“I Am Not an Engineer”: Understanding How Clinicians Design & Alter Assistive Technology

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Abstract
In the emerging maker movement, clinicians have long played an advisory role in the development of customized assistive technology (AT). Recently, there has been a growing interest in including clinicians as builders of Do-It-Yourself (DIY) AT. To identify the needs of clinicians-as-makers, we investigated the challenges that clinicians faced as they volunteered in an AT building project where they were the primary designers and builders of assistive mobility devices for children. Through observation and co-building of modified ride-on toy cars with clinicians, we found that the rapid pace of development and transient relationship between user and builder did not allow for a complete assessment of the child’s mobility. Furthermore, clinicians struggled to actualize concepts borne out of their clinical intent due to a lack of engineering skill. This study highlights the need for tools that support clinicians-as-makers in the AT maker process and a new conceptualization of the role of DIY-AT maker programs within the AT provider ecosystem.

Author Keywords
Assistive Technology; Making; Physical Therapy; Children

CCS Concepts
•Human-centered computing → Empirical studies in accessibility;

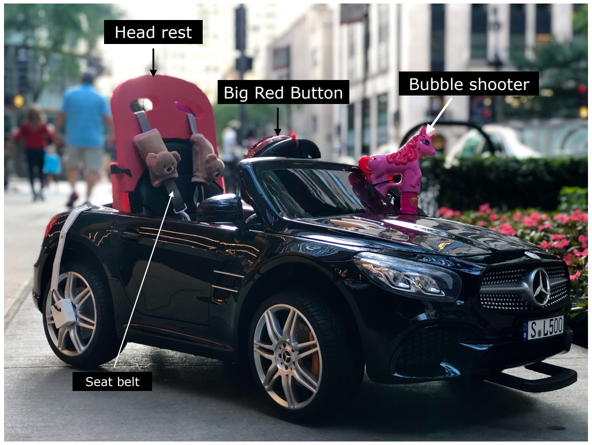


Figure 1: Modified ride-on car standing outside of our study's build location. The modifications are annotated.

Introduction

For children with mobility disabilities, lack of access to assistive technology (AT) at an early age has long term negative social and cognitive impacts [19, 11, 18]. Children with disabilities are predicted to have worse educational and health outcomes when compared to their able-bodied peers [26] and are systematically stigmatized and excluded from social institutions [8]. The goal of AT such as the walker and the power chair is to reduce the impact of disability on one's life by allowing independence and enabling exploration. However, there are numerous barriers to obtaining and using commercial AT, such as cost, size, ease of transportation, and social acceptance [2, 17]. One means of circumventing these barriers inspired by the maker movement is to hack together AT solutions from cheap and readily available products found in hardware or department stores.

A focus on healthcare within this "maker movement" translates to the creation and provision of rapid and patient-specific solutions [30, 10, 20, 4]. Prior studies have investigated the needs of clinicians as advisors to non-clinician makers of AT during the building process to ensure the patient's safety and comfort [14, 12, 24]. However, a number of clinician groups have surfaced over the last few years where clinicians themselves are makers [22, 9], yet little research has investigated the role of clinicians as makers in this community and the unique challenges they may face in a non-clinical environment.

In order to better design for clinician makers, we conducted observations and interviews with clinician (physical therapist) volunteers of GoBabyGo![1], a program that provides children with AT by modifying toy cars into mobility devices. We examined the challenges that clinician-as-makers face in maker environments and found that (1) due to the limited access to children and their parents, clinicians were unable to conduct a full assessment of the child's abilities and (2) due to a lack of confidence and engineering skill, clinicians struggled to actualize concepts derived from their clinical training. Finally, we discuss the implications for designing technologies and processes that can support clinicians in a time-constrained making process.

Background

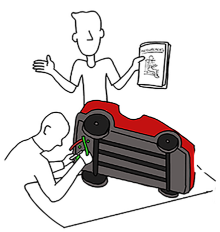
In this section, we provide a closer look at the specific challenges in both design and distribution of AT, specifically focusing on pediatric mobility and how the maker movement has made strides in addressing these issues. Then, we provide a brief overview of the involvement of clinicians as makers.

[1] https://sites.udel.edu/gobabygo/

Phase	**(a) Initial assessment**	**(b) Build days**	**(c) Hand-off day**
Duration	2 hours	2 days/ 4 hours each	2 hours
Members	Children, parents, and clinicians	Clinicians and engineers	Children, parents, and clinicians
Activity	Clinical evaluation of child and interview parents	Assemble and build	In-person adjustments

Table 1: Summary of the stages in the GoBabyGo! program.

(a) Initial assessment



(b) Build days

(c) Hand-off day

Figure 2: Visual breakdown (a-c) of the GoBabyGo! process

Limitations of the powered wheelchair
Children learn through navigating their surroundings and for those with limited mobility [23], specialized pediatric interventions such as assistive technology AT can be prescribed to afford them the same opportunities for social and emotional development [19, 15]. One commonly prescribed AT for mobility is the powered wheelchair, however commercial power wheelchairs are developed for a homogenized population, failing to meet the complex and individual needs of those who fall out of standardized dimensions [6]. Numerous attributes of powered wheelchairs limit their utilization in naturalistic real-world settings including classrooms and playgrounds [5, 19]. The cost of a powered wheelchair may start from $2000 with many costing more than $20,000 [28, 1] which is often a barrier to low-income families considering how young children may quickly outgrow their device [25]. In response to these shortcomings, individuals such as family, friends, or caregivers of children with disabilities have started looking to build their own AT.

From AT prescribers to AT makers
Studies on the AT maker movement have mainly positioned clinicians as advisors to makers [12, 24], yet there is a growing number of programs in which clinicians participate as makers themselves [13, 22]. Traditionally, clinicians such as physical therapists and occupational therapists prescribe their patients' AT, fit the AT, and train patients and caregivers on how to use the AT. Having clinicians play a larger role in the development of AT may lead to the creation of devices that are more medically functional and safe [14]. Early studies have explored the difference between the experiences of clinicians and volunteers in DIY-AT spaces, concluding that clinicians and non-clinical volunteers had differing conceptions of risk and challenges around collaboration [12, 24].

In order to gain a deeper understanding of the needs of clinicians volunteering to build AT within a rapid "maker" environment, we conducted observations of clinicians building for GoBabyGo!, a program hosted at various institutions that provides an alternative to the power wheelchair, customized modified ride on cars (mROCs), to children with mobility disabilities.

Study setting: GoBabyGo!
The primary mission of GoBabyGo! is to increase access to powered mobility devices for children ages 2 through 5 that have some mobility impairment due to conditions such as cerebral palsy, hypotonia, or developmental delay. mROCs afford users the agency to choose where they go and who they interact with, fostering environmental and social exploration, all while motivating them to complete therapeutic exercise and have fun [7, 27, 21]. Built from commercial ride-on toy cars, modifications are designed to encourage children to acquire physical skills. For example, one modification requires the child to stand in order for the

car to move forward; when they sit down, the car stops [16]. Other common modifications include the Big Red Button for moving forward (instead of gas pedal), headrest for support, and seatbelt for safety. Additionally, volunteers often tailor features of the car according to the child's preferences such as the bubble shooter seen in Figure 1. While free to families, the cost of making each mROC is less than $400 and depending on the modifications, may make the mROC a substantially more affordable alternative to the powered wheelchair.

At the institution we studied, a GoBabyGo! car is built during two 'build days' when clinician volunteers (physical therapists), engineering volunteers, and others come together to transform toys car into AT devices. Groups of 3 to 5 volunteers form a team that are responsible for building one car. These teams typically consist of 3-4 clinicians and one engineer, but may not involve an engineer depending on availability. Table 1 provides an outline of the GoBabyGo build process at the midwestern institution where we conducted our study.

Methods

We observed and assisted volunteers across two build days. Afterwards, we conducted semi-structured interviews with a subset of the volunteers. By directly observing their build process and assembling mROC with the clinician volunteers, we were able to better understand GoBabyGo's maker environment and culture. We took photos and notes during build days which were used to inform the semi-structured interview guide. We sent an email to all those who volunteered in the observed GoBabyGo! build and eight volunteers agreed to participate in the semi-structured interview. The semi-structured interviews took place remotely via phone and each call lasted for 60 to 70 minutes. Upon obtaining consent, audio recordings were transcribed verbatim. In the following sections, for anonymity we refer to each participant as P##. P05 mentioned that they were pursuing a doctoral degree in engineering making them a significant anomaly and thus was disregarded from analysis, leaving a total of seven transcripts in our analysis. Our methods were reviewed and approved by Northwestern University Institutional Review Board.

We reviewed our data throughout the data collection process using an iterative open coding process [29]. In accordance with Braun and Clark's thematic analysis [3], as our corpus grew, we organized our codes into axial codes and developed a code book which was continuously refined. All transcripts were re-coded using the final code book.

Findings

Based on our observations and interviews, we found that participants lacked the opportunity to conduct a complete assessment of the child's mobility and overall context of use for the mROC due to complications with children's mood at the time of assessment and lack of time to gather information from the parent. We also found that clinicians required engineering support and lacked confidence to implement the modifications they envisioned.

Incomplete assessment of the child's needs

In contrast to traditional AT fitting processes in the clinic, during the GoBabyGo! maker process, volunteers only had a few hours in a single day to assess the child's posture, balance, and strength, which led to an incomplete picture of the child's abilities. During the Initial Assessment (see Figure 2), P07's child was having a 'bad day' and unresponsive; their team attempted to assess strength by convincing the child to push against the palms of their hands. P07 mentioned that evaluations in a clinical pediatric physical therapy setting typically occurred over the course of time as the child continued to attend treatment sessions, allowing for a more complete picture of the child's abilities. P08 also discussed the need for multiple sessions with the child to observe their posture in order to design the seat, arguing that a one-time meeting with the child led to the accumulation of fitting errors. During the hand-off day, P08 recalled seeing that the car did not fit the child well: *"We were looking at her and she didn't sit right....there was a hundred different things wrong about her posture."* This prompted last-minute modifications that took two-hours to address before handing off the car. In essence, the lack of extended time to observe and perform a variety of clinical assessments led to the need for last minute modifications on the day the parents and child came to pick up the mROC.

Clinicians aimed to draft the design of the mROC according to the families' goals for their children's mobility while keeping in mind the environment within which they intended to use the AT. Ideally, parents would inform how the mROC should be designed, according to P02: *"If [home is where] the child is going to be using the car, it's not a bad idea to see how this child is going to be navigating in the environment and what modifications to the car [are needed]."* When asked how they would re-imagine GoBabyGo! build days, all clinicians wanted the families and children to be physically present for the build process rather than solely meeting them during the initial assessment. However, half of the of the clinicians recognized that parents of children with disabilities are extremely busy, as P01 explained: *"Moms are busy. Moms with children of special needs are three times busier. It's a lot of work. Adding a two-hour commute to their schedule is unreasonable."* Clinicians stressed the necessity of longer and recurrent sessions with the children and parent to better design and customize their AT, but believed that it is an impractical request.

Struggles actualizing clinically-derived design concepts
While ideas for modifications were informed by interviews with the parents and some understanding of the users' mobility, not having engineering skills was a barrier to the implementation of these clinically-informed designs. Compared to non-experts, clinicians are uniquely equipped to identify biological and ergonomic requirements when designing the mROCS, yet among our participants, most expressed that they did not have the confidence to construct substantial modifications to the car. Concerns around implementing modifications were most apparent when making electrical modifications to the car. Clinicians struggled to distinguish which wires to cut and attach in order to install the *Big Red Button* modification, which is a button that replaces the standard but less accessible gas pedal (see Figure 1). Numerous clinicians reported avoiding the task of wiring the button entirely and sought assistance from the engineers, as P03 notes *"I don't feel like I would have been able to do that successfully. I'm not an engineer and I don't understand how any of that works."* In one example, P02 wanted to build an accessible button on their mROC so that the child can easily press it to play music. However, they struggled with the electrical wiring and could not receive engineering assistance as all the volunteers with engineering experience were occupied. The idea was dropped and P02's team shifted their focus to more achievable tasks that did not require circuitry manipulation. Existing technical manuals for GoBabyGo! that are available online and distributed in the builds were left unread due to a lack of confidence and a sense of risk as P03 described, *"I feel like that would have been really hard to try to learn engineering from a manual and rewire a car even if they were directions. I still would have screwed that up quite honestly"*. Participants believed that without the involvement of engineers, very few modifications would have been implemented. Clinicians understood that their clinical expertise is important

during the design phase, but they were not equipped for the build phase.

Discussion & Future Work

We investigated a DIY-AT maker space in which clinicians volunteer as designers and builders of AT to explore the needs of clinician makers. While all participants successfully provided a child with AT, the time constraints lead to an incomplete assessment of the child's mobility which resulted in last minute modifications during the hand-off process, when the child and their parents were present and the child's mobility could be reassessed. Our research corroborated prior findings by Hofmann et al. who found that clinicians strongly recommend following up with patients after they receive their AT [12]. We also identified a skills gap that prevented clinicians from actualizing some of their own proposed design specifications. We propose that future research should investigate how to provide clinician-maker volunteers with the engineering training required to execute their envisioned designs as well as a conceptual shift in the role of volunteer DIY-AT project models from providing "complete" AT to an AT "work-in-progress."

Future work should investigate the socio-technical environment in which these clinician-as-makers projects are situated in and how clinicians within and outside of such projects can collaborate to provide and maintain AT for their patients. The value of the DIY-AT maker-movement is that it increases access to otherwise expensive AT at low cost in potentially less time. With adequate training and support, clinicians-as-makers can ensure that the DIY-AT provided is clinically informed and safe. Clinicians-as-makers can also ensure that the AT recipient's primary physical therapist can understand and adjust the AT as needed. A pediatric physical therapist may be able to continue modifying the AT such that it could adequately fulfill a child's changing needs. While our research has surfaced significant design challenges, there are clear opportunities to further support clinicians as makers.

Conclusion

In this study, we conducted observations and interviews with clinician volunteers of GoBabyGo!, a clinician-led maker program that has been established to create low-tech and affordable AT for children. Our results highlighted how clinicians were unable to adequately assess the child's mobility due to the limited interaction with the children and their parents during the building process. Furthermore, we found that clinicians struggled with actualizing design ideas that involved electrical circuitry due to a lack of engineering training. As we deepen our understanding of how to support clinician-makers, we can begin to envision a future where DIY-AT processes may eventually connect back to formal clinical processes in order to deliver low-cost customized AT for all.

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