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# "Knowledge Comes Through Participation": Understanding Disability through the Lens of DIY Assistive Technology in Western Kenya

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People with disabilities in Low- and Middle-Income Countries (LMICs) have limited access to digital assistive technologies (ATs). Most ATs in LMICs are manufactured elsewhere and are expensive and difficult to maintain. Do-It-Yourself Assistive Technologies (DIY-ATs) designed, customized, and repaired by non-technical users offer exciting directions in these contexts. We have been exploring the possibilities and challenges of DIY-ATs in Western Kenya, using community-engaged workshops in rural and urban special education schools for the past three years. We present findings from a concluding-stage research activity: a multiple stakeholder focus group where teachers, disability advocates, and representatives from the local government and technology innovation hubs, discussed the possibilities and challenges of addressing disability issues through DIY-ATs in this context. Participants identified opportunities for DIY-ATs for social inclusion, disability assessment, and inclusive education, and shared concerns about their sustainability, safety, and contextual relevance.

CCS Concepts: • Human-centered computing → Accessibility ~ Empirical studies in Accessibility

Additional Key Words and Phrases: Kenya, Disability, DIY Assistive Technologies, Participatory Design, Community Engagement

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#### **1 INTRODUCTION**

According to the World Health Organization (WHO), only 5-15% of people with disabilities in Low- and Middle-Income Countries (LMICs) have access to assistive technologies (ATs)

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[52]. Furthermore, most research on assistive technologies in LMICs is concentrated in a few countries (i.e., India and China), and there is a gap in research in Africa and the Middle East [22]. There is a crucial need for researchers and practitioners worldwide to envision a global role for emerging interactive technologies to help overcome sociotechnical barriers to empowerment and social inclusion for people with disabilities [4,22,29]. The potential of developing and applying new approaches to create better access to ATs in LMICs through capacity-building and community engagement is understudied. In this work, we investigated diverse stakeholder perspectives on the possibilities and challenges of digital Do-It-Yourself (DIY) assistive technologies (DIY-ATs) to support the inclusion and empowerment of people with disabilities in Western Kenya with a view of informing similar efforts in other LMICs. We sought to create a space of inquiry in which stakeholders could situate their discussions of DIY-ATs within a larger discourse of local sustainability and infrastructure needs and to take up postcolonial critiques more generally [21,49].

In recent years, Kenya has taken a leading role in East Africa, both in digital technology innovation and in disability rights policy reform [14,44,48]. The rapid expansion of the tech industry in Kenya since the mid-2000s and its connection to the global fiber optic cable network since 2010 has led to the nickname "the Silicon Savannah" [44]. Numerous innovation hubs and incubation centers are active in the country, including makerspaces and FabLabs that provide access to digital fabrication and hands-on technology design activities to community members [9,14]. Many of the most widely-used technologies in the region, such as the m-Pesa mobile banking platform [19], are being developed in Kenya.

Kenya has also shown leadership in the regulatory approaches to recognize the rights of people with disabilities. The Kenyan government ratified the U.N. Convention on the Rights of Persons with Disabilities (CRPD) in the mid-2000s, and the National Kenyan Constitution officially recognized disability rights in 2010 [48]. In response to these developments, several initiatives were launched to develop new technologies and services for people with disabilities. For example, in 2019, the Global Disability Innovation Hub and Amref Enterprises Limited initiated the Assistive Technology Innovation Ecosystem and Startup Accelerator in Nairobi [54]. With a budget of almost two million dollars, the program is designed to support 50 assistive technology startups over the next 3-5 years. Thus, it is timely to study diverse stakeholder perspectives in Kenya on how a new wave of ATs can support people with disabilities.

Do-It-Yourself (DIY) and Do-For-Others (DFO) assistive technologies (DIY-ATs) refer to customized solutions designed to be fabricated, assembled or redesigned, and remixed by people with disabilities and their caregivers, teachers, therapists, and peers [17,18,31,40]. Fueled by the availability of consumer-market digital prototyping and fabrication tools, such as 3D printers and the Arduino and Raspberry Pi microcomputers, increasing numbers of technology enthusiasts and amateur designers have been drawn to making activities that result in the design, sharing, and fabrication of DIY-ATs. Examples of these technologies include customized computer input devices [18] and 3D printed grips and prosthetics [28].

Previous research has shown that DIY-ATs can be customized for each user and often cost less than commercially available options [13,17,18,31]. People with disabilities and their family members, teachers, therapists, or volunteers who design and fabricate DIY-ATs can also feel increased empowerment and agency [36, 44]. Despite their potential, research has also identified challenges in this space. These include a lack of resources on ensuring

DIY-AT designs are safe and reliable and how to decrease the technical skills needed by users to fabricate and troubleshoot DIY-ATs [16].

However, research on DIY-ATs has so far focused on Western contexts, and few projects have explored the potential of this approach to provide access and increase social inclusion of people with disabilities in LMICs. Moreover, to our knowledge, research has not studied the space of DIY-AT development for people with cognitive disabilities or with communication disorders in LMICs.

In our longitudinal project, we studied two research questions. First, what are the current political, social, and technical factors that impact accessibility and access to assistive technologies in Kenya, and how may they inform a potential role for DIY-ATs in this context? Second, what longitudinal reflections would be brought to the table by diverse stakeholders invested in improving the lives of people with disabilities regarding the infrastructures and social and technical conditions needed for DIY-ATs to be feasible and effective solutions in Kenya? Distinct from work previously presented on the experience of children with disabilities with DIY-ATs in this context [13], the current paper focuses on the results of concluding-stage research activity within the project: the longitudinal reflections of community stakeholders about the possibilities and challenges of DIY-ATs after experiencing the use of such an open-ended system in several local schools over time.

We used a Community-based Participatory Design (PD) approach [7] to include diverse stakeholder engagement on the possibilities and challenges of DIY-ATs in Kenya. DiSalvo et al. describe Community-based PD as "a distinctive field of Participatory Design research and practice that highlights the social constructs and relations of groups in settings that include, but go well beyond, the formal organizational structures commonly foregrounded in more traditional workplace studies [7]." DiSalvo et al. further describe that this field of PD focuses on participation by a community formed with shared geography, identity, or interests and In our project, the community consisted of organizations, including practice [7]. community-based organizations (CBOs) and individuals in Western Kenya invested in the education and inclusion of children and young adults with cognitive disabilities that impact communication skills. PD has been successfully used in previous projects that focus on the design and evaluation of assistive technologies (e.g., [11,32,53]). In our project, adopting a PD approach reflected a commitment to include diverse stakeholders at every stage of the project and from the outset and use participatory tools and methods to create opportunities for mutual learning for both designers and stakeholders. We used an open-source DIY prototyping platform [12] for creating augmentative and alternative communication (AAC) devices as a technology probe [19] to facilitate conversations about the possible futures of DIY-ATs in Kenya.

This paper contributes to a better understanding of diverse stakeholder perspectives on the possibilities and challenges of DIY-ATs in Kenya. Specifically, it describes how assistive technologies are situated in a web of political, economic, and sociocultural factors that impact their potential roles and should inform how they are designed, deployed, and sustained in today's Kenya. Beyond increasing access to education and social inclusion, which are no doubt important goals, ATs can be used to contribute to a broader effort for challenging stereotypes, advocating for disability rights, and creating new sociotechnical networks of support. Additionally, our study demonstrates how the hands-on design process of a functional prototype helped facilitate community-engaged conversations about future technologies.

#### 2 RELATED WORK

Several previous projects have studied the possibilities and challenges of Do-It-Yourself (DIY) and Do-For-Others (DFO) assistive technologies (DIY-ATs) for different populations with disabilities. These approaches have been shown to open up possibilities for people with disabilities and their caregivers, teachers, and therapists to design and fabricate their own technologies, a process that may lead to feelings of empowerment, as well as increased investment in the end product and resulting gains in quality of life [17,18,31,37,40]. Despite these possibilities, research has also identified challenges in ensuring DIY-ATs are safe and usable, especially when they are created without consultation with therapists or people with disabilities themselves [17,18]. We briefly summarize previous related work in this section.

Several research projects have described empower-related and creative expression outcomes when people with disabilities create their own DIY-ATs. For example, Meissner et al. conducted a series of workshops where participants with disabilities engaged in maker activities, such as 3D printing, laser cutting, and electronic prototyping, to design and fabricate accessible interactive devices [31]. Following the workshops, participants described how they viewed maker skills as extensions of their own abilities, as ways to help others, and as tools to gain recognition in their community. In another project, Profita et al. found that deaf individuals in an online community used hearing aid customization and adaptation for creative self-expression [40]. Bennet et al. found that users of DIY-ATs (even ones that had technically failed) saw the use of the devices as having a positive impact on popular culture, identity, and community-building [2].

Engaging in DIY-AT making activities is also found to offer opportunities for collaboration and community-building [37,40]. For example, in a study of e-NABLE, a distributed online community composed of volunteers and clinicians that designed and fabricated customized upper-limb prosthetics using 3D modeling and printing techniques, Parry-Hill et al. found that community members were motivated to use their skills to help others and that clinicians and volunteers could work together effectively to combine complementary skills [37]. A similar study of an online community of deaf makers found that members supported each other by shared knowledge and skills about customizing hearing aids and providing encouragement [40].

Despite these possibilities, previous research has also identified several significant challenges for creating and maintaining useful and safe DIY-ATs and for creating inclusive maker tools, activities, and communities. For example, Buehler et al. found a wide range of designs specifically developed for use by people with disabilities on the Thingiverse.com online repository of open-source 3D models **Error! Reference source not found.** However, most designs were created by people without disabilities, making it unclear whether these designs meet the needs of people with disabilities or are safe to use. In another study, Hook et al. conducted a series of stakeholder interviews and found that creating DIY-ATs requires considerable skill and time, which were often difficult for parents or teachers to invest in developing [17]. Additionally, the research showed that creating durable and aesthetically-pleasing DIY-AT devices is an ongoing challenge. To address these

challenges, the authors recommended both the development of rapid prototyping tools that can be used easily by non-professionals and the creation of "practical communities" that connect parents, special education teachers, students, volunteers, and community members such that they may support and help each other in creating these technologies [17]. Research has previously identified this need for developing sociotechnical approaches that support people with disabilities and their families in "infrastructuring," the practice of assembling services and technologies to support better quality of life and inclusion [41]. Building on earlier work by Star and Bowker [45], Pipek and Wulf outlined a series of activities of infrastructuring that include actions that change infrastructure visibility, connect different social and technological structures and standards, change the longevity of existing infrastructure, and change conventional practices, among others [39].

Beyond the amateur makers, research has identified a similar need to bring together multiple professional stakeholders with complementing perspectives to support the creation of sustainable and safe DIY-ATs. For example, in several studies with occupational therapists and medical makers, Hoffman et al. found that while therapists and medical professionals are enthusiastic about the possibility of using rapid prototyping and maker technologies for creating customized solutions, they had concerns about DIY-ATs that were not validated and checked for safety by professionals [15,16]. The participants in the studies called for the development of better documentation and standardization procedures that can help mitigate the risks of solutions while still building in mechanisms to support innovation.

To summarize, previous research has shown that DIY-ATs can increase access to customized assistive technologies for people with disabilities. Perhaps more importantly, their design and deployment may be used to enable empowerment and creative expression, as well as to bring stakeholders together and to act as a site of collaboration, provided that they include people with disabilities at every stage. However, despite these possibilities, important challenges in this space exist, including a lack of robust mechanisms to ensure DIY-ATs are safe and useable by their intended users and a shortage of inclusive and sustainable maker practices. Furthermore, and of particular relevance to this work, all of the research reviewed in this section has focused on North American and European contexts of DIY-AT creation. As a result, there is a shortage of studies on the possibilities and challenges of emerging assistive technologies, including DIY-ATs, in Low- and Middle-Income Countries (LMICs).

In a recent paper, Morgado-Ramirez et al. reflected on four projects with people with disabilities in LMICs [33]. The projects were situated in Uganda, Kenya, and Jordan. They included a study of prosthetics in these settings, studies on how to leverage mobile phone use to connect people with different disabilities together in social networks of support, and to use 3D printing for new wheelchair modification and evaluation applications. Reflecting on the particular characteristics of accessibility and assistive technology research in LMICs, the researchers emphasized the importance of conducting exploratory research to build relationships and inform research with the specifics of each context early on; establishing clear expectations among stakeholders and building in time to understand ethical concerns in each setting (including ethics approval requirements); and resolving funding and logistical issues that may arise in each context. Morgado-Ramirez et al. further identified a shortage of research on system design for people with disabilities in LMICs [33]. Much of the

prior research in this area has so far focused on creating assistive technologies to help people with motor or vision impairments, including customizable prosthetics, mobility devices, and assistive software applications (e.g., [33,42]). However, this landscape is evolving as studies are emerging that focus on accessibility in LMICs more holistically and from a value-sensitive perspective. For example, Kirabo et al. used a value-sensitive approach to understand the public transit needs of people with disabilities in Uganda, which centered on understanding participants' lived experiences, which resulted in a detailed stakeholder ecosystem map [26]. This research shows the importance of including perspectives from diverse stakeholders in accessibility design. In another study, Kirabo et al. identified possibilities for technological intervention, including speech recognition technology to help people with motor disabilities or automatic systems for fare payment, to improve the usability and accessibility of public transit services for people with disabilities in Uganda [25]. More importantly, they emphasized giving weight to stakeholders' aspirations when designing future assistive technologies since this is important for improved future adoption and uptake. To our knowledge, the space of DIY hardware/software systems for individuals with cognitive disabilities is underexplored in LMICs (and non-LMICs). We believe using our particular technology probe has resulted in the elicitation of comments and opinions that put the social aspects of disability, especially stigma, around cognitive disabilities front and center.

DIY-ATs may hold particular appeal in LMICs since previous research has shown that much of existing assistive technology appropriation in these contexts is dictated by necessity and technology availability [36]. Furthermore, research in sub-Saharan Africa has underlined the importance of considering the local and cultural context in which technologies are developed and deployed (e.g., [6,50,51]). Several recent studies have shown how existing digital technologies, such as social networks or smartphones, are creatively appropriated in LMICs, including in Kenya (e.g., [34,35]). Beyond technology appropriation, a growing body of HCI literature, most notably postcolonial computing [21,38], is moving to a position of "continual, careful, collective, and always partial" investigations of the specific "cultural-technical" contexts in which technology design negotiations may take place [38]. Postcolonial computing chooses to look beyond a "technoscientific" object and into the "infrastructures, assemblages, and political economies that are the conditions of its possibility [38]". Furthermore, rather than trying to distill a set of stable requirements, postcolonial computing makes its objective of inquiry "understanding of cultural change," such that it may enable long term transformations in which technology design may play a role [21]. Finally, following Suchman [47], this approach recognizes the importance of improvisational activities as generative practices out of which technologies are made. As such, it views an important role for design processes as "shaping and staging encounters between multiple parties [21]."

Our investigation is similarly inspired by the postcolonial approach in that it responds to the recognized limitations of design-centered efforts that disregard contextual factors in favor of global technological solutions. We thus investigated the perspectives of multiple stakeholders towards the current social, political and cultural state of disability and assistive technology in Kenya with the goal of better understanding the potential role that DIY-ATs may play in this context.

# **3 METHODS**

We investigated the possibilities and challenges of designing and fabricating DIY-ATs in Western Kenya over three years (July 2017-2019). We used a Community-based Participatory Design (PD) approach [7] where multiple stakeholders participated in community discussions, co-design activities, and in-situ evaluations. We utilized a low-cost open-source DIY-AT prototyping platform, TalkBox [12], as a technology probe [19] to better understand the contextual factors that contribute to the development and uptake of this type of technology. In the following subsections, we first describe the platform (section 3.1) and then provide an overview of the longitudinal research activities (section 3.2). We then provide details about the concluding-stage research activity that is the focus of this paper: the activity setting and the participants (section 3.3) and our data collection and analysis methods (section 3.4). We also discuss the research team positionality (section 3.5).

## 3.1 Using a DIY-AT Prototyping Platform as Technology Probe

In this project, we used TalkBox, a technology probe [19] and as a participatory tool [3] to support stakeholders in talking about and enacting future possible scenarios for DIY-ATs in Western Kenya. TalkBox is a DIY assistive technology prototyping platform for creating customized Augmentative and Alternative Communication (AAC) devices for non-verbal users and users with limited speech that was developed by Hamidi et al. [12] over a period of 2 years, using an iterative human-centered design approach in collaboration with a special education teacher, a speech-language pathologist and an assistive technology expert [12]. AACs, such as communication-boards, allow non-verbal users to communicate with others using synthesized or recorded speech [20]. TalkBox combines a Raspberry Pi single-board computer running an open-source software code base, a capacitive touch sensor, USB speakers, and battery to detect touch and playback customized audio files in response (Figure 1). It can be used to fabricate customized communication-boards based on each user's specific needs. The user plays back customized audio files by touching a conductive area connected to the touch sensor. Figure 1 (Right) shows an assembled communication-board created using TalkBox.



Fig. 1. The TalkBox prototyping platform, as a kit (Left), assembled as a communication board (Middle) and redesigned to be more robust with increased touch surfaces (Right).

TalkBox has a modular design in which the key components (e.g., the audio system, the power supply component, the mounting chassis, and input buttons) are easily replaced by alternatives. This design approach is in line with previous research [27] that identifies the importance of including flexibility and open-ended customizability to support system

customization and end-user appropriation. These requirements are echoed by similar practices in open-ended software designs in which a high degree of user autonomy in system reconfiguration and redesign is supported as part of design requirements [2].

Hamidi et al. developed TalkBox as a kit of components (and instructions) that users can assemble themselves. A unit can be assembled to have between 1 to 12 input buttons. Users can also specify what audio files will be played back by the system by loading them onto a USB stick and inserting it into the Raspberry Pi's USB port. The system scans the USB stick and copies the files onto its memory, overwriting older files and using a naming convention to order them. In this way, users can modify and update audio files played back by the system without the need to re-program that Raspberry Pi or to connect it to additional input and output devices.

#### 3.2 Overview of Longitudinal Research Activities

The current paper presents findings from a concluding phase of a longitudinal research project that took place over three years, with focus groups, workshops, and interviews spread throughout a distributed framework. We believe it is important to provide an overview of the project, both to contextualize the findings in the current paper and also to be clear about who was and wasn't included in the research activities, as this information may be relevant for future researchers conducting similar work. We have included a detailed table in the appendix that provides details of each phase and the outcomes. Here, we provide a brief overview of these activities.

The project had four phases. The first phase included broad consultation using a stakeholder focus group activity and generated a stakeholder map which identified 35 stakeholders, including local, national, and international advocacy groups active in the region, and local special education schools and universities, among others. In the second phase, stakeholders, including special education teachers and university students, were engaged in interdisciplinary workshop facilitator training in which they learned about the platform and how to use it in community-engaged workshops at local special education schools. In the third phase, TalkBox technology was introduced in two local schools (St Francis Oriang' and Lutheran School for the Mentally Handicapped), and then teachers (n=4) and children (n=24) used the technology for a period of 10 months. During this time, we also conducted interviews with the children's primary caregivers (n=23) (mostly mothers) to better understand their experience with disability and assistive technologies and their perspectives on DIY-ATs. The purpose of this phase was the in-situ observation of technology modification. Finally, in the fourth phase (the focus of the current paper), stakeholders (n=25) were brought together to reflect on the possibilities and limitations of DIY-AT and technology more broadly to address issues of accessibility and inclusion in Kenya.

Over the course of the project, we worked with many stakeholder groups, including children with disabilities and their parents, special education teachers and therapists, representatives from local governmental and non-governmental organizations, and local university students from diverse disciplines. The children that we worked with had a variety of intellectual and physical disabilities, cerebral palsy, and Down Syndrome. This project included children on the Autism Spectrum as participants, and Autism Spectrum Disorder (ASD) was considered by stakeholders to be a disability, but we recognize this Disability through the Lens of DIY Assistive Technology in Western Kenya

categorization as contested. In our recruitment, we prioritized working both with representative users of future assistive technologies that we were investigating (i.e., children with disabilities and their families) and with professionals whose jobs it is to serve and improve the lives of people with disabilities in Kenya (i.e., government officials, NGO representatives, special education teachers). We based our community engagement activities, as well as the participant selection and recruitment, on the stakeholder network map that was developed in phase one. We recognize that it is crucial to have the voices of people with disabilities and their families represented and also believe that including representatives and advocates in research both provide a different and potentially broader of issues that need to be investigated and reduce the burden of direct participation in research and design activities on people with disabilities themselves. Members of the research team were present at all of the described research activities and conducted all data collection and analysis.

## 3.3 Concluding Focus Group: Setting and Participants

The study took place in Kisumu in Western Kenya. The city is home to a diverse population with several languages widely spoken, including English, Swahili, and Luo. We translated all data collection instruments into the three main languages prior to the start of research activities.

The focus group we present in this paper was conducted at the conclusion of the community-engaged workshops and included 25 participants (13 males, 12 females). Participants included 5 representatives from local CBOs, 6 government representatives including from social services, education and development offices, 6 special education teachers, 2 therapists, 3 members of the local media, 2 students from the local university, 1 participant from an innovation hub. Eight participants had taken part in the first focus group during the first phase as well (Section 3.2).

## 3.4 Concluding Focus Group: Data Collection and Analysis

The focus group took place over two sessions in one day (each session was approximately 3 hours). It was facilitated by two members of the research team (first and second authors). The first session began with introductions and a description of roles and involvement in the project so far by each participant. This was followed by a brief presentation by the facilitators about the project and outcomes to date. During this time, participants were also given a demo and presentation of TalkBox, using both the working prototype and videos of it being used by children with disabilities. This was important since, while many participants knew about TalkBox and had seen and used it before, for others, it was new. During the presentation, TalkBox was described as an exemplar DIY-AT with specific examples of how it was customized and used by children at the participating schools. The rest of the focus group consisted of group discussions of the social, technical, and economic barriers to accessing assistive technologies in the region, followed by the possibilities of open-source DIY-AT in this context. A discussion guide developed previously by the research team was used to facilitate the sessions.

We recorded the discussion during the focus group and transcribed all data. Two members of the research team (first and second authors) independently thematically analyzed it using an inductive analysis approach. Identified themes and subthemes were then discussed with the rest of the team, who helped further analyze and synthesize the findings.

While participant-level demographic and organizational information can be relevant in qualitative research, we have decided to include only summary data since there was a small number of participants from each organization, and triangulating their data may result in de-anonymization and attribution of specific quotes.

During the focus group, we assigned each participant a pseudonym to preserve their privacy and asked them to say their pseudonym when making a comment. However, we found this approach inadequate, and during data analysis, we could not confidently assign quotes to specific participants and report the type of organizations they represented. However, we were able to track comments made by the same participants which we indicate with participant numbers in the findings section. We acknowledge this as a limitation of our data collection and analysis.

### 3.4 Research Team Positionality

Through the course of the project, our research team consisted of five Kenyan and three Canadian researchers who each contributed to the project in different capacities. Four members of the research team contributed to the writing of the current paper. The first author is an HCI expert from the Middle East and currently working in a US university. The second author is from Kenya and directs an NGO focused on improving the lives of people with disabilities and individuals living with HIV. He is also pursuing a PhD in anthropology at a US university. The third author is a Psychology professor, and the fourth author a Computer Science professor, specializing in HCI, both at a Canadian university, respectively. In addition to the authors, the research team included a professor in Critical Disability Studies who is faculty at a local university, a Kenyan research coordinator with both public and private sector experience and two research assistants from the local university. None of the research team members has a disability.

Our choice for conducting the project in Kenya was influenced by two factors: one because the second author is from Kenya and has long term community relationships there, and the other because, as mentioned in the introduction, Kenya has been the site of both innovation and disability advocacy in East Africa in recent years. These conditions make it an exciting site to explore the future design space at the intersection of technology innovation and accessibility.

## 4 FINDINGS

Participants described how, despite existing legislation put in place to recognize the rights of people with disabilities, many people with disabilities still face barriers in accessing vital educational, economic, and social resources. Participants expressed hope that a new generation of ubiquitous and DIY assistive technologies can help bridge this gap between legislation and implementation and, in particular, identified the importance of using technology to support the social inclusion and advocacy of people with disabilities. Participants also emphasized the importance of considering the question of sustainability and safety when designing and deploying DIY-ATs. In the following subsections, we describe the gap between legislation and implementation and then present findings on how technology may positively contribute to overcoming it.

## 4.1 Sociopolitical Aspects of Disability in Kenya

4.1.1 Policy and Implementation. Participants described how legislation to address discrimination against people with disabilities has been in place in Kenya for a long time: "More than 50 years ago legislation came out to address calling people with disabilities as 'imbeciles' or 'idiots' (P1)." Participants described how in the last decade there had been improvements in accessibility in many domains, however, implementation is still lacking: "Accessibility to initial health, accessibility to medication, to social aspects is more increasing. But the biggest [issue] ... is implementation (P2)."

Participants identified structural issues that still remain:

"Everything is improving but implementation is still lacking. For example, if anyone needs to access services, the building that houses all the departments of the government in [name of county] doesn't have a lift so if anyone needs to visit there, they can't." (P23)

They further described that many public buildings and institutions are not yet accessible and there is a need for more advocacy for increased access: "We have to think about all of the aspects because the venue is not accessible, and this is something that needs to be requested so that there is pressure on organizations (P12)."

Several participants identified a lack of accountability and consequences as more reasons for the gap between legislation and implementation. Another participant described how currently anti-discrimination "fines are very low (P13)."

This gap between legislation and implementation was also apparent in the educational context: "The Act talks about inclusion. So how many schools have adopted that? They are very few. And for the few that have adopted you will find that they are still lacking the professional teachers (P3)."

In this context, one participant described how: the inclusion is there, but just as a name. Another participant described how "legislation has to be combined with resources and teachers (P5)."

However, participants also described how we should go beyond current legislation and take affirmative action. They acknowledged that while the regulatory body has accomplished a lot in this space, many social problems still persist for people with disabilities in Kenya. They further described that positive shifts in the conditions of people with disabilities can only come about with sensitization (i.e., shifts in perspectives and practices) and increased representation and recognition.

4.1.2 Formal Assessment and Community Engagement. Participants identified several issues concerning the identity position of those with disabilities. For example, they identified issues concerning the collection of demographic data, both historically and in contemporary practice, particularly around identifying the number and types of disabilities present within the population. This is an important tool for advocacy and necessary to allocate adequate resources to implementing accessibility initiatives and speaks to the lack of resources identified above. Participants noted a "need for data to inform how many people have disabilities so that the Kenyan Dream can be realized (P20)." The participants described how current data does not represent the true numbers of people with disabilities, nor does it provide enough nuance to allow for accurate planning. Some participants expressed hope that the current year's census would include questions about disabilities,

which may lead to the collection of more up-to-date information. However, others were skeptical about whether a modification to the census would have the intended benefit. Participants drew a connection between demographic data collection and formal assessment, pointing to the fact that the collection of accurate information could be predicated on formal disability assessment, but formal disability assessment is expensive and difficult to access. People with disabilities sometimes need to travel far from where they live to undergo assessment and have to pay for the assessment themselves. Yet other participants raised issues with the source of the data, identifying the need for community engagement:

"A critical mass is needed to take action, so that there is data to back up the numbers of who [have a] disability. This data shouldn't just be derived from census, it should also be informed by community members and by grassroots organizations." (P11)

Another aspect of formal assessment identified by participants concerned its gatekeeping function since it is required in order to receive services and benefits. A lack of formal assessment was also linked to a lack of technology, which can lead to further barriers for people with disabilities claiming their rights and access to resources as described by this participant: "Education for people with disabilities is free, the funding is there but to claim it, sometimes people have to walk 20 [kilometers] to a facility to be diagnosed to get a wheelchair! (P3)"

Furthermore, even if qualified for receiving disability benefits, these benefits only cover basic needs such as food and accommodation, whereas the cost of assistive technologies, including wheelchairs or crutches, are not covered.

Participants identified a possibility for ubiquitous and mobile technologies, such as smart phone and other DIY solutions, to implement accessible applications for conducting assessments remotely. A participant described how "using smart phones to do assessments can remove the barrier to traveling long distances (P1)." However, participants were also quick to point out that there would be limitations to the potential of digital technology to replace widespread access to in-person services and described how the role of on-theground social and health workers are crucial and cannot be replaced by technology:

"There are services that need to be done by social workers or other organization... [for example] we have disabilities that are not visible and it makes sense if [assessing] them may be left for the Ministry of Health." (P3)

Despite its challenges and limitations, most of the participants advocated for more decentralized services that can be completed by members of the public as well as community-based organizations.

## 4.2 Assistive Technologies Supporting Inclusion

*4.2.1 Disability as Economic, Social and Cultural Construct.* Many participants described a bleak picture of how disability impacts the lives of people in Kenya and how it is a complex construct with economic, social and cultural aspects. These aspects also impact the availability and uptake of assistive technologies.

Participants described how social stigma negatively impacts the lives of people with disabilities as noted in the quote below:

"Currently the stigma is so high ... with these laws why are we still hiding people with disabilities? There is a low level of awareness....stigma is so high that is why even families find it easy to lock [children with disabilities] in the house." (P20)

Stigma against disability remains such a major issue that the word "disability" is sometimes used as a derogatory term. Participants described how these issues often result from "a low level of knowledge, low level of awareness." Some mentioned that it persists even among professionals, such as teachers who may discriminate against their student: "For example, it is not uncommon to go to a school and find the teachers within that school themselves discriminating those children living with disability (P12)."

Prevalent cultural stereotypes were identified and discussed in terms of how they impact people with disabilities: "The heroes are portrayed as tall, brown, etc., different from children with disabilities, and these perceptions lead to people hiding their children instead of taking charge (P23)."

Additionally, they described how some cultural beliefs and language itself can exacerbate the difficulties faced by people with disabilities and their families, as in the following quotes. They stated how there are issues with "names and labeling" that impact people with disabilities.

"The family [of people with disabilities] are outcast when they have a disability because people think someone in their network has sinned." (P4)

"Cultural beliefs and issues [can also be] causes [of discrimination]: You will be surprised that some of us may even be bringing issues of curses, [a belief that disability] could be as a result of maybe that family was cursed ... Even language itself the way it describes a person with disability there is already something that somebody is starting from a point of a disadvantaged person." (P2)

Despite this multifaceted nature, participants described how disability is often still viewed as a medical phenomenon, with its social and cultural aspects ignored:

"...parents in the hospital, the way they are informed is very medical, you need some social and psychological support." (P9)

"We need to start looking at disability as a complex construct that is situated in multiple sites: not only in the health domain but also education, political and other domains." (P17)

Several participants described an intersection between low socio-economic status and disabilities, stating disability is "expensive! (P23)" Participants described how the current census data shows that, in Kenya, the majority of people with disabilities are economically vulnerable.

Some participants also described how the general public often disregards the needs of people with disabilities: "People are also lacking in awareness where [riders on] motorbikes don't let people [with disabilities] cross the road (P13)."

These problems are amplified with respect to cognitive disabilities that are often "not visible which makes things more complicated (P3)." They stated that a cultural and social

shift and sensitization with respect to attitudes towards people with disabilities is needed to alleviate these issues.

Given these multifaceted factors, many participants believed that public institutions should provide support and assistance to people with disabilities and their families, as the status quo leaves much to be desired:

"It's the institutions that make people with disabilities suffer not the other way around." (P1)

"[The government should] promote and fulfill the rights of every person in the country including the person with disability." (P5)

However, in reality, disability as a "social issue, a political issue, and even an economic issue is left in the back burner (P6)."

Participants believed that these factors negatively impact people with disabilities' access to assistive technologies. As noted above, being assessed for disabilities in order to be eligible to receive support is in itself expensive, but the costs and lack of resources are seen as pervasive, and assistive technologies (including TalkBox) required funding, support, and personnel.

These factors make it difficult for individuals and small organizations to obtain and maintain assistive technologies at scale, leading many participants to agree that providing assistive devices is the responsibility of the government.

4.2.2 DIY-ATs as Tools for Social Inclusion. Participants were enthusiastic about the possibilities of digital assistive technologies in general and DIY-Ats in particular in Kenya. They identified a series of concrete roles that they could play in different contexts, such as contributing to inclusive education and increased social participation and described how they can act as a bridging mechanism to challenge and connect the experience of people with disabilities across social, educational, and therapeutic contexts. Furthermore, they saw the role of digital assistive technology as an important one in removing barriers to access: "technology can come in to reduce the gap between ability and disability (P4)."

Referring back to the idea that disability is often seen to fall within the medical context, participants described how: "If [assistive] technology is a way to embed and implement values into objects, and as a tool for inclusion, it should embody these values and transgress the boundaries of specific domains (P11)."

Specifically, with respect to DIY-Ats, participants saw great potential for a redefining of users' relationship with the technology. They described how in the past many legacy systems were either expensive or hard to use or both. This created a fear in people to use technology leading to some avoidance. However, several participants described how this is quickly changing in modern Kenyan society:

"Technology is indispensable at this stage...can we embrace technology? For us to do that, we have to accept to learn, not be afraid of computer or that we don't touch the keyboard to not destroy the computer." (P8)

By explicitly inviting participants to change and mold them, DIY-Ats give a positive invitation to users to approach them in a new way.

Several participants identified possibilities for DIY-ATs within the medical context, for example as assessment and communication tools:

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"As a therapist working in a hospital, we find it important to categorize disabilities so that technologies can be effectively applied. It is hard to know if someone has a hidden disability, you need medical professionals to find out whether someone has hysteria, schizophrenia or psychosis." (P21)

However, they also described how DIY-Ats could provide opportunities for their users to practice agency and complete daily tasks that are not situated only in a medical context: "...for example, the child can use [TalkBox] to do self-care (brush teeth, etc.) even though they also have to deal a lot with the medical realm. (P9)"

In the quote below, a participant with disabilities described how having access to technologies that enhance communications can result in more participation:

"With respect to communication, if I can enhance my communication and interact with my environment better, it will help others see my abilities and not as someone who has limitations. Knowledge comes through participation, communication, ... and leads to progression. Not being able to communicate so that a person can't be assessed or go to school should be of the past." (P4)

Therefore, participants saw technologies supporting communication as a means to facilitate social participation: "Technology is so important at this stage. Communication will open space for all other things (P8)."

Beyond abstract contexts of use, participant also identified multiple concrete settings in which DIY-Ats can exist. For example, they described how TalkBox can be used both in the home and school and that it can be personalized and take on a different role in each context. Participants described how TalkBox could also be shared by different family or community members more broadly, similar to the way that it was shared in the classroom during school workshops: "The facilitators said that they have used the device for community use, the community should start from the family, so that the progression is made from family to school (P15)." This sharing across contexts would make it easier for learned skills to be transferred from the school to home context and beyond to more public everyday contexts.

Besides customizability, participants described how the intuitive way in which the system was designed could makes it easy to use to communicate with people with disabilities and vice versa by people who want to communicate with people with disabilities but do not yet have learned how to do so (such as learning sign language). TalkBox's openended design made it something that could potentially be adopted widely and supported by government initiatives that could be administered by schools or CBO:

"This is even more universal than sign language because you don't need to [learn a language to use it]." (P6)

"The device would be portable so that the device can be moved around with the person ... maybe schools can assign devices to children. So, the government can support the device." (P5)

In this sense, the technology may help streamline services across different contexts, or make it possible for services to be offered in schools or other institutional settings rather than having the role of service delivery fall so heavily on families. At the same time, participants urged that any new technology should also be designed with the family and home context mind as the starting point of change: "I would like to recommend that the community should start with the family so when you have a device the family should [also] have it to benefit ... so that there is progression from family to school (P15)."

In addition to possibly playing key roles in multiple contexts and settings, participants described how DIY-ATs can engage stakeholders at multiple levels, integrating both national "roll outs" of assistive technology as well as local deployments. This combining of top down and bottom-up approaches was a key thread that ran across the discussions of how DIY-ATs can connect different stakeholders together. For example, they described how "mobility devices and [DIY assistive] technologies can be provided by the government on a national level so that [everyone] can participate (P1)." But then this access to devices needs to be complemented by the knowledge of stakeholders who work directly with people with disabilities to ensure proper training is provided. In the words of a participant:

"The [technologies] we have need intelligence and know-how. Training is important for proper technology use, including users and trainers to ensure that people have minimal knowledge to help them navigate through these solutions." (P7)

Finally, participants identified a key role for assistive technologies in general and TalkBox in particular, which is to increase users' capacity for self-care and provide them with independence and agency: "We need to have self-care and with technology you know a child or any person who has a disability can be able to do the self-care (P21)."

4.2.3 DIY-ATs Serving Inclusive Education. In addition to barriers to family and community inclusion for people living with disabilities, many participants described challenges in implementing effective inclusive education solutions in Kenya. Several participants expressed dissatisfaction with how special education is often an afterthought and that this needs to be remedied for programs to be effective: "Distill disability issues in programs so that they are not an afterthought and are really built into things from the very beginning (P3)."

Others described how, in the educational context, it is important for everyone to have a basic understanding of special education and how to work with and serve people with disabilities:

"...even in programs that are designed for people without disabilities, it is important to have a basic understanding and set of ways to know how to deal with disabilities...there [is] a lot of sensitization that needs to happen." (P12)

Participants believed that sustained access to assistive technologies and training in how to use them effectively can contribute positively to educational outcomes for children with disabilities. They described the importance of providing training in assistive technology for special education teachers so that they may meet the needs of their students. With respect to TalkBox, participants described how it "can enhance the learning environment because it can improve their performance and abilities (P6)."

Participants described how it is important to have technological interventions early on for children with disabilities so that they get used to feeling empowered and included: "For you to empower a person then you need to do that when he is still a child, and this mostly happens when kids are in school (P15)."

Furthermore, including children with disabilities early on in the process would also sensitize children without disabilities and help educate them in how to work and collaborate with people with disabilities beyond the school.

With respect to continued access at the schools, the participants stated that it is not enough to drop off the technology there, but that both teachers and students should take ownership of the technology by understanding how it works and giving feedback on how it can be improved. At the school level, there should be clear instructions for how to safely store the DIY-ATs, so they are "not stolen or messed with (P5)."

Finally, P2 identified the crucial role of families who need to have buy-in with respect to new technologies to ensure that they are used in both school and home settings. She stated that in her work as a therapist the receptivity of families is a key factor in whether the provided services are effective. In her words, "engaging families is important."

#### 4.3 DIY-ATs: Sustainability and Risk Mitigation

While participants were generally positive and enthusiastic about the possibilities of novel assistive technologies in general, and DIY-ATs in particular, they also expressed several concerns about challenges that are involved in successfully deploying DIY-ATs in Kenya: ensuring they are sustainable and sensitive to the context of their deployment, and that they are safe and do not pose a threat to users' health, privacy and environmental well-being.

4.3.1 Sustainability of DIY-ATs. Participants described how it is important to ensure that DIY-ATs can last as long as possible after deployment. They described how it is important to ensure educators and schools have continued access to the technology, and that there should be local capacity to keep the software and hardware components of this technology up to date. This capacity can be built by training local experts in the technology and also by ensuring high-quality documentation "both for techies and also for non-technical users (P8)" on how to maintain, customize and troubleshoot DIY-ATs.

P11 described how having local experts "can create jobs" and that this is not inconsistent with technology end users having an active role in technology customization and appropriation through having a basic knowledge of how the system works. He provided the example of smart phones and how they are "as smart as [users] are" because knowing about their features and various functions helps end-users benefit from them more and also does not eliminate the need for technology experts to design and manufacture them.

Furthermore, participants saw an opportunity for DIY-ATs as a way to create local, homegrown technology. In the words of P8:

"[There is a need for a] transition from a design that is from outside to a design that is organic. For example, training a prototype that is a generic product that is more organic in the sense that it is local."

Participants described how homegrown technology can start small and even benefit people beyond its immediate place of origin: "It will be less expensive to make the technology locally and see if there are other people around Kenya who can benefit under similar contexts (P12)."

Despite acknowledging this possibility of DIY-ATs helping people globally, participants also stressed the importance of prioritizing the usefulness of the technology to the immediate community of users, as the following quote shows: "We can check so that we don't [focus on] coming up with something that is a global gamechanger but [rather something that] makes a big difference in the community (P15)."

Participants described how using material that can be locally sourced or replaced can help with maintaining the technology over time. The need for material localization was also related to a need for local technicians who can help maintain both the hardware and software of the system over a long period of time. Several software-specific questions were also brought up that included whether the software needed maintenance over time and if it relied on other systems to function properly. In the words of a participant, key questions to be considered included:

"Are the parts locally available or [will] we be able to use things that are locally available to form those parts so that they can be easily acquired or sourced for the case of it is not functioning well? Are there technicians who are able to design the software, able to do a repair on the hardware, you see, so that it can run a longer course and have a longer life span?" (P23)

While participants were positive about the DIY aspects of DIY-ATs, they also recognized the importance of resources that are consistently maintained and "bring everyone together." A key strategy identified by participants was that to make DIY-ATs successful there is need for networking and collaboration among stakeholders. They described how technology design and deployment can be a site where multiple organizations and departments come together to design and develop solutions. Some of the participants also pointed out that when creating such a network it is important to be clear about what each organization plans to achieve so that there is transparency and different stakeholders can support each other in the face of challenges. Additionally, they described that this sharing of responsibility can lead to increased technology ownership. Some participants identified a role for an oversight committee to "monitor and evaluate if the [technology] is effective or not effective and determine the challenges that they are facing and record [it] (P1)."

4.3.2 Mitigating Risk and DIY-ATs. In addition to concerns about DIY-AT sustainability and maintenance, participants also had several other concerns about the potential risks of deploying new DIY-ATs in Kenya that need to be considered. An expressed concern was whether using this technology can negatively impact the development of a young user's ability to communicate. P9 described how upon using a system that aids with communication a child user might "be kind of complacent and say I am tired because I am opting to use this [device which] is easier than going the long way of training." In other words, participants were concerned that an AT may become a crutch for a user who may otherwise develop communication skills that do not rely on technology. The participants stressed the importance of combining the use of technology with work with teachers and therapists to ensure it does not replace human intervention. Furthermore, the participants recognized that to use the technology effectively, users need to be trained to use it and have to access to it early on, so they become familiar with it and can use more sophisticated systems that meet their needs over time.

Another concern was about privacy and understanding how assistive technologies that are increasingly connected to the Internet collect and utilize data. While several participants acknowledged that TalkBox in its current implementation does not collect data, they were also concerned about how communities may be assured that future technologies are Disability through the Lens of DIY Assistive Technology in Western Kenya

transparent about how they protect their users against privacy threats. The participants also stated concerns about how it is common for technologies to be counterfeited in Kenya and there is a need to ensure the safety and authenticity of assistive technologies. This concerns both the hardware components of assistive technologies that may harm users if poorly constructed, and their software components that may hide computer malware or viruses. Participants, therefore, suggested including security safeguards in future DIY-AT systems to protect them against hacking. One participant specifically mentioned the potential of open-source software that is available for public scrutiny as a promising direction for keeping software components of DIY-AT safe.

Finally, participants had concerns about the environmental impact of new digital technologies, especially computer hardware. Several participants described how being exposed to radiation or harmful material used in digital technologies may cause health issues in the long run. Participants also described how disposing and recycling of old computers is an issue and they have seen them "being thrown out to dustbins (P23)." The participants also stated that technologies need to be maintainable in the local context to avoid having disposable technologies that after a short period of use contribute to long-term pollution. Therefore, when designing new technologies, including assistive technologies, questions of environmental sustainability and safety need to be considered.

### **5 DISCUSSION**

#### 5.1 Stigma, Disability, and DIY-AT

In being asked about their experiences working with people with disabilities, their beliefs about the barriers that people with disabilities face in society, and their opinions about DIY-AT and TalkBox, many of the points made by the focus group participants concern stigma and attitudinal barriers more generally (Section 4.1). It is clear from our findings that participants both recognize the leadership position taken within public policy and also clearly identify the frictions of everyday life that thwart the envisioned implementation of said policies. Many of these frictions concern stigma and attitudes (and also the built environment and socioeconomic factors).

In reflecting on these findings, we seek to draw connections between DIY-AT and factors concerning stigma and attitudes more generally. It is tempting to view DIY-AT through an operational lens: to think of DIY-AT as a potential direct intervention to stigma. For instance, one might imagine DIY-AT as providing a platform for disabled children to acquire, master, and demonstrate new skills, which would therefore positively intervene in the formation of attitudes. In fact, this very idea informed some of our early plans in this research project. We saw empowerment and self-efficacy as a potential positive social identifier, and, over the course of this project, collected longitudinal survey data concerning this construct from several stakeholders, data that we decided to discard as more interesting and relevant outcomes emerged in the qualitative data.

Seeing DIY-AT as a means to directly and positively intervene in attitude formation is seductive indeed. As seductive as this vision is, however, we note that looking across our thematic findings, there is little to support this view. DIY-AT is positioned only occasionally in our findings as having the potential to directly intervene in an extant sociopolitical dynamic. We note that this stands in contrast with other depictions of DIY and making,

which can tend to have an overly promissory rhetoric through valorizing technology, while subordinating its aspects that are consumerist [1] and exploitative of global structures [24]. Rather, our findings from the focus group show that participants were enthusiastic about the possibilities of digital assistive technologies and DIY-ATs in Kenya and point to subtler and more nuanced interrelationships among policy, government, societal attitudes, and technology access more generally. For example, participants identified increased representation and recognition (Section 4.1.1) as well as social inclusion (Section 4.2.2) as overarching goals for people with disabilities in Kenya; goals that assistive technologies might play a role in achieving (Sections 4.2.2 and 4.2.3), but also require effort on all fronts, including through policy work, social and cultural activism, and education (Sections 4.1.1, 4.2.1, and 4.2.2).

# 5.2 DIY-ATs and Political Legibility

We gained several insights regarding an unanticipated leveraging of our project. Our findings demonstrate that participants understand and identify many subtle and nuanced aspects of disability and acknowledge the existence of an "ableist habitus" that normally "disappears in everydayness" [8]. This is to be expected, given that disability as a construct is complex and contingent; it intertwines complex political and relational dimensions, and not only biopsychosocial dimensions [23]. Our findings did point to variation among conceptual framings, particularly in terms of the medical vs post-medical models of disability (Section 4.2.1). There is considerable scholarship and debate about the different 'models' of disability (e.g., charity, medical, social, biopsychosocial, political-relational, among others), with much variation in terms of their epistemological stances (their 'forness', or which aspect of disability is in focus, being explained, described, accounted for, etc.). Critical Disability Studies has been critiqued for 'its inherent whiteness' and for its 'colonial, Western European and North American versions of disability politics and advocacy' [10]. Our point here is to not entertain the question of which model of disability is held most widely or prominently; we are looking to dispel a colonial perspective. A colonial perspective would seek to impose a 'correct' view (on how disability gets constructed, in our particular case) and would seek to impose its sociocultural context as if it were universal [30]. What we can point to is the prominence of the issue of political legibility, and its strong connections to 'formal' and 'clinical' assessment (Section 4.1.2). Formal, clinical assessment can be strongly connected to a medical model of disability and locates disability in the body of an individual. Participants readily acknowledged intersectionality with socioeconomic standing and poverty. Tensions between socialcultural groups, which has been present in the political arena in recent years in Kenya, did not emerge as an intersectional issue for disability (possibly attributable to the methodological approach that was employed). Also, interestingly, we note a gap in findings that concern gender-based issues.

The findings affirm our view of DIY-AT as multifaceted: it is both a kind of digital, technological artifact (and thus part of the world of computing, ICT, and technology design), and also it is a provocation and a challenge to the status quo (and thus part of the world of socio-political action and advocacy). These multiple aspects are what animate the use of the technology probe methodology [19] which has been adopted in this project. They also make DIY-AT a 'boundary object,' that is, an object that is part of multiple social worlds and

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facilitates communication between them; it has a different identity in each social world that it inhabits [46]. The work undertaken by project stakeholders, including focus group participants and ourselves, has taken place within a 'trading zone', a term which is often used "to denote any kind of interdisciplinary partnership in which two or more perspectives are combined and a new, shared language develops" and a place where groups who may have difficulty communicating with each other can come together and manage to communicate [5], and a place where "colleagues with differing skills come together to solve technical problems [43]."

In this framing, it is clear how the discussion facilitated by TalkBox connected issues of political legibility for people with disabilities in Kenya via technology-mediated formal assessment. These findings suggest that stakeholders position TalkBox alongside other assistive technologies and then position ATs in terms of their role within political agency.

### 5.3 Community-based Sustainability and DIY-ATs

When discussing possible desired roles for future DIY-ATs in Kenya, participants identified practical and ethical considerations that may well apply beyond Kenya, in other LMICs, and also in Western contexts. While recognizing the strength of DIY approaches for providing opportunities for design appropriation, stakeholders were quick to point out that the success of such projects requires multifaceted social, cultural, and infrastructural support (Section 4.3.1). They warned against developing or deploying solutions without first securing multiple stakeholder buy-in and without first building local technical and social capacity, identifying both as important to the sustainability of a decentralized technology deployment and maintenance plan over time (as also identified in previous research [15,16]). The challenge of putting in the time and effort to troubleshoot DIY-Ats has been noted in previous research and identified as a barrier to technology uptake and a factor in its abandonment [17,18].

Consistent with the postcolonial computing perspective [21,38,49], these findings confirm the necessity of seeing a technical artifact, such as TalkBox, as one component of an overall and multifaceted reform program in assistive technology access that needs technological infrastructure and support, professional training and curriculum development for teachers, and the formation and strengthening of support groups and volunteer facilitators who can help with the customization, redesign and community uptake of DIY-Ats to effectively utilize, customize and incorporate the system in their practice [49]. This question of sustainability is particularly salient in Kenya since it came up about negative experiences with legacy systems that have been previously deployed there without much consideration for contextually relevant or long-term maintenance plans. In particular, participants were wary of technology that may replace existing social support structures in the short term without robust strategies for long-term sustainability. Finally, and on a positive note, participants were cautiously optimistic about a technology deployment program that focuses on creating open-source platforms in place of consumer-focused strategies that may lead to increased reliance and disempowerment [21].

We can interpret participants' perspectives and input using an infrastructuring lens [39]: first, in considering the material and technical support needed to make digital DIY-Ats a sustainable reality in Kenya, participants increase infrastructure visibility, bringing attention to the invisible consumer networks that make these projects possible in Western

contexts. Second, participants outlined how successful and equitable deployment of assistive technologies requires new types of connection, coordination, and collaboration between different social and technological structures at the national and international levels. Finally, participants pointed out that for technology to positively impact the lives of people with disabilities, changes in conventional practices are required, changes that need to be imagined, planned, and made into reality through continued participation with diverse stakeholders.

## 5.4 Future Opportunities for Using DIY-Ats in Kenya

In addition to the above insights, our study also points to practical scenarios where DIY-Ats, such as TalkBox, can be helpful in Kenya. In addition to our initial envisioned role of supporting inclusion and engagement in educational contexts (Section 4.2.3), DIY-Ats can also be used to facilitate the collection of disability data from remote parts of the country, for example, by creating low-cost, accessible communication devices for use by social workers to conduct disability assessment, an effort that our participants posited may result in more advocacy and representation. The customizability of TalkBox that allows its audio vocabulary to be switched easily between different languages is of particular interest in Kenya, where many languages and dialects exist and need to be considered when creating communication devices.

Furthermore, while DIY-Ats may not be suitable for the creation of long-lasting personal technology solutions and, therefore, cannot replace the need for sustained government support for assistive technologies, they may still serve as bridging devices that can temporarily replace more sophisticated assistive technologies, for example, if someone's device is broken or does not fit the user's needs and should be replaced. Again, in these cases, the customizability and low cost of DIY-ATs are important and would give them an advantage in low-resource contexts. Additionally, the customizability and low cost of DIY-ATs make it possible to use them both in school and home settings which participants identified as an opportunity to connect these contexts better and to mitigate families' burden (Section 4.2.2). However, despite these possibilities, issues of sustainability and limited functionality, as discussed in the previous section, need to be considered.

#### **6 LIMITATIONS**

The current study has several limitations. First and foremost, more input is needed from community members with disabilities, including both children with disabilities and their family members. As mentioned earlier, we have collected data from the children who used the system and their families and will share their perspectives in the future. We also identify an opportunity for a future co-design workshop to bring together children with disabilities and their parents with the other stakeholders who participated in our project. Despite its logistical challenges, such a workshop can lead to more shared experiences and opportunities for mutual learning.

A second limitation of the study is that we used the DIY-AT platform in formal learning (i.e., classroom) activities. While this choice provided us with insight on how DIY-ATs may be used in inclusive classrooms, exploring informal learning contexts (e.g., afterschool programs, summer camps, etc.) would result in relevant and different outcomes. A third

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limitation is that while the project has resulted in insights into disability and assistive technology in Kenya, despite our best efforts, it has not yet resulted in a concrete DIY-AT system that can be used at scale and over an extended period. We are exploring ways that our findings may inform the creation of a local DIY-AT system that may be produced and used by the stakeholders in the future.

## 4 CONCLUSIONS

Possibilities have emerged that make it possible for communities to take up Do-It-Yourself practices for Assistive Technologies (DIY-AT). We have been engaged in a multi-year, multi-stakeholder research project where we worked with community stakeholders to identify possible futures of DIY-ATs in Kenya. In this paper, we presented findings from a concluding stakeholders' focus group. Our results point to a set of complex, interleaved factors that concern the sociotechnical and infrastructural aspects of assistive technologies and their relationship with the cultural, political, and social aspects of disability in Kenya; these findings complement prior findings that DIY-ATs can offer valuable opportunities to build customizable and affordable technological artifacts. They further nuance the impact of participating in the design process of technological artifacts and the enactment of possible future ways in which they can support the furthering of socio-political legibility and agency.

In our study, we found several factors in Western Kenya that may resemble conditions in other LMICs: (1) lack of access to infrastructures to make technology-focused DIY practices sustainable (necessitating the need for DIY infrastructuring), (2) aspirations to participate in technological innovation coupled with a sensitivity to avoid creating foreign dependencies and further marginalization, and (3) increased recent awareness of the social nature of disability (including legislation to formalize it) but a lack of resources and concrete efforts to facilitate impactful change. Thus, our findings place DIY-ATs in a web of political, economic, and sociocultural factors that impact their potential roles and limitations. Future comparative studies can provide more insight into these factors in other parts of Kenya and other LMICs.

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