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Making Equity: How the Disability Community Met the Maker Movement

Emeline Brulé

I first read about the *Open Hand Project* and *e-NABLE* initiatives in 2013. Both were filling the mainstream news with heart-warming accounts, all centered around the exciting potential of anyone planning to 3D-print customizable upper limb prosthesis. A father made a “special” prosthetic hand for his own son. A teen produced mechanical fingers for a neighborhood kid born without any. Both groups were sharing their designs, inspiring a movement that seemingly revolutionized what could be made and by whom. As I am writing in 2022, these initiatives have taken separate paths. The *Open Hand Project* has become the *Open Bionics* company. It still produces myoelectric prosthesis using 3D-printing for affordability, but no longer uses hobbyist printers and has not shared the blueprints of their latest product, the *Hero Arm*.¹ The *Hero Arm* has been clinically tested, approved and is offered through clinics; whereas *e-NABLE* has refined a small number of designs, to be used at one’s own risks and printed by volunteers.

But in 2013, these two projects were still a promise: that computer-controlled fabrication tools such as 3D printers could enable anyone, including disabled people, to become “makers” and design and manufacture anything at any time at will, locally and for a low(er) cost (Gershenfeld

2005). What if any person might design and produce their own technologies? Might this new form of production remake systems of inequality, oppression and injustice? Could consumers become active makers and creative citizens? Rooted in ideas of open-source software and electronics hacking, the global “maker movement” began to take shape in the 1990s. The movement increased its influence after the financial crisis of 2007-2008. But as illustrated above, 3D-printing underpins very different approaches to the design of assistive products; and interactions between makers and the disabled community take many shapes.

In this chapter I introduce the central discourses and hopes underpinning encounters between the making and disability community, and highlight why making is of limited help in facing the challenge of bringing assistive products to all who need them. I draw on seven years of direct involvement, from meeting stakeholders in this space, collecting projects documentation and exhibition catalogs, reviewing research or attending making events and organizations: a patchwork ethnography. I do not aim at exhaustively mapping this field,² but rather at teasing the tensions at its core.

My first task then is to circumscribe the topic. While I consider many do-it-yourself (DIY) practices and crafts as belonging under this umbrella, I largely focus on initiatives using automated production tools and electronics, instead of, for instance, hobbyist making of adapted clothes. Similarly, while I cursorily refer to digital fabrication in medicine, medical implants or models are

beyond the scope of this chapter, as they present a specific set of safety and organizational issues. In discussing the promise of digital fabrication and making, I look at the topic through three perspectives: the types of objects that digital making is framed as uniquely positioned to produce; the actors involved in sustaining making these initiatives; and the technical benefits of digital fabrication beyond hobbyists. I conclude with a discussion of the persistent—and inevitable—challenges to making assistive products. Prototyping is easy (enough); developing and maintaining a product is hard. Nevertheless, even if the initial promises of the makers movement are now dimming, it remains an invitation to reconsider how we design equitably with disability.

A History of Making

Disabled people have long designed and shared ideas for custom assistive technologies. Polio survivors documented and shared their experimentations and home alterations through the *Toomeyville Gazette* from 1955 to 1998 (Williamson 2019). The *Bulletin mensuel de l'Union des Aveugles de Guerre* (Monthly Bulletin of the Union of Blind Veterans) published from 1919, included an open rubric used by members to communicate about adaptations they had developed. As Liz Jackson put it, people with disabilities “*are the original lifehackers*” (2018).

By the 2000s, however, the possibilities surrounding custom assistive technologies appeared to shift radically. In their article spearheading research into making for accessibility in the field of Human-Computer Interaction (HCI), Hurst and Tobias (2011) highlight the work of a

volunteer creating assistive or adapted objects in a home workshop; they asked how computer-controlled fabrication tools and electronics platforms could expand these practices, for both disabled people and their able-bodied family and friends. Among those tools, the 3D-printer stood out. Essentially, it seemed to promise that any user could download the file of an object, push a button, and obtain a high-fidelity copy. The actual construction process occurs by adding material in strata, following a digital model. There are a variety of approaches to doing so, but fused deposition modeling, which consists in melting plastic (for instance *Ultimakers* or *Makerbots*), is historically the most common for hobbyist printers.

The maker movement built on traditions of DIY, craft, and open source hardware and software (Turner 2018), but emphasized little skills was needed to put the means of production back in the hands of the people—at least according to public coverage (Hepp 2020). In practice, their use required developing an infrastructure (Davies 2017) of websites for sharing and documentation such as *Thingiverse* and *Instructables*; physical makerspaces to meet and provide access to more complex or large machines like laser cutters, further visibility-making practices, and recruiting and supporting new members; events and demonstrations framing making as a new path to innovation, economic development and for education; and user-friendly 3D modelling tools supporting beginners with creating their first objects, possibly leading to the development of more advanced engineering skills, and transforming users into makers, but this never happened at scale (Roedl et al. 2015).

I have been involved with projects for social and digital inclusion and the empowerment of young people and people with disabilities for many years. It is far from a homogenous movement. In late 2014, sometime after I first learned about the *Open Hand Project* and *e-NABLE* initiatives, I started studying an organization providing services to visually impaired children and adults undergoing sight loss in southern France. A small group of workers who were interested in making for accessibility had recently become interested in the local makerspace, and they had a partnership with HCI researchers at the local university. I stayed for eighteen months for field work and continued doing interviews and collecting their documentation of their making practices for four more years. Throughout, I was involved in making myself, focusing especially on more complex three-dimensional representations used in classrooms, for instance tactile globes and models of insects (Brulé and Bailly 2021).

In parallel, I became personally involved in a local makerspace, which had several initiatives in that area: supporting the printing of hand prosthesis, often for educational purposes as an introduction to 3D-printing; helping individuals seeking to repair assistive or adapted products to organizing events for designing new accessible objects, such as physical games; or more complex assistive technologies requiring electronics and software design. I was encouraged in 2016 to join one of these initiatives, *E-Fabrik*, because makerspace employees knew of my PhD research. *E-Fabrik* sought to strengthen social solidarity through the co-design of assistive products, inspired by the *Fixperts* project. *E-Fabrik* first focused in 2015 on involving secondary school students in designing

and building custom objects with people with disabilities receiving services from, or institutionalized in, partner organizations. In 2016, it attempted to match more experienced makers and disabled individuals. From 2018, it trained young adults from Seine Saint-Denis, an underprivileged urban area, to use digital fabrication tools and develop design skills, as part of a national scheme to develop workers' digital skills.⁵ Rather than an accredited diploma opening employment as makers for accessibility, trainees receive support to develop professional and social skills and usually go on to further training or towards socio-educational work.⁶

I draw on these experiences to write about the multiple configurations of collaborations between the making and disability communities. From the *Toomeyville Gazette* to *E-Fabrik*, the ultimate goal of these initiatives is to make design and fabrication more equitable and responsive to individual needs. Nevertheless, the range of objects, discourses, structures and people under the umbrella of making and disability make for markedly different understandings of how to get there.

The Objects of Making

One key argument for digital fabrication in the design of assistive products is that it enables the production of objects that could not be manufactured otherwise. In this section, I focus on objects that are **customizable** automatically or semi-automatically and **empowering** objects that go beyond assistive functions, aiming to convey identity or empowerment through participation in the design process.

Customizable prostheses are the best example of how making captured the popular imagination. To design a prosthesis, there are several parameters (e.g., length, width, design of a cover) and constraints (e.g., weight, mechanical properties such as stiffness) vary from one person to the next. Parametric modeling is an approach to design enabling automatic changes to an object based on the input of different parameters value, or to explore solutions optimizing different constraints. For more complex shapes, a model could include a part based on a 3D scan. This is the approach used in *GripFab*, a design tool for occupational therapists to create custom grips for everyday objects (Buehler et al. 2014). In contrast, previous methods of automation have relied on a range of standardized sizes, necessary to create the molds for plastic, or other industrial fabrication processes. The conjunction of wider availability of parametric modelling tools (for instance, the *Makerbot Customizer* available on *Thingiverse* or the *LimbForge* project for prostheses specifically) and of reliable 3D-printers for production makes customization by the actual user of an assistive device feel possible.

Part of the promise of customization is the ability to cut out intermediaries, or accelerate their work, improving the availability of assistive products. For instance, obtaining a custom-fit prosthesis involves a lengthy process. First, the user must secure funds for these highly specialized objects. Next, he or she must meet a prosthetist, itself a rare type of expertise. The latter may then outsource production or request the assistance of colleagues to make the prosthetic device itself.

Each step in this process lengthens the wait for a prosthesis, an especially challenging issue for children as they grow up. The initial appeal of using parametric customizable models is considerable. Yet, achieving that promise is often difficult to achieve. *e-NABLE* for instance is limited to below-elbow prosthetics despite efforts to expand to leg or full arm prosthetics. Moreover, the promises of automation may hide the complex manual work required to finish, assemble, and fit these devices. I spent 90 minutes of an *e-NABLE* workshop held at the 2018 edition of the *Mozilla Festival*, an event dedicated to open technologies, polishing just two knuckles. The parametric, customizable, *Knick's* prosthetics finger similarly requires significant manual work, as described in its documentation. In other words, digital fabrication does require labor; but it shifts who can undertake it and where it takes place.

Making may also foster the empowerment and the participation of disabled people in creating assistive products. Its appeal was that disabled people could easily become designers and create products for needs otherwise overlooked or ignored, or products that are too costly because they are manufactured in small numbers. The activist Raul Krauthasen for example designed and printed a wheelchair ramp (Rose 2014). Empowerment is also a core value of the research about making for accessibility. Hurst and Tobias' (2011) influential article on making for accessibility frames both participation in the making process and the type of objects produced as empowering. Similarly, De Couvreur and Gossens argue that involvement in making is key to living an independent life, because it allows designing for highly personal goals, situations and skills, and a focus on personal aesthetics. Calling their approach "design for (every)one," they argue that making is a new approach to personal rehabilitation engineering, lifting the stigma of using assistive products and positively impacting self-perception (2011). They give examples of co-created designs, including a guitar slider, an adapted badminton shuttle and a device for eating ice-cream bars. With examples like these in mind, I define objects for empowerment as objects crafted for or with individuals, that cannot be automatically customized through parametric models, and that may diverge from needs that are considered essential by rehabilitation specialists, such as conveying identity.

Again, outside academic circles, prosthetics have been some of the best known of these empowering objects. Prosthetics or prosthesis attachments made to fit the activities of the wearer are nothing new, but it is unlikely professional prosthetists could develop many of these for playful

or imaginative purposes. One widely publicized object is the 2016 *Project Unicorn*, a 3D-printed arm prosthesis shooting glitter, designed with a ten-year-old girl.⁷ Here, 3D-printing and electronics prototyping kits enable rapid iterations at lesser costs, while the use of plastics offers flexibility for the design of the shape. Free hobbyist modelling software does open avenues for the autonomous fabrication of simpler designs. *Tinkercad*, for instance, is based on the assembly of basic geometric shapes by addition and subtraction and is used in educational contexts (Hansen et al. 2017). Hand drawings or paper and cardboard shapes can be scanned for a laser cutter and applied to other materials. This enabled the *Quietude* project in which Deaf participants drew hearing aids as jewelry. But these types of objects and design processes are close to DIY traditions, and often remain prototypes. Indeed, the fully realized design of *Project Unicorn* required the expertise of an industrial designer.

The need for more specialized knowledge brings out another characteristic of the maker movement: online documentation and communication systems allowing free access to models and tutorials for inspiration, sharing knowledge and guidelines for new volunteers, collaborating worldwide, or asking help from other experts.⁸ National and international DIY competitions often supported by more generalist disability organizations, like *Papas bricoleurs* (DIY-Dads) which started in 1998, now named *Fablife*, have aimed to encourage these collaborations. De Couvreur and co-authors (Ostuzzi et al. 2017) have run a program matching designers, rehabilitation specialists and disabled users to produce these empowering *designs for one* for close to a decade, and have developed typologies of

design features. For instance, they attempted to systematically explore how two surfaces can be joined or handles that can be added on objects. This modular approach to design, aiming at scaffolding what amateurs can do through simple guidelines, goes beyond assistive products for people with physical disabilities. Nevertheless, projects like these suggest another singular aspect behind making, namely the sheer variety of people involved—and often necessary for—its undertaking.

The People in Making

The initial promise of initiatives like *Open Hand Project* and *e-NABLE* was that their designs could be made by anyone. As I have outlined in the previous section, making and disability initiatives are not only built around certain types of objects but also around collaborations, with making in itself framed as an empowering process. But who is making and using these devices, in practice? First, I consider the various roles of **disabled makers**, and the immediate community of family and friends. I then discuss partnerships with **educational institutions** or **disability professionals**. I conclude with the networked approach aiming at independently matching **amateur makers** with users.

The promise of the maker movement is that users could become designers (Roedl et al. 2015). Rose's coverage on making for accessibility emphasizes the ability of Designing it Yourself and the ability to share and improve designs with other disabled people (2014). Disabled makers argued it could lower the price of pieces of specialized equipment such as wheelchair cup holders or allow

them to resolve everyday difficulties. Others hoped making could also provide new employment opportunities or a path into the design and engineering industry (Meissner et al. 2017). This underpins the *BOOST* program, bringing together disabled youth and makers. To support disabled makers, HCI scholars have proposed adapted design and prototyping tools (Siu et al. 2019), and investigated how to make makerspaces more accessible (Brady et al. 2014).

This is where “Do-It-Together design” comes in: calling for disabled people to work with designers and engineers in a sharing of expertise, instead of expecting one person to learn it all (Tehel 2019). Makers and researchers have strived to identify and support possible partners for all stages of the design process. Family and friends are at the forefront of these initiatives. For instance, when designing for children, parents are already involved in identifying accessibility needs and possible solutions. They seek and buy mainstream products that are or can be adapted to their child’s needs (for an example, see the crucial role in iPad cases in the use of alternative communication devices in (Alper, 2017)) or make small tweaks such as adding sticky pads to plates so they stay in place while eating (Hook et al. 2014). But parents lack the time or confidence to get involved in making, and worry about the safety of the objects they would design from scratch or print out. They do however feel confident about making repairs if parts were available, another area in which digital fabrication could be useful (Hook et al. 2014). Research on peers’ involvement generally concerns different types of objects, more oriented towards playing or media, as they would between non-disabled children: Kim et al. for instance proposed a tool for children to make accessible tactile pictures out of building blocks like Legos, much like one would make a scrapbook or card for a friend (2014).

While family and friends can partner in making, the need for cheap or free labor and technical skills means that educational institutions, especially universities, are sought out as partners. Students may be asked to collaborate with occupational therapists to

design one-off assistive devices (De Couvreur and Gossens 2011), develop interactive prototypes as part of class projects (Brulé and Bailly 2021) or explore how to make makerspaces accessible (Worsley and Bar-El 2020) to teach technical or creative skills and accessibility through an authentic task. Some making initiatives, like *E-Fabrik*, also establish themselves as vocational training programs, thereby ensuring the involvement of students until completion of the project. Others like *Fixperts* offer educational content that teachers can use, then publicize the results. In their messaging, they evoke problem-solving skills and making as citizenship. This should be understood within a broader history of involving students in initiatives for development. *Engineering without Borders* for example organizes competitions between undergraduate programs, aimed at solving a problem far removed from students' experience.

And yet such approaches carry their own risks with disability activists highlighting their limitations, or even damaging impact. Ashley Shew has described these impulses as techno-ableism (2020) while Elizabeth Guffey and Bess Williamson suggest that the desire to "cure" disability through newer technologies might constitute a newer *design model of disability* (Williamson and Guffey 2020). Liz Jackson coined the term "disability dongle" for design concepts that purport to address a problem in style, but fail to understand and answer accessibility issues (2018). The dongle embodies the aspirations of many young designers and is a particular concern with student projects. In my relatively short teaching career, I met no less than seventeen students proposing "technologies

to guide the blind.” Depending on the fashion of the moment, these may involve drones, robots or electronics embedded in textiles. While earnest young designers want to produce impactful products, students may lack the time and guidance to fully research needs or avoid simpler products and focus on aesthetics to gain advantage in course evaluation or attract public coverage. Emphasizing the value of small, collaborative but useful DIY projects in evaluation rubrics may avoid this pitfall.

Disability professionals also play a role in digital fabrication projects. I discuss earlier in this chapter research and projects aiming at changing disability professionals' practices, especially occupational therapists', by introducing digital fabrication tools and the design and engineering skills for making. *Maker Nurse*⁹ for instance provide tools, space and an online sharing infrastructure for nurses. For disability professionals, this is a way to see their often overlooked (Royer 2015; Hofmann, et al. 2019) creativity recognized. Here, making is presented as a driver for innovative care practices, with the goal of improving services at no or low cost.

However, the extent to which digital fabrication and making is changing existing professional practice is unclear. For example, Slegers et al. suggest that occupational therapists are less likely to believe hobbyist 3D-printing would change their profession after using it, in part because they believe that collaborating with professional designers would be necessary and this would not lower costs (2020). I similarly observed that disability professionals such as tactile document makers may

add digital fabrication tools to their existing toolset; nevertheless, it does not replace traditional, expensive equipment such as tactile image makers. In fact, 3D printers are more likely to fail, and prints often require hand finishes. They also found that while 3D models are sometimes helpful, tactile or bas-relief representations are often better indicated. Moreover, while many models are shared online, educational materials need to be adapted for local contexts and then to individual children. These issues often meant that digital fabrication added to the costs and to the workload of document makers; maintaining the skills need to make such changes was difficult, often necessitating that extra staff with design and engineering skills had to be hired. Such users continued to support digital fabrication, and especially using laser cutters. At the same time, however, after six years of collaboration with makers only one member of staff remained highly involved in making, (Brulé and Bailly 2021).

Initiatives such as *Makers Making Change*, *E-Fabrik* or *Match My Maker* instead encouraged amateur makers to get involved. These groups aim to find makers with engineering or computer programming skills to help with designing or building solutions to an accessibility problem. These volunteer makers get involved of their own volition, but lack incentives beyond moral and civic fulfillment. There are no guarantees they will be able to complete or maintain a project, especially complex ones. *Makers Making Change* also recruits volunteers to assemble their project kits as part of team building activities. However, this only concerns small and easily reproducible projects, like adding a switch to toys.

These difficulties are similar to those of the open-source movement, using a decentralized and largely unpaid community to maintain software projects (Eghbal 2020). In my experience as both a maker and a researcher, it is difficult to recruit volunteer makers in the local making community for an accessibility project; this is why many projects turn to students for help (Brulé and Bailly 2021). While some makers get involved in accessibility work as a hobby (Hurst and Tobias 2011), and they are motivated by the moral rewards or public exposure for their involvement (Hoffman et al. 2016), volunteers' involvement is typically limited to a one-off project or event (Eghbal 2020). More complex projects require on-going collaborations, not only for development but for maintenance and improvement, and need significant funding. For instance, *Makers Making Change* received a large grant to develop a mouth-controlled computer input meant to enable people with limited motor skills to operate a computer. Conversely, the *Open Hand Project*, which was originally funded through crowdsourcing, raised venture capital from investors to become *Open Bionics*. The latter initiative allowed them to hire engineers, establish a lab and the production of low-cost customizable prosthetics. Ultimately, approaches to making for disability that casually connect demands and makers are likely to result in widely different outcomes, with more complex or less easy to show off projects understandably receiving far less attention.

Maintenance, Repair and Innovation: A Different Economy of Scale

So far, I have outlined how digital fabrication tools have been understood as a way to dramatically change who can get involved in making, and how they have (not) met those expectations. But digital

fabrication can also an industrial advantage, spurring new businesses and enabling a different approach to distribution and customization. Moreover, while digital fabrication was reserved for prototyping historically, computer-controlled fabrication at scale may improve mechanical performance. Although these practices may seem distant from the initial promise of casual and creative forms of digital making, it still offers a complementary approach to understanding or building new accessibility initiatives that leverage digital fabrication tools. I will focus on two aspects potential advantages, specifically digital fabrication for **small series** and hopes that **distributing digital models** could foster innovation. The making movement offers an invitation to rethink how we manufacture products more broadly, taking advantage of different production scales.

Repairing assistive products remains one of the areas of digital making which disabled people as well as their immediate community might find highly effective and practical (Hook et al. 2014). When a disability organization asked me in 2015 to make a copy of a screw for a needed repair, I thought I had found a great example of what amateur digital fabrication could achieve. This screw was not standard and could not be bought (a wider issue that recent "Right to Repair" legislation aims to address). Replacing the bed transfer device it was part of would be expensive. Repairing accessible and assistive products often comes with hefty price tags, as replacement parts are difficult to source and may have to be made in small numbers. Industrial grade 3D-printers or computer-controlled drills can manufacture a wider range of materials, including metal (Chekurov et al. 2018). While I rapidly realized that the 3D scanners I had access to were not precise enough, and

our drilling machines could not produce this screw safely, a local company owning industrial *computer numerical controlled* (CNC) milling machines agreed to produce a copy at no cost.

More generally, improving the industrial production of small product series could make them more affordable. For instance, I found that tactile document makers often laser cut and then hand-paint accessible rulers every year (Brulé and Bailly 2021: 10). This seems less expensive to make than buy, but that's only because it is added to workers' existing schedule, hiding labor costs. It is also, likely, less energy efficient. Similarly, bottle openers for people with arthritis are needed in large enough numbers that they can be produced with traditional manufacturing techniques and are sold at a low cost. There are models that can be downloaded and 3D printed locally, but it is unclear if using digital fabrication results in a product as robust or as efficiently manufactured. Improvements to production can be found beyond digital fabrication. The *Adaptive Design* organization builds custom cardboard seats for disabled children, largely by hand. It's a perfect approach for this particular problem, although it may not seem as innovative as 3D printers.

Finally, a core argument for encouraging digital fabrication is that providing open access to models could speed innovation, inviting more people to iterate and improve designs. There are good reasons to believe this type of decentralized innovation can work, from scientific innovation contests to open-source software.¹⁰ Regardless of the short-term design outcomes, creating assistive products in maker spaces can have profound implications for civic participation, the

consolidation of accessibility as a shared value, the development of skills and the creation of formal and informal communities well-placed to rethink approaches to manufacturing. From this perspective, open-source plans for assistive products would enable designers and engineers to learn more easily from the work of others. But the path to a global community involved in accessibility innovation is not so clear. Sophisticated myoelectric prostheses can be especially difficult in this regard; *Hackaday* listed four open-source myoelectric hands projects in 2016, but only the *Open Hand Project* appears to have gone beyond prototyping, and it is unclear whether makers built upon each other's work. In their study of models for protective equipment, Mack et al. found that innovation mostly originated in existing professional teams: amateur makers would innovate at the periphery, for example proposing tweaks for using a different printer (2021).

Making as a Powerful Horizon for Equality

As I was writing this chapter, my discussions with makers focused on a paradox: it feels like we have achieved so much yet so little through making. There are many hopes and promises, but just as many failures. While discourses on making focus on customization or empowerment, I am still struck by the frequent emphasis on **decreasing costs of assistive products**. This has been the case with *e-NABLE* and *OpenBionics*, as well as many of the educational and research initiatives I am part of. We certainly should incentivize manufacturers to keep prices low, but by emphasizing how making drives down the costs of qualified workers by instead using volunteers as cheap or free labor, we also avow

an acceptance that states will not take responsibility towards disabled citizens. Positing making as an alternative to state-supported services risks transferring even more responsibilities to unpaid volunteers and caregivers, while still posing significant maintenance problems.

Others argue that making is better than nothing. A focus on customization and empowerment does have the potential to open new direction for disability design. As we begin to assess over a decade of digital making, however, I want to emphasize **equality in accessing assistive products**. This requires a state-operated approach¹¹ to develop and maintain new assistive products taking advantage of innovations in manufacturing, based on employing professionals to provide products for all. This does not preclude regularly from involving makers and volunteers to work on certain problems, or supporting disabled individuals in developing and sharing their everyday hacks. Many makers are concerned acting towards institutional change would have no results, at least for the foreseeable future. They instead advocate for emphasizing **the innovation potential** that can funnel funding to the people who can develop assistive products at lower costs with responsible entrepreneurial practices, and that we just need more time for prototypes to come to fruition. They rightly point that this is more attractive for public institutions in a context of austerity measures. What concerns me is that funding innovative practices may draw resources away from disability organizations, especially as they are already asked to provide more services than their original mandate; this scenario comes at the risk to see it used for day-to-day functioning and have organizations compete for sources of funding that are ever less sufficient.¹² I summarize these

discussions because they show that the same technologies, while accompanied by a certain set of values (Davies 2017; Turner 2018) can be recontextualized in different ways in the service of accessibility.

When we examine the design implications for these new technologies, we make assumptions about what they allow: the transfer of labor, a decrease in skills needed to accomplish the same goals. This view oversimplifies the complex organizational work that was necessary to bring about the open-source software movement, which additionally draws on a much larger and well-resourced group of software professionals. Moreover, when discourses on making and disability have focused on empowerment, projects held as successes that expanded beyond individual prototypes and have spread to countries with low access to assistive products, such as *e-NABLE*, are still to be evaluated.¹³

To summarize and conclude, media, civic and disability organizations have framed the maker movement and its tools as a significant opportunity for decentralized and rapid innovation in accessibility. It still invites us to rethink how we produce products, moving us beyond the mass-produced solutions of earlier decades. But the groups involved in digital making vary in terms of motivations, organization and focus. They often emphasize the moral value of volunteering and center empowerment and artifacts to effect change. This can translate into a materialization of hopes for an inclusive future. But while initiatives like *Open Hand Project* and *e-NABLE* provide compelling

stories and can bring communities together, they downplay the difficulties to bring about the advantages of digital fabrication for manufacturing. In that regard, they reflect concerning trends that focus on innovation rather than maintenance, or that emphasize autonomous access to technologies rather than concerted training as a path to progress and justice.

Notes

1. The company announced through social media in 2018 the files would be available, but they currently are not. See: <https://twitter.com/openbionics/status/991691284162195457>.
2. I will mostly refer to projects, but there are atlases of maker spaces interested in accessibility, such as <https://www.careables.org/community-map/> or http://wiki.fablab.fr/index.php?title=Groupe_Travail_Accessibilit%C3%A9_Handicap.
3. An example can be found in Volume 1, May 1919 edition, p.20
4. Fixperts is an initiative encouraging students to design for a disabled person in their community.
5. La Grande École du Numérique (*The Great School of the Digital*).
6. According to their website, see list of Project References at conclusion of this chapter.
7. See <https://jordanreeves.com/project-unicorn>.
8. There's a long tradition of studies into documentation, in particular different types of tutorials, and their importance in the informal and decentralized learning advocated by many makers. I would recommend Torrey et al. (2007).

9. Maker Nurse initially was supported by MIT, simultaneously highlighting the role of educational institutions in making for accessibility and the role of a technological imaginary in which MIT retains a place of choice.
10. Lakhami and co-authors have long investigated the conditions under which these processes are possible. See for instance, Lakhani et al. (2013).
11. It is worth noting that there are astoundingly few initiatives to structure international collaborations around assistive products. This is changing; in 2021, the World Health Organization published guidelines on minimum requirements for assistive technology and products.
12. This goes beyond the scope of this article, but as an example, the disability organization studied during my thesis provided educational services to more children than stated in the regional agreement for funding. For years, they received additional annual funding, until they did not. Disability organizations are incentivized to develop their own resources to compensate for state public austerity measures, including through research and the provision of services beyond their core missions. A 2018 report, "Scenarios for the Evolution of National Institutes of Deaf and Blind Youth," makes visible this evolution of funding. Long funded at state level as the first schools for disabled children, it argues that this separate status prevents them from competing for additional sources of funding for research or innovative practices. I do not doubt the appropriateness of public funding needs to be regularly examined. However, expanding responsibilities of public educational organizations to make them more responsible financially has often resulted in

decreasing public funding rather than increasing educational equality, as has previously been the case for French universities.

13. Fiedler et al. (2018) proposed a study, but to my knowledge results have not been published.

References

- Bennett, C. L., E. Brady and S. M. Branham (2018), "Interdependence as a Frame for Assistive Technology Research and Design." In *Proceedings of the 20th International ACM Sigaccess Conference on Computers and Accessibility*, 161-173. New York, NY, USA: Association for Computing Machinery.
- Brady, T., C. Salas, A. Nuriddin, W. Rodgers, and M. Subramaniam (2014), "MakeAbility: Creating Accessible Makerspace Events in a Public Library," *Public Library Quarterly*, 33 (4): 330-347.
- Brulé, E. and G. Bailly (2021), "'Beyond 3D printers': Understanding Long-Term Digital Fabrication Practices for the Education of Visually Impaired or Blind Youth." In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1-15. New York, NY, USA: Association for Computing Machinery.
- Buehler, E., A. Hurst and M. Hofmann (2014), "Coming to Grips: 3D Printing for Accessibility." In *Proceedings of the 16th International ACM SIGACCESS Conference on Computers & Accessibility*, 291-292. New York, NY, USA: Association for Computing Machinery. *Bulletin mensuel de l'Union des Aveugles de Guerre* (Monthly Bulletin of the Union of Blind Veterans). Available online: <https://argonnaute.parisnanterre.fr/ark:/14707/a011447430312YuCgOW/af4e3d2895>. Accessed on 2 December 2021.
- Chekurov, S., S. Metsä-Kortelainen, M. Salmi, I. Roda, and A. Jussila (2018), "The Perceived Value of Additively Manufactured Digital Spare Parts in Industry: An empirical investigation," *International Journal of Production Economics*, 205: 87-97.
- Davies, S. R. (2017), *Hackerspaces: Making the maker movement*, Cambridge; Malden, MA: Polity Press.
- De Couvreur, L., and R. Goossens (2011), "Design for (Every) one: Co-creation as a Bridge Between Universal Design and Rehabilitation Engineering, *CoDesign*, 7 (2): 107-121.
- Eghbal, N. (2020), *Working in Public: The Making and Maintenance of Open Source software*, San Francisco: Stripe Press.

- Ferreira de Oliveira, R., G. Pétreault, F. Carayon, T. Leconte, P. R. Ambrogi, (2018), Scénarios d'évolution des instituts nationaux des jeunes sourds et des jeunes aveugles (Scenarios for the evolution of national institutes of Deaf and Blind Youth). Available online: <https://www.igas.gouv.fr/IMG/pdf/2017-069R.pdf>. Accessed on 2 December 2021.
- Fiedler, G., S. Savage, J. Schull, and J. Mankoff (2018), "The Case For Broad-Range Outcome Assessment Across Upper Limb Device Classes," *Canadian Prosthetics & Orthotics Journal*, 1 (1): 1-4
- Gershenfeld, N. A. (2005), *Fab: The Coming Revolution on Your Desktop--from Personal Computers to Personal Fabrication*, New York: Basic Books (AZ).
- Hansen, A. K., E.R. Hansen, T. Hall, M. Fixler, and D. Harlow (2017), "Fidgeting with Fabrication: Students with ADHD Making Tools to Focus." In *Proceedings of the 7th Annual Conference on Creativity and Fabrication in Education*, 1-4. New York, NY, USA: Association for Computing Machinery.
- Hepp, A. (2020), "The Fragility of Curating a Pioneer Community: Deep Mediatization and the Spread of the Quantified Self and Maker Movements" *International Journal of Cultural Studies*, 23 (6): 932-950.
- Hofmann, M., J. Burke, J. Pearlman, G. Fiedler, A. Hess, J. Schull, and J. Mankoff (2016), "Clinical and Maker Perspectives on the Design of Assistive Technology with Rapid Prototyping Technologies." In *Proceedings of the 18th International ACM SIGACCESS Conference on Computers and Accessibility*, 251-256). New York, NY, USA: Association for Computing Machinery.
- Hofmann, M., K. Williams, T. Kaplan, S. Valencia, G. Hann, S.E. Hudson, and P. Carrington (2019) "'Occupational Therapy is Making' Clinical Rapid Prototyping and Digital Fabrication." In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1-13. New York, NY, USA: Association for Computing Machinery.
- Hook, J., S. Verbaan, A. Durrant, P. Olivier, and P. Wright (2014), "A Study of the Challenges related to DIY Assistive Technology in the Context of Children with Disabilities." In *Proceedings of the 2014 Conference on Designing Interactive Systems*, 597-606. New York, NY, USA: Association for Computing Machinery.
- Hurst, A., and J. Tobias (2011), "Empowering Individuals with do-it-yourself Assistive Technology." In *The Proceedings of the 13th International ACM SIGACCESS Conference on Computers and Accessibility*, 11-18. New York, NY, USA: Association for Computing Machinery.

- Jackson, L. (2018), "We Are the Original Lifehackers," *The New York Times*, 30 May. Available online: <https://www.nytimes.com/2018/05/30/opinion/disability-design-lifehacks.html> (accessed 2 December 2021).
- Kim, J., A. Stangl, and T. Yeh (2014) "Using LEGO to model 3D tactile picture books by sighted children for blind children." In *Proceedings of the 2nd ACM Symposium on Spatial User Interaction*, 146-146. New York, NY, USA: Association for Computing Machinery.
- Lakhani, K. R., H. Lifshitz-Assaf, and M. L. Tushman (2013), "Open Innovation and Organizational Boundaries: Task decomposition, Knowledge Distribution and the Locus of Innovation," in Anna Grandori (ed), *Handbook of economic organization*, 355-382], Northampton, MA: Edward Elgar Publishing.
- Meissner, J. L., J. Vines, J. McLaughlin, T. Nappey, J. Maksimova, and P. Wright (2017), "Do-it-yourself Empowerment as Experienced by Novice Makers with Disabilities." In *Proceedings of the 2017 Conference on Designing Interactive Systems*, 1053-1065. New York, NY, USA: Association for Computing Machinery.
- Oehlberg, L., W. Willett, and W.E. Mackay (2015), "Patterns of Physical Design Remixing in Online Maker Communities." In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, 639-648. New York, NY, USA: Association for Computing Machinery. Available online: <https://doi.org/10.1145/2702123.2702175>
- Ostuzzi, F., L. De Couvreur, J. Detand, and J. Saldien (2017), "From Design for One to Open-ended Design. Experiments on Understanding how to open-up Contextual Design Solutions," *The Design Journal*, 20 (sup1): S3873-S3883.
- Roedl, D., S. Bardzell, and J. Bardzell (2015), "Sustainable Making? Balancing Optimism and Criticism in HCI Discourse," *ACM Transactions on Computer-Human Interaction (TOCHI)*, 22 (3), 1-27.
- Rose, D. (2014), "Could 3D Printing Provide New Solutions for Disabled People?" *BBC News*, January 31. Available online: <https://www.bbc.com/news/blogs-ouch-25947021> (accessed 2 December 2021).
- Royer, M. (2015), "De l'instrument à la prothèse: ethnographie de trajectoires d'objets biotechnologiques en cancérologie (From instrument to prosthesis: ethnography of the trajectories of biotechnological objects in cancerology)," PhD diss., EHESS, Paris.
- Shew, A. (2020), "Ableism, Technoableism, and Future AI," *IEEE Technology and Society Magazine*, 39 (1): 40-85.

- Siu, A., Kim, S., Miele, J., and Follmer, S. (2019), "ShapeCAD: An Accessible 3D Modelling Workflow for the Blind and Visually-Impaired Via 2.5D Shape Displays." In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '19)*, 342–354. New York, NY, USA : Association for Computing Machinery. DOI:<https://doi.org/10.1145/3308561.3353782>
- Slegers, K., K. Kouwenberg, T. Loučova, and R. Daniels (2020), "Makers in Healthcare: The Role of Occupational Therapists in the Design of DIY Assistive Technology." In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1-11. New York, NY, USA: Association for Computing Machinery.
- Tehel, A. (2019), "Do It Yourself: la fabrication numérique comme empowerment des corps handicapés?" *Terminal. Technologie de l'information, culture & société*, (125-126).
- Torrey, C., D. W. McDonald, B.N. Schilit, and S. Bly (2007), "How-To pages: Informal systems of expertise sharing" In *ECSCW 2007* (pp. 391-410). Springer, London.
- Turner, F. (2018), "Millenarian Tinkering: The Puritan Roots of the Maker Movement," *Technology and culture*, 59 (4): S160-S182.
- Walter, M. (2016), "Hackaday Prize Entry: Open-Source Myoelectric Hand Prosthesis," *Hackaday*, , May 26. Available online: <https://hackaday.com/2016/05/26/hackaday-prize-entry-open-source-myoelectric-hand-prosthesis/> (accessed 2 December 2021).
- Williamson, B. (2019), *Accessible America: A History of Disability and Design*, New York, NY, USA: NYU Press.
- Williamson, B., and E. Guffey, eds (2020), *Making Disability Modern: Design Histories*, London: Bloomsbury Publishing.
- World Health Organization (2021), "First Ever Global Guide for Assistive Technology to Improve the Life of Millions," 2 March. Available online: <https://www.who.int/news-room/feature-stories/detail/first-ever-global-guide-for-assistive-technology-to-improve-the-life-of-millions>.
- Worsley, M., and D. Bar-El (2020), "Inclusive Making: designing tools and experiences to promote accessibility and redefine making," *Computer Science Education*:1-33. Available online: <https://www.tandfonline.com/doi/full/10.1080/08993408.2020.1863705>.

Project references

Adaptive Design: adaptivedesign.org

BOOST, a program of Born Just Right: boostxbjr.org/about

Careables: careables.org

E-Fabrik: efabrik.fr/parcours

e-NABLE: enablingthefuture.org/about

Fablife / Papas bricoleurs et mamans astucieuses: fondationleroymerlin.fr/realisations/32-actualites

Fixperts: fixing.education/fixperts

My Human Kit/Human Lab: myhumankit.org/le-humanlab

Ikea This Ables: thisables.com/en/new-developments

Limbforge has merged with Victoria Hand Project: victoriahandproject.com/history-timeline

Makers Making Change: makersmakingchange.com

Match My Maker: matchmymaker.de

New York Public Library program: <https://www.nypl.org/about/locations/heiskell/dimensions>

Open Hand Project, which became Open Bionics: openhandproject.org, openbionics.com

Project Unicorn: jordanreeves.com/project-unicorn