, AT developed to meet the needs of a homogenized population can fail to address the specific and complex needs of individuals [10, 29]. As a result, people with disabilities are often given AT that only provides an approximate response to their requirements [8, 10] and may need to be customized or modified before they can be used effectively [18, 23]. DIY-AT has the potential to be tailored to meet the needs of individuals [9, 10, 15, 16] and, therefore, might provide a solution in situations where an off the shelf product is not suitable.

The varied contexts within which AT is used further complicates its design and provision. The effectiveness of AT depends on its relationship with a user's surroundings, situation, views, values and goals [10, 18, 24, 28]. Previous research has found that existing AT procurement does not often adequately consider the contexts within which devices are going to be used [5, 32]. Furthermore, a lack of

involvement of people with disabilities and their caregivers when selecting AT has been shown to be a significant contributing factor to high abandonment rates [8, 25, 29]. People with disabilities and their families, friends and caregivers are likely to have an excellent grasp of the circumstances that AT is going to be used in. Therefore, their involvement in the development of DIY-AT might lead to designs grounded in a more holistic consideration of the life of an individual user [9]. Moreover, the development of DIY-AT presents the opportunity for designs to be iterated *in situ* and, therefore, continually updated in response to a user's circumstances [10, 20].

The process of obtaining AT has been reported to take many months and involve referrals to multiple, often uncoordinated, organizations [5, 7]. Such delays can leave people without the aids they need for long periods of time and can prevent AT from being updated in response to changing needs and priorities that result from the development of conditions [25, 32]. Making DIY-AT might, in some cases, provide an alternative to relying on these lengthy and complex processes [15].

The cost of AT has also been found to be a significant problem for many. The essential specificity of AT leads to high development costs, small production batches and, consequently, high prices [10]. As a result, people with disabilities and their caregivers often rely on government and charity funding to purchase and maintain AT. However, finite resources and eligibility criteria mean that the AT that a person requires cannot always be funded through these channels [7]. Making DIY-AT can be cheaper than buying commercial products in many cases and, therefore, may lower costs and provide access to devices that might otherwise be prohibitively expensive [16].

RELATED WORK

A number of resources, services and technologies have been developed to assist people in making DIY-AT. Resources have been developed that provide amateurs with knowledge and information that will guide them through the design and development of DIY-AT. These include a number of books [33, 34], specialist websites [13, 31, 35], blogs [11] and online communities where people can find and share ideas, designs and experiences of making DIY-AT [2]. Additionally, there is a growing body of users on the online maker community Instructables [17] and the photo-sharing site Pinterest [e.g. 26], who post designs for DIY-AT. These resources offer a wealth of information that has the potential to inspire amateurs to become involved in making DIY-AT and guide the design, development and iteration of practical and functional devices [10, 15, 20].

Previous work has also explored how the use and development of accessible and easy to learn tools might support non-professionals and people with disabilities in making DIY-AT. Researchers have argued that digital rapid prototyping tools, such as 3D printers, might provide non-professionals with the capability to create precisely

engineered DIY-AT, using simple software running on a personal computer [10, 15, 16]. A number of specialized tools have also been developed to support the makers of DIY-AT. The Easy Make Oven is a tabletop interface that is designed to allow amateurs to quickly and easily combine physical objects and sketches into models for DIY-AT, which can then be fabricated using rapid-prototyping technologies [15]. Nickel for Scale is a computer vision application that allows objects in a camera image to be measured to scale, by automatically finding a coin in the image and using it as a reference, which was developed to help people quickly and easily take measurements of physical objects when designing DIY-AT [22].

OUR STUDY

While the vision of parents, friends, caregivers and even older children with disabilities making and adapting their own AT is profoundly engaging, the social and technical challenges related to DIY-AT are as yet underexplored. In the remainder of this paper, we present the results of a study that explored these challenges, from the perspective of medical professionals, and the parents, teachers and caregivers of children with disabilities. We adopted a qualitative approach for the study design that focused our aims, methodologically, on trying to understand the everyday, lived experiences and attitudes of the group of individuals that comprised our sample [4]. This approach determined our use of interview techniques combined with reflective resources to invite dialogue with the researchers about participants' everyday DIY-AT practices.

Our study comprised eleven semi-structured interviews with stakeholders involved in the support for daily living, medical care and provision of AT for children with disabilities. Three of the interviews were with Occupational Therapists (OT1-3), one of whom worked exclusively with children with disabilities (OT2). These OTs provided treatment and support to help people with disabilities develop and maintain activities of daily living; a practice that often involved the provision of AT. One interview was held with a medical physics practitioner (MP1), who led a team of engineers that designed and developed custom AT, and modified existing technologies, in situations where an off the shelf solution could not be found to meet an individual's specific needs. Two representatives from charities (CH1-2) that developed and adapted AT to meet individuals' specific needs were also interviewed. We interviewed two teachers, the headmaster (T1) and head of Information Technology (T2), from an additional needs school that had a large cohort of pupils who used AT. Additionally, an interview was conducted with a person with disabilities who makes DIY-AT for himself and others as a hobby, and runs a website to share his designs (HB1).

We also interviewed the parents of two children with disabilities. The first of these interviewees (P1) was the father of an eleven-year-old girl with mild to moderate learning difficulties and left-sided hemiplegia, which

limited her mobility and made it difficult for her to do activities of daily living like bathing independently. P1 also had hemiplegia. The second interview was with the father (P2) and mother (P3) of a sixteen-year-old girl with athetoid cerebral palsy, which limited her mobility, her ability to speak and caused excess movement that prevented her from completing many activities of daily living, such as eating, independently. We intended that the range of different perspectives offered by this broad sample would allow us to develop a contextual and holistic understanding of DIY-AT practice and its relationship with existing systems of care for children with disabilities.

All of our participants were based in the UK, except for HB1 who lived in the USA. Participants were initially recruited with the assistance of the headmaster of a local additional needs school, who identified a number of people involved in the provision and adaptation of AT for the pupils at his school, sent letters to parents and placed an article in the school's newsletter that described our research. A snowball sampling [21] approach was used to recruit additional participants, whereby interviewees were asked to recommend further potential participants. Interviews were audio-recorded with the prior knowledge and permission of participants.

Kuznetsov and Paulos define DIY as "any creation, modification or repair of objects without the aid of paid professionals" [19]. We adopted a similarly inclusive definition of DIY-AT during the interviews, which included any form of involvement in making, appropriating or adapting AT by non-professionals. Participants were encouraged to talk about any situations in which they or others had taken DIY action, at any scale and in any form, in response to a child's needs. To assist participating parents and teachers in understanding what we meant by DIY-AT, we showed them examples of DIY-AT downloaded from Pinterest, ranging from a pen with tennis racket grip tape wrapped around it to more complex projects that included the construction of a tablet PC stand from plastic piping.

Professionals, Charities, Teachers and the Hobbyist

Interviews with the OTs, medical physics practitioner, charity workers, teachers and the hobbyist were approximately one hour in length and were conducted by either one or two researchers. Where possible, we travelled to the participant's place of work to conduct the interview in person. However, three of the interviews were conducted using Skype (CH1-2 and HB1). The interviews broadly addressed topics that included issues and challenges currently faced by children who use AT, the participant's role in the existing provision and adaptation of AT for children with disabilities, the participant's knowledge of existing DIY-AT practices and their views about the prospect of technologies and services that enable people to make their own DIY-AT. A tailored schedule was written for each participant, to reflect the different roles that they

played in the care of children with disabilities. Additionally, the questions asked were designed to be open enough to allow each participant to elaborate about their own particular experiences of children's AT use.

Parents of Children with Disabilities

We anticipated that the prospect of making DIY-AT might be novel to many parents of children with disabilities. Therefore, we adopted an alternative interview procedure with parents, which used a *sensitizer pack* to inspire them to reflect on their child's AT use, and any situations where they or someone they knew might have developed a piece of DIY-AT, prior to taking part in the interview. This sensitizer pack was a resource developed specifically for our study and included an AT "playbook" that comprised a number of short activities that parents were asked to complete together with their child, in the week before they were interviewed. These activities included placing small colored stickers onto a cartoon map of a house, to show where their child used AT; sketching and photographing the AT that their child likes and those that they don't like, using a Polaroid Pogo camera that printed photographs onto stickers that could be stuck onto the pages of the playbook; and photographing any DIY-AT that had been made for their child by their parents, friends or caregivers. The aim of this resource was to invite everyday reflection between parents and children prior to the interview.

Interviews were conducted at a location of the parent's choice. The interview with P1 lasted approximately one and a half hours and was conducted by two researchers in the headmaster's office at his daughter's school. The interview with P2 and P3 lasted approximately two hours and was conducted by one researcher at the participants' home. The parents were asked prior to the interview whether they would like their children to take part in the discussion. In both cases they opted against direct involvement in the interview, as they felt that it would not be enjoyable for their child. However, P2's daughter joined the discussion at times to demonstrate how she used her AT.

The interviews comprised three stages. During the first stage the parents were asked about the AT used by their children. They were asked to comment on the positive and negative aspects of these technologies and the process through which they were acquired. During the second stage, parents were asked about any occasions in which they, or someone they knew, had made AT or adapted an existing object or technology to support their child. Where previous cases of DIY-AT could be identified, participants were asked about the motivation for the design and development of the technology, how it was made or adapted and by whom, any challenges that had been encountered, any sources of information that were consulted for help and how it could have been made better. The third stage of the interview commenced by asking participants to think of ideas for DIY-AT that would solve problems their child had experienced. For each design idea, the parents were asked

to comment on how they would go about making it, any problems that they anticipated encountering, and where they might go to find help with the making process. Throughout the three interview stages, parents were encouraged to use their completed playbooks to evidence and scaffold discussion.

ANALYSIS AND FINDINGS

The eleven semi-structured interviews produced a data set that comprised 11 hours and 58 minutes of audio recordings. In keeping with our methodological orientation, we performed a thematic analysis on transcripts of these recordings, in accordance with guidelines set out by Braun and Clarke [4]. This analysis followed an inductive method: transcripts were first open-coded to highlight initial themes in the data; and the themes were then iteratively refined. In the following sections, we discuss a selection of these themes that we believe will inform future research into, and design for, DIY-AT practice for children with disabilities.

Figure 1: DIY-AT by P1 (clockwise) step for garden access, rubber mat to stop plates and bowls from slipping on a table, specially installed faucet and electric can opener.

Evidence of Existing DIY-AT Practice

The interviews revealed a number of cases where AT had been developed or adapted by non-professionals. P1 spoke about a number of creative DIY projects and practices that he and his wife had completed in support of their daughter. They had purchased a number of everyday items to meet their daughter's specific needs, which included a clipboard that helped her hold the paper still when writing and drawing, a rubber tablemat that stopped plates and bowls moving around while she ate, and an electronic can opener that could be used with just one hand. Additionally, P1 and his wife had made a number of modifications to their home, which included the installation of a wet room, the construction of steps to allow their daughter to more easily access the garden and garage, and the purchase and installation of a faucet that their daughter could use more easily (Figure 1). They had developed the requirements and plans for these modifications, with help from their child's occupational therapist and a builder.

P2 had made and adapted a number of assistive devices for his daughter. His daughter often struggled to use some of the AT that she had been given, as devices would slide around on the table or desk. To resolve this problem, he attached sticky pads to the keyboard and joystick from his daughter's PC and fixed her Neater Eater, a device used to support independent eating, to the kitchen table. P2 had also made a custom spoon for this Neater Eater device, as the one supplied with it was too flexible and would bend, preventing his daughter from being able to pick up food from her plate. He made this custom spoon by molding Polymorph, a low temperature setting form of thermoplastic that is gaining increasing popularity in DIY projects, around a metal spoon so that it could slot into the device. P2 was excited about the prospect of using Sugru [30] instead of Polymorph in similar future projects, because he thought it would be easier to use and would give more robust results. P2 had also attempted to repair AT. In one case, he had used gaffer tape to reattach a broken keyguard onto his daughter's AAC device. P2 mentioned some devices and adaptations that he had chosen not to make because he was worried about damaging and voiding the warranties on expensive equipment and because of concerns about aesthetics and robustness.

HB1 had created a large number of pieces of DIY-AT. Many of the devices that he had made were simple aids for daily living, such as a rope and hook that helped him pick up objects from the floor. He had also made DIY-AT that allowed him to participate in outdoor pursuits, like hunting and fishing. He made some of these devices himself and with friends, while local crafts persons were commissioned to make more complex and ambitious designs. He shared the designs for these technologies on his website, which received around 18,000 hits per month from 126 countries. HB1 had recently begun to explore whether 3D printing could be used to help him make devices. He had experimented with an online mail order service that would print designs made using computer aided design (CAD) software. However, he had encountered problems, as having a design printed was expensive, took a long time and, therefore, permitted *"no room for error"*.

The design and development of DIY-AT by staff was quite common at T1 and T2's school. Devices made at the school included a ramp that children could roll a ball down when playing Boccia, which one of the teaching assistants had made from a piece of guttering; the adaptation of a laptop computer as a digital camera for a child who only had coarse motor skills, by using a piece of cardboard with a hole in it to mask off all but the space bar on the keyboard; and a wooden footstool that the school caretaker had made, which allowed a girl whose feet did not touch the ground when sitting in a chair to sit comfortably in class. The development of these pieces of DIY-AT was said to have often been highly collaborative; drawing on a combination of teachers' knowledge of children's needs, clinical advice from the occupational therapists and physiotherapists based

within the school, practical assistance from the caretaker and input from parents, who would often visit or call the school to discuss their child's AT needs.

While these examples reveal a variety of simple and more complex DIY-AT that has been developed by non-professionals, we are tentative about using the practices of a, potentially, vocal minority in our sample as evidence for widespread participation in DIY-AT practice. The occupational therapists, medical physics practitioner and one of the charity workers said that participation in DIY-AT practice amongst their clients was rare and, when observed, aligned more closely with the kinds of everyday creative DIY practices completed by P1 than the bespoke development and adaptation of assistive devices described by P2, P3 and HB1. The medical professionals had only seen or heard of a few cases where people had created or carried out significant alterations to AT for themselves and those around them. OT2 told us that P2 was the only parent in her caseload who had designed and developed his own AT. Furthermore, both of the teachers told us that they were not aware of many occasions where parents had made DIY-AT for children at their school. We believe that the perspectives of these participants on the issue of existing participation in DIY-AT practice are particularly important, as they are grounded in the experience of working with large numbers of people with disabilities.

Skills and Confidence

While a selection of the projects described by HB1 and P2 involved specialist making-skills (e.g. the use of Polymorph) most others, including all of those described by P1 and the teachers, did not seem to require practical skills beyond those used in a typical household DIY project. Moreover, a large number of functional pieces of DIY-AT that can be built with similarly basic making skills are found online [e.g. 13]. Such examples suggest that the development of a wide variety of useful DIY-AT should be within the capabilities of many non-professionals.

There was a consensus amongst many of our participants that despite the making of such devices being within the practical capabilities of many parents and caregivers, most would shy away from making or adapting AT due to a lack of confidence in their own practical skills. CH2's and T1's experiences of working with people with disabilities led them to conclude that most parents and caregivers would have the skills to make simple DIY-AT, but would lack the self-confidence to give it a go. HB1 believed that this lack of confidence stemmed from the assumption that the design and construction of AT cannot be simple and would require substantial engineering knowledge and skill. He had found that this misconception would often lead people to *"mentally move themselves out of the picture"* before even attempting to design and make a solution. He argued that nearly anyone can become involved in making their own AT, but only *"if they can develop the right attitude towards approaching those things"*. P1's account showed signs

mirroring these concerns, commenting that he did not believe he had the creative design skills required to envisage solutions to the problems faced by his daughter and would not be able to practically implement designs as he wasn't *"particularly DIY minded"*.

The participants' accounts of making DIY-AT suggested that non-professionals' skills and confidence would be boosted through learning by doing, once they had taken the step to develop their first device. HB1 told us that he had *"never made stuff"* before becoming disabled, but through attempting to make AT for himself he was able to gradually build up his skills and self confidence to successfully develop harder and more ambitious designs. Additionally, P2 said that his ability to design solutions for his daughter had come about through years of experimentation with different AT and the iteration of his own devices. Moreover, P2, P3, T1 and HB1 emphasized that their and others' success in making DIY-AT had not come about from having just one go, but had required significant perseverance in the face of many failed design iterations. T1 underlined the importance of the school's *"no blame"* culture in fostering such perseverance.

These findings suggest that the success of technologies and services seeking to increase participation in DIY-AT may depend on giving people the self confidence to attempt to make a first simple device, to be developed within the margins of their pre-existing skills and abilities. P1 stated that, for him, such a confidence boost would come from a practical, hands-on demonstration that would allow him to evaluate whether a technology would be useful and suitable for his daughter and whether making it would be within his capabilities. OT2 also commented that she did not believe that online resources alone would be enough to persuade parents that they can make AT themselves, as she felt they would need endorsement from, and engagement with, professionals before they would initiate their first projects.

Scarcity of Time
The availability of time to design and make DIY-AT was also highlighted as a potential barrier to participation. CH2 and T1 stressed that parents of disabled children are extremely busy, as they must find the time to manage the healthcare and wellbeing of their child in addition to work commitments and day-to-day parenting. T1 told us that the scarcity of parents' time might be particularly problematic for DIY-AT practice, as *"the children who have the greatest need take a lot of individualized support, which doesn't give parents the time to try, and to research and to look into things"*. P2 found that he had the time to make and experiment with DIY-AT for his daughter, as he was self-employed. However, he warned that his wife and other parents with full times jobs would not be able to invest similar amounts of time. Additionally, T1 commented that lack of time was a major factor that prevented teachers from developing DIY-AT for their pupils.

The parents interviewed were found to spend significant amounts of the scarce time available to them trying to procure the right AT for their children through traditional channels. Therefore, we argue that, if the making of DIY-AT can provide a quicker route to providing a child with a device that they need, parents might be persuaded to invest some of their valuable time in the practice. However, our participants' comments suggest that persuading parents to risk investing their valuable time in making DIY-AT will prove to be challenging and might not be accomplished using online resources alone.

When discussing the availability of design ideas for DIY-AT on the Internet, P1 commented that he would be reluctant to attempt to make DIY-AT unless he was sure that it would function correctly in the context of his daughter's individual needs and situation. OT3 and CH2 raised similar concerns, stating that in their experience parents would be reluctant to spend their time making DIY-AT for their child unless they could be sure that it was going to pay off with a functional and useful device. Additionally, P1, P2 and T1 believed that the presence of websites that share designs for DIY-AT would not provide parents with sufficient evidence that a particular design was worth trying. Rather, they suggested that practical demonstrations of the functionality of DIY-AT devices, and how simple they are to make, such as those held at a child's school, might do a better job of persuading parents to give it a go.

Figure 2: P2's Neater Eater mount, which couldn't be easily removed from the table for cleaning once attached.

Practicality and Robustness
P2's experiences of making and adapting AT for his daughter highlighted a range of problems related to the practicality, durability and reliability of DIY-AT. The devices that he had made often did the job that they were designed for, but suffered from a range of impracticalities. For instance, the Neater Eater mount that he had developed for the kitchen table worked fine, but the *"peculiar arrangement of plastic chocks and various screws and bolts"* he had used meant that the aid couldn't be easily removed for cleaning (Figure 2). Additionally, P2 had seen a tutorial on the Internet that showed how to make a set of accessible switches for a Kindle e-book reader. Although he had wanted to make an accessible e-book reader for his

daughter for a while, he decided against following this tutorial because the design consisted of wiring and electronic components attached to a plank of wood. He felt that this design would be too large and impractical for his daughter to use in her everyday life, and would have an appearance that she would have found unattractive (see later discussion of aesthetics).

When talking about AT use by children in general, both T1 and MP1 stressed that AT needed to be extremely robust to cope with the continuous hard use that it received in the school and home environment. A number of the pieces of DIY-AT that P2 had made had failed to withstand the pressures of everyday usage. The kinds of materials that he ended up using to create DIY-AT, *"bits of wood, tape and garden wire",* were not durable and reliable enough to create permanent solutions to his daughter's needs. For example, he had found that Polymorph thermoplastic was a particularly good material for making AT for his daughter and had used it to create a custom spoon for her Neater Eater and also an attachment for her wheelchair that would make her more visible in the crowd at a music festival. While this material allowed these devices to be made very quickly and easily, both had failed when subjected to heat: the spoon in the dishwasher and the wheelchair attachment in a hot car.

These findings demonstrate a need for the use or development of tools and services that will allow non-professionals to make DIY-AT that is practical enough to be used in, and robust enough to withstand the pressures of, a child's everyday life.

Aesthetics

The appearance and aesthetics of devices was said to be a crucial issue that would negatively impact children's experiences of using AT and lead to abandonment or rejection. OT2, OT3 and CH2 recounted cases from their own experience where AT, which would have addressed a person's needs functionally, was rejected, as its appearance would have made their user look unusual, different and highlighted the presence of their disability. OT2 stated that the appearance of AT was a particularly important issue when working with children in mainstream education, who are desperate not to stand out or look different in any way.

A number of the participants thought that the potentially rudimentary and unpolished appearance of DIY-AT might limit its usefulness in the context of children with disabilities. OT3 mentioned a number of cases in which people had rejected devices developed by volunteers from a charity that creates bespoke AT, due to their crude and unsophisticated appearance. He commented that, while capable of creating functional and practical devices, the people who volunteer for such organizations would struggle to develop technologies that have an aesthetic comparable to that of a commercial product. OT2 raised similar concerns about some of the AT that she had seen developed

by medical physics practitioners, despite these devices being made in a professional context.

P2 had already encountered such problems when considering whether or not to develop lights for his daughter's powered wheelchair, so that it could be used safely at night. While he felt that he would have had the necessary skills, materials and tools to make this adaptation, he decided against doing so, anticipating that his daughter and wife would have been unhappy with the *"gaffer tape and string"* aesthetic that he expected the result to have.

Safety and Conflict with Medical Care

The participants had a number of concerns about the potential safety of DIY-AT in certain situations. MP1 and CH2 spoke of the thorough risk assessments that they conduct to ensure that every piece of AT that they make or adapt will be safe for its intended user. They questioned whether or not non-professionals would have the required engineering knowledge and experience to be able to take similar precautions. These concerns were illustrated by OT1, who told us about a ramp that had been made by the son of a mobility scooter user. While the son had been able to make a ramp that enabled his parent to drive their scooter into the house, his design did not have a non-slip surface or side guides to prevent the scooter falling off the ramp; essential safety features that a professional with appropriate experience and training would have included.

Despite these concerns, the OTs spoke of cases in which people had made functional and safe DIY-AT. OT3 had experienced that his clients were generally very risk averse, especially the parents of children with disabilities, and, as a result, would not develop assistive devices that had the potential to endanger their users. However, he was worried that technologies and services encouraging and assisting people to make their own DIY-AT may lead people to attempt to develop devices without the necessary skills, knowledge and experience to implement them safely. OT3's comments might be of particular concern to researchers exploring DIY-AT, as the association of any technology or service with an institution such as a university might be assumed by its users to equate to a reassurance about the safety of any AT created.

MP1, OT2 and both charity workers were also anxious that DIY-AT might negatively impact upon people with disabilities, by interfering with the medical treatment that they receive. MP1 told us how people with certain neurological issues, such as cerebral palsy, could have spasms that are worsened by particular postures, movements or activities. For these patients, clinical involvement in the design process was essential to ensure that AT did not aggravate conditions or conflict with therapy. He felt that in these cases DIY-AT practice might not be conducted safely by the parents and caregivers of children with disabilities alone, but would need to involve medical professionals.

In contrast to these fears, all of the parents interviewed exhibited a strong reluctance to the prospect of making adaptations to AT that had been provided to them as part of their child's medical treatment, despite being aware of a number of simple practical changes that they would like to make to AT used by their children. P1 told us about a situation in which he and his wife had been tempted to cut a piece of Velcro off a foot orthotic to make it more comfortable for his daughter. However, he decided against doing so, concerned that making such an adaptation without permission might undermine and, therefore compromise, the family's relationship with his daughter's OT.

Professional involvement in the design process was proposed as a solution to both of the aforementioned safety concerns. The medical physics practitioner had already been asked to inspect the safety of DIY-AT created by non-professionals on a number of occasions. In cases where he found these devices to be unsafe, he would work with the people who had made them to develop a more satisfactory solution. OT3 had also inspected the safety of DIY-AT and P1 spoke of how an occupational therapist had inspected a plan for a step and a rail that would help his daughter use the backdoor, before he commissioned a builder to make it.

These findings suggest that professional involvement in the development of DIY-AT is already well established and, therefore, might offer a practical way to ensure that DIY-AT is safe for its users. However, due to the scarcity of time and resources available to medical professionals such as occupational therapists, alternative ways to ensure that DIY-AT is safe, which don't involve medical professionals, might be required if the practice is to scale.

Repair
Our findings also highlight a number of challenges faced by users of AT when devices break. Our participants told us that AT is often subjected to continuous and hard usage and, as a result, often breaks and becomes unusable. When devices break they must either be repaired or replaced. Our participants said that both routes could often take as long as the process through which a device was originally acquired. Consequently, broken AT would often leave users without the aids they needed for long periods, unless alternative or back up devices (e.g. an older version that has been replaced) could be found. For example, HB1 had worked with his son to help him fix the arm support on his wheelchair, when faced with such a situation.

The experiences of P2 and P3 suggest that many repairs to AT could potentially be made by non-professionals, but are currently often impossible to do. When asked about the most problematic aspects of their daughter's AT usage, they recounted a number of cases where expensive pieces of equipment had been rendered unusable for long periods of time due to small components, usually pieces of plastic, breaking or being lost. For example, their daughter's AAC device would sometimes be rendered unusable, due to the small plastic clips that hold the keyguard in place snapping.

Additionally, the footplates on her wheelchair would often come loose due to the small plastic spacers that hold them in place breaking. P2 also told us about a case where another child had been unable to use her powered wheelchair, because the plastic handle on the joystick used to control it had fallen off and been lost.

In such situations, attempts to repair devices were hindered due to these small parts not being available for purchase, as the companies that produce AT were often not used to dealing directly with the end-users of their technology. Also, attempts to replace parts of AT with readily available components (e.g. nuts and bolts that might be purchased from a DIY or car repair shop) were said to have failed, as manufactures commonly used bespoke components. P2 questioned whether this might be an intentional decision.

These findings highlight the difficulty of obtaining custom parts as a major challenge preventing non-professionals from repairing AT. However, they also illustrate a willingness to conduct such repairs amongst amateurs and, therefore, reveal an *opportunity* for the design of technologies and services that might circumvent this challenge. For example, 3D printers or other rapid prototyping technologies could potentially be used to fabricate replacements for lost or broken components.

DISCUSSION AND IMPLICATIONS FOR DESIGN
Our study revealed a number of challenges that non-professionals may face when making and adapting AT for children with disabilities. To conclude, we discuss the implications of our findings for future research and design that seeks to enable people to make and adapt DIY-AT.

Focusing on Rapid Prototyping Technologies
The findings of our study reinforce previous work that has argued for the use of rapid prototyping technologies as the basis of DIY-AT practice [10, 15, 16]. Technologies such as 3D printers have the potential to address a number of the challenges identified in our participants' accounts. By giving non-professionals the capability to produce precisely engineered physical forms using software available on a home computer, rapid prototyping technologies have the potential to support the development of more robust and practical DIY-AT. Additionally, we anticipate that the use of rapid prototyping tools will allow for the development of DIY-AT with a much more refined aesthetic, which, in turn, may be more acceptable to children with disabilities.

Our findings also suggest that rapid prototyping technologies could play an important role in supporting the repair of commercially produced assistive devices, when failure has been caused by simple components breaking. CAD and 3D printers could be used to facilitate such repairs by allowing non-professionals to replicate parts that might otherwise have been difficult or impossible to source. In cases where a part might be too complex for a non-professional to easily replicate, photogrammetry software [e.g. 3] could be used to support the modeling process.

Alternatively, designs for parts that are known to break frequently could be made available by manufacturers or shared amongst members of local and online communities.

Recent discourse [e.g. 12] has argued that a personal scale manufacturing revolution is coming, which will place rapid prototyping technologies into the hands of the general population. However, we anticipate that most non-professionals would require some degree of training before they could use such tools to make DIY-AT. Moreover, our findings relating to parents' unwillingness to invest time in DIY-AT activities without reassurance they will result in a useful outcome for their child, suggest that many would not investigate and begin to use rapid prototyping technologies without some form of encouragement and support.

Increasing Participation through Practical Communities
Our findings suggest that only relatively small numbers of people are currently involved in the development of DIY-AT for children with disabilities. We believe that these findings demonstrate a need for future research and design that seeks to increase these levels of participation, if emergent online resources about DIY-AT and the development of novel rapid prototyping tools are to have an impact on the lives of large numbers of disabled children. Our study has highlighted a number of barriers that may prevent non-professionals, and parents especially, from making DIY-AT. In particular, our study suggested that a lack of self-confidence in practical skills and a scarcity of, and apprehension to invest, time might prevent people who would otherwise have the skills and resources to begin to make DIY-AT from attempting to do so.

Existing online communities – and the resources they have developed for DIY-AT – have the potential to address a number of these challenges. The simplicity of the designs found on these sites, and the basic skills and materials required to make them, could be used to convince people that making DIY-AT is within their capabilities. Furthermore, the functional and useful nature of the designs on these sites, which are often demonstrated with an accompanying case study of the person that they were designed for, might also reassure prospective makers that time invested in DIY-AT will often be repaid with a positive outcome for a child's care. However, the lack of awareness and use of these sites amongst our participants suggests that their existence alone may not be sufficient to achieve these outcomes. Instead, our participants' comments suggested that a more practical approach based around the hands-on demonstration of, and experimentation with, DIY-AT would be required to convince greater numbers of people to attempt to make their own AT.

The school where the teachers worked stood out as offering such a practical environment, where non-professionals (i.e. school staff) were encouraged and supported to make DIY-AT by their peers. We found that the DIY-AT made at the school was designed, implemented and iterated through discussion and collaboration between staff with differing ideas, experience and practical skills. Furthermore, the DIY-AT practice at the school was founded on a *"no blame culture"* that encouraged the staff to experiment and persevere with design ideas, when they didn't work first time. We draw inspiration from the case of the school to argue that similar communities of people making DIY-AT established amongst the parents, friends and caregivers of children with disabilities might have the potential to encourage participation, boost skills and demonstrate the practical utility of DIY-AT practice amongst these groups.

One approach to foster the development of such practical communities might be to create open and freely available courses that teach people the skills required to make simple DIY-AT. Such courses could draw on the rich knowledge base already available on the Internet to provide people with the practical confidence boost, and illustration of utility, that our findings suggested would be essential to encourage larger numbers of people to make DIY-AT. We envisage that motivated individuals, like P2 and HB1, within existing communities of parents, teachers and caregivers of children with disabilities might use these courses to inspire and support their peers to make their first DIY-AT and, subsequently, to develop a collaborative and supportive culture of making DIY-AT similar to that which was emerging at the school. Such courses might also teach the skills required to incorporate rapid prototyping technologies into DIY-AT practices; therefore, addressing the aforementioned concerns about the lack of such competencies amongst non-professionals.

An alternative but related approach to fostering participation in DIY-AT practice would be to connect parents, teachers and caregivers of children with disabilities with members of the wider maker community. For example, online tutorials could be augmented with a link that allows a person, who might not have the skills or self confidence to make a device on their own, to post a request for help to members of their local Maker Space, and work with them throughout the design and development process. Involving members of the wider maker community may also foster the sharing of know-how, advice and access to materials and tools to scaffold the development of more advanced, robust, practical, aesthetically pleasing and safer DIY-AT.

In summary, we envisage that the combination of such practical communities with new rapid prototyping technologies and promising existing online resources may help address the challenges highlighted in this paper and, consequently, allow DIY-AT to have a greater impact on the lives of larger numbers of children with disabilities.

REFERENCES

1. Anthony, L., Kim, Y. & Findlater, L. Analyzing user-generated YouTube videos to understand touchscreen use by people with motor impairments. In *Proc. of CHI '13*, ACM (2013), 1223-1232.

2. Assistive Technology Needs: A Do-It-Yourself Resource. http://www.at-needs.com.

3. Autodesk 123D - 123D Catch turn photos into 3D models. http://www.123dapp.com/catch.

4. Braun, V. & Clarke, V. Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3, 2 (2006), 77-101.

5. Copley, J. & Ziviani, J. Barriers to the use of assistive technology for children with multiple disabilities. *Occupational Therapy International*, 11, 4 (2004), 229-243.

6. Cowan, D. & Turner-Smith, A. The role of assistive technology in alternative models of care for older people. In Sutherland, I. (ed.) *With Respect To Old Age: The Royal Commission for the Long Term Care of the Elderly* (1999), Stationary Office, 325-346.

7. Cowan, D. & Turner-Smith, A. The user's perspective on the provision of electronic assistive technology: Equipped for life? *BJOT*, 62, 1 (1999), 2-6.

8. Dawe, M. Desperately seeking simplicity: how young adults with cognitive disabilities and their families adopt AT. In *Proc. of CHI '06,* ACM (2006), 1143-1152.

9. De Couvreur, L., Detand, J. & Goossens, R. The role of flow experience in co-designing open-design assistive devices. In *Proc. of Include '11*, (2011).

10. De Couvreur, L. & Goossens, R. Design for (every) one: co-creation as a bridge between universal design and rehabilitation engineering. *CoDesign*, 7, 2 (2011), 107-121.

11. DIYAbility: Where MacGyver meets Assistive Technology. http://diyability.org.

12. Gershenfeld, N. *Fab: the coming revolution on your desktop—from personal computers to personal fabrication.* Basic Books, 2008.

13. Handihelp. http://www.handihelp.net.

14. Hasselbring, T. & Glaser, C. Use of Computer Technology to Help Students with Special Needs. *Children and Computer Technology*, 10, 2 (2000), 102-122.

15. Hurst, A. & Kane, S. Making making accessible. In *Proc. of IDC '13,* ACM (2013), 635-638.

16. Hurst, A. & Tobias, J. Empowering individuals with do-it-yourself assistive technology. In *Proc. of ASSETS '11*, ACM (2011), 11-18.

17. Instructables: Assistive Technology. http://www.instructables.com/group/Assistive_Tech.

18. Kintsch, A. & DePaula, R. A framework for the adoption of assistive technology. In *Proc. of SWAAAC '02*, E3 (2002), 1-10.

19. Kuznetsov, S. & Paulos, E. Rise of the expert amateur: DIY projects, communities, and cultures. In *Proc. of NordiCHI '10*, ACM (2010), 295-304.

20. Leduc-Mills, B., Dec, J. & Schimmel, J. Evaluating accessibility in fabrication tools for children. In *Proc. of IDC '13*, ACM (2013), 617-620.

21. Morgan, D. *The SAGE Encyclopedia of Qualitative Research Methods*. SAGE Publications, 1998.

22. Nickel for Scale. http://nickelforscale.com.

23. Ossmann, R., Thaller, D., Nussbaum, G., Pühretmair, F., Veigl, C., Weiß, C., Morales, B. & Diaz, U. AsTeRICS, a Flexible Assistive Technology Construction Set. *Procedia Computer Science*, 14 (2012), 1-9.

24. Parette, P., VanBiervliet, A. & Hourcade, J. Family-centered decision-making in assistive technology. *Journal of Special Education Technology,* 15, 1 (2000), 45-55.

25. Phillips, B. & Zhao, H. Predictors of Assistive Technology Abandonment. *Assistive Technology: The Official Journal of RESNA*, 5, 1 (1993), 36-45.

26. Pinterest: Low Tech AT Ideas. http://www.pinterest.com/cmcormier/low-tech-at-ideas.

27. Riemer-Reiss, M. & Wacker, R. Factors associated with assistive technology discontinuance among individuals with disabilities. *Journal of Rehabilitation*, 66, 3 (2000), 44-50.

28. Scherer, M. Outcomes of assistive technology use on quality of life. *Disability & Rehabilitation*, 18, 9 (1996), 439-448.

29. Scherer, M. The change in emphasis from people to person: introduction to the special issue on Assistive Technology. *Disability & Rehabilitation*, 24, 1-3 (2002), 1-4.

30. Sugru: The Future Needs Fixing. http://www.sugru.com.

31. The Remapedia. http://www.remapedia.org.uk.

32. Verza, R., Carvalho, M., Battaglia, M. & Uccelli, M. An interdisciplinary approach to evaluating the need for assistive technology reduces equipment abandonment. *Multiple Sclerosis*, 12, 1 (2006), 88-93.

33. Werner, D. *Disabled Village Children: A Guide for Community Health Workers, Rehabilitation Workers, and Families* (2nd ed.). The Hesperian Foundation, 1987.

34. Willkomm, T. *Assistive Technology Solutions in Minutes: Make a Difference Today!* ATECH Services, 2005.

35. Workshop Solutions: Homebuilt Assistive Devices for the Disabled. http://www.workshopsolutions.com.