

Document Version

Final published version

Licence

CC BY

Citation (APA)

van Grunsven, J. B., & Ijsselsteijn, W. A. (2022). Confronting Ableism in a Post-COVID World: Designing for World-Familiarity Through Acts of Defamiliarization. In *Values for a Post-Pandemic Future* (pp. 185-200). Article 10.1007/978-3-031-08424-9_10 (Philosophy of Engineering and Technology; Vol. 40). Springer. https://doi.org/10.1007/978-3-031-08424-9_10

Important note

To cite this publication, please use the final published version (if applicable).
Please check the document version above.

Copyright

In case the licence states "Dutch Copyright Act (Article 25fa)", this publication was made available Green Open Access via the TU Delft Institutional Repository pursuant to Dutch Copyright Act (Article 25fa, the Taverne amendment). This provision does not affect copyright ownership.
Unless copyright is transferred by contract or statute, it remains with the copyright holder.

Sharing and reuse

Other than for strictly personal use, it is not permitted to download, forward or distribute the text or part of it, without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license such as Creative Commons.

Takedown policy

Please contact us and provide details if you believe this document breaches copyrights.
We will remove access to the work immediately and investigate your claim.

Chapter 10

Confronting Ableism in a Post-COVID World: Designing for World-Familiarity Through Acts of Defamiliarization



Janna van Grunsven and Wijnand IJsselsteijn

10.1 Introduction

The COVID-19 pandemic has brought about a dramatic change in how we interact with others in our everyday activities. Two-dimensional screens and online platforms have profoundly mediated how we work, learn, stay in touch with friends and family, and connect with health care providers and therapists. For many, the pervasive digitalization of our social and practical lives has signified a substantial loss, with the pandemic underscoring that in-person interactions play a key if not constitutive role in well-being. At the same time, a significant number of people have experienced the digitalization of our social and practical lives not as detrimental but precisely as conducive to their overall well-being. In particular, many disabled people and disability rights activists have celebrated the increased accessibility to practical and social spaces enabled by the pandemic-induced embracing of online communication platforms and other digital technologies.¹ In the words of Ashley Shew:

¹We will use identity-first as opposed to people-first language in this paper. In doing so, we are following Elizabeth Ladau's (2015) argument that by "intentionally separate[ing] a person from their disability ... it ... implies that 'disability' or 'disabled' are negative, derogatory words. In other words, disability is something society believes a person should try to dissociate from if they want to be considered a whole person. This makes it seem as though being disabled is something of which you should be ashamed. PFL [people-first language] essentially buys into the stigma it claims to be fighting."

J. van Grunsven (✉)
Delft University of Technology, Delft, Netherlands
e-mail: J.B.vanGrunsvan@tudelft.nl

W. IJsselsteijn
Eindhoven University of Technology, Eindhoven, Netherlands
e-mail: w.a.ijsselsteijn@tue.nl

Many accommodations demanded under COVID-19 were implemented within weeks These are all things that disabled and chronically ill people have wanted for a very long time. I hope that when we've flattened the curve and saved as many people as possible, we don't return to a world in which disabled people are ignored (especially when COVID-19 will probably produce more of us). (Shew, 2020a)

Not wanting to return to the 'old normal,' Shew suggests, that a new post-COVID world should retain many of the now widely implemented technology-enabled forms of access that have benefitted so many disabled and chronically ill people.² Yet, as Shew readily acknowledges, we must be cautious about the role of digital technologies in a post-COVID world, and the idea that these technologies straightforwardly promote access. For one thing, disability is often co-opted by technology developers in order to illustrate the alleged societal benefits of their products, raising the concern that the genuine access-enabling potential of digital technologies for disabled people can play into a more problematic "screens everywhere" temptation that is "representative of today's dominant approach to technology design" (IJsselsteijn et al., 2020, p. 37). Furthermore, as Shew explicitly warns, although many digital technologies may have made it easier for disabled and chronically ill people to access a range of spaces and resources, *ableist* biases that (de)value some bodies and minds over others are rampant in tech-development. Without combating these biases – biases that "shape how and what we design" (Shew, 2020b) – the return to the 'old normal' that Shew warns against seems all but inevitable.³

Our aim in this chapter is to take Shew's call for technology-supported access *and* her warning against technology's ableist tendencies seriously. Starting from the premise that promoting accessibility and resisting ableism in technology development are morally imperative, our paper discusses two distinct conceptions of accessibility, paired with two conceptions of how access thus understood can be promoted through technology development. The first conception builds off the notion of *affordances*, taken from the field of ecological psychology (Gibson, 1979). Using the pandemic as an illustrative case, we show (Sect. 10.3) that an affordance-based notion of access underscores the link between a person's sense of well-being and their habitual sensorimotor embeddedness in a world that they experience as a space of familiarity – a space in which they know their way around and are able to respond effortlessly to the many perceived possibilities for action that the world affords (Van

²This is not to say that these communication technologies were not available prior to COVID, but rather that everyone is now forced to resort to them. Arguably, this has created a level playing field of sorts, where quite unlike people's access to physical meeting spaces, and the unequal distribution of social and physical affordances embedded therein, interactants meet in virtual spaces that allow them similar affordance to the other. Of course, due to the video-centric nature of digital communication platforms this point only goes so far.

³Shew refers not just to technological accommodations but also to a widespread increase in flexibility when it comes to scheduling, deadlines, etc. A more flexible (and critical) approach to productivity and the organization of time, she argues, is something we all benefit from. This signifies another dimension of how we design daily life that could benefit from the experience and knowledge of disabled persons.

Grunsven, 2020). In Sect. 10.4, we will present *Warm Technology* (IJsselsteijn et al., 2020) as a paradigmatic example of a design-approach aimed at designing for world-familiarity – thus supporting accessibility in one sense of the word. The second conception of accessibility comes from the field of Crip Technoscience (Hamraie & Fritsch, 2019) and underscores technology’s potential to create access not by promoting world-familiarity but precisely by creating friction and disruption within habitual practices and ways of perceiving the world – particularly when those practices are ableist. Though these two perspectives may appear to be in conflict with one another our goal is to defend the importance of both. Promoting accessibility, we suggest, involves a readiness to oscillate between two normative imperatives: (1) recognizing how human well-being depends on world-familiarity, which, in turn, can be materialized through design and (2) recognizing how world-familiarity can harbor pernicious biases that can be called into question through material gestures of *defamiliarization* (Bell et al., 2005) with Crip Technoscience providing an important framework for such defamiliarization. By presenting these two perspectives as mutually required in efforts to design for accessibility, and, furthermore, by framing the pandemic as an event that has placed us, en masse, in a defamiliarized position capable of attuning us to the normative significance of world-familiarity, we hope to better enable technologists and laypersons alike to reflectively evaluate if and how a technological innovation may (or may not) be access-promoting, such that it can contribute to a more just post-COVID world.

10.2 Why We Must Foreground and Finetune the Notion of Accessibility in HCI

As mentioned in the introduction, our proposal starts from the premise that promoting accessibility (and resisting ableism) is a moral imperative in technology development. Our focus is on digital technologies and the space of human-computer-interaction. We first want to briefly elaborate on this premise, before delving into the specifics of our proposal.

First, one might question the need to foreground and finetune the notion of accessibility in the field of human-computer-interaction. After all, this field has been emphatically concerned, at least *prima facie*, with developing participatory and inclusive design methods that place the needs of digital technology-users at center stage. As Cynthia Bennett notes, “accessibility was one of the most popular keywords describing publications at the 2019 CHI Conference on Human-Computer Interaction” (2020). At the same time, she adds that “despite increased momentum, perspectives from the people with disabilities accessible designs purportedly benefit are under-represented, and these absences may negatively impact people with disabilities and the field of professional design” (2020). There is a need, then, to meaningfully claim and cash-out the notion of accessibility for the field.

Still, one might ask, why focus specifically on *accessibility*, as opposed to, say, *inclusivity*? We believe *accessibility* is the right value-concept to foreground for several reasons. Firstly, the notion of *inclusivity* (and of *being included*) can evoke associations of disabled people *being invited* or *brought into* some pre-existing space by those who are in a position of power to extend such an invitation (typically the non-disabled technology experts within that space). While communal belonging is arguably a moral good, we wager that it matters how this belonging is achieved in a procedural sense. The notion that one needs to be included into a space by others, for instance in virtue of design-choices made by non-disabled ‘experts,’ may (implicitly or explicitly) diminish the degree of agency one is credited with. IJsselsteijn et al. (2020) worry that “this starting point can lead to an inherent disempowerment, and an implicit lack of respect in data collection practices towards [the relevant stakeholders] and in the resulting designs made for them” (p. 40). This is particularly problematic in the context of designs intended for disabled users, given the pervasive tendency (both by tech-developers and society at large) to view disabled people as somehow less agential than non-disabled people and merely as the passive users of technology (Shew, 2020b). This tendency in fact discredits a long history of disabled people actively modifying (“tinkering with” or “hacking”) the artefacts they rely on in navigating the environment so as to gain *access* to a world that is by and large designed for non-disabled people. Before non-disabled people started to consider the importance of ‘including’ marginalized disabled people into ‘their’ spaces, disabled people were in fact already actively creating and claiming access to those spaces – while simultaneously critiquing and challenging the ableist value-system contouring those spaces (Hamraie & Fritsch, 2019).

Second, then, the notion of *accessibility* is significant because it underscores the environment’s constitutive role in the experience of disability and the work involved in making the material and digital built environment more hospitable to all. The notion of *inclusivity*, with its connotation of ‘bringing people in’ may leave unquestioned the normative status of the world that technology designers and developers are attempting to include people into. As Shew discusses, a paradigmatic example of an innovation reflective of this perspective is the exoskeleton, which is designed with the purpose of providing *some* paralyzed wheelchair users with the required abilities that would enable them to quite literally step into a world organized around walking. The idea that this world is better and more desirable is itself left unquestioned. Shew has coined the term *technoableism* to capture this phenomenon, which “describe[s] a rhetoric of disability that at once talks about empowering disabled people through technologies while at the same time reinforcing ableist tropes about what body-minds are good to have [in this case body-minds that are upright and ambulant] and who counts as worthy. Technoableists usually think they have the good of disabled people in mind. They do not see how their work reinscribes ableist tropes and ideas on disabled bodies and minds” (Shew, 2020b, p. 43). The notion of *accessibility*, we wager, reminds us of the idea (also central to the social model of disability) that what disabled people very often need – and indeed very often already bring about through their own active hacking and tinkering – is not necessarily a change to their individual body-minds such that they can participate in ‘our’ world,

but precisely a change to the wider social and material environment. Combatting ableism, then, crucially involves promoting changes in the environment that increase accessibility.⁴ As we will suggest in a moment, an affordance-based approach offers resources for fleshing out this idea; making perspicuous how, in our thriving as agents, we rely upon an embodied habitual familiarity with the possibilities for action afforded by the material and digital built environments in which we are embedded.

Of course, in a straightforward sense ‘inclusivity’ and ‘accessibility’ are simply concepts that allow for a range of interpretations. Indeed, as Hamraie and Fritsch (2019) note, the notion of access can also be developed in assimilatory directions. However, they highlight that “the etymology of the word *access* reveals two frictional meanings: access as “an opportunity enabling contact,” as well as “a kind of attack,” adding that “Taking access as a kind of attack reveals access-making as a site of political friction and contestation” (Hamraie & Fritsch, 2019, p. 10). Following this idea, our final reason for focusing on accessibility is that it encourages us to consider how digital technologies may be designed so as to promote accessibility in this critical friction-creating sense.

In sum, what we will be arguing in the remainder of this chapter, is that promoting accessibility through technology design involves an oscillation between (1) appreciating and designing for accessibility understood as world-familiarity and (2) turning to mechanisms of defamiliarization to critically reflect on the habits, biases, and assumptions that are always an ineluctable part of one’s world-familiarity.

10.3 An Affordance-Based Take on Accessibility: Lessons from the Pandemic

The idea that worlds, in virtue of how they are designed and built, can be more (or less) accessible to some people than to others can be further deepened via the notion of *affordances*. Affordances, a term coined by ecological psychologist J.J. Gibson, captures the idea that living beings perceive their environment in terms of the practical possibilities for action it affords them as embodied embedded beings (Gibson, 1979; see also Van Grunsven, 2015; Rietveld & Kiverstein, 2014; Dreyfus, 2007). For instance, a chair is built for sitting and a living being whose needs, embodied sensorimotor skills, and socio-cultural practices make sitting desirable, possible, and meaningful will typically directly perceive a chair as *affording-to-be-sat-on*. When, as affordance-responsive beings, our embodied sensorimotor skills are attuned to the artefacts that surround us, we typically know our way about in the

⁴Crucially, as Shew (2020b) notes, increased accessibility through changes in the wider social and material environment isn’t just what disabled people need. Whereas the exoskeleton is only capable of (potentially) benefitting some wheelchair users, public ramps – as opposed to steps – benefit many people with limited mobility, including people with various disabilities, many aging adults, parents with young children, people who are temporarily injured etc.

world without requiring much effort or reflection. To borrow an example from Van Grunsven (2020), when you enter a crowded subway car you typically do not have to thematize the number of passengers around you to take up an appropriate distance from them, nor do you have to pay attention to the shape of the subway pole in order to be able to grab it and maintain your balance. You effortlessly and habitually negotiate these social and practical affordances. If you had to focus on how to shape your hand in order to grip the subway pole appropriately; how to maintain your balance while the train was in motion; how to maintain an appropriate distance from the other passengers on the train, you would have a hard time directing your thematic attention to other, arguably more meaningful, activities (having a conversation with a friend; reading a book; rehearsing an important conversation with your boss that you plan to have later that day, listening to your favorite music or podcast, etc.).

The effortless pre-reflective embeddedness in practical environments described here depends on a close-coupled match between an agent's embodied sensorimotor skills on the one hand and the material environment on the other hand. Accessibility, we propose, can be understood in terms of this match between the affordances available in a given environment and the embodied skills and capacities that enable situated agents to perceive these affordances as familiar features of a world in which they habitually know their way around. Crucially, this means that not everybody enjoys equal access to the world understood as a space of familiar affordances. Stair cases, door-handles, public bathroom, bicycles, cars, tablets, smart phones, key boards, screens – all these artefacts and features of the technological built environment are designed for certain types of embodied minds (often young adult, neurotypical, able-bodied, and digitally literate) who possess certain (sensorimotor) skills, capabilities and preferences. When this is forgotten or ignored in technology development, seemingly innocuous choices made at the level of design effectively legislate who has access to the world as a space of familiarity.

Many of the habitual flow-like interactions with the environment that people (especially able-bodied people) are typically able to take for granted in the course of everyday living have been disrupted as a result of the pandemic; particularly in its early stages when the world seemed to transform overnight from a place of familiarity into a defamiliarized space. As Van Grunsven has noted:

Many of the most basic features of our practical environment (door-handles, elevators, public transportation, cash, produce, our mail) seem to warrant a new form of engagement. ... The transformation of social affordances—both in the private sphere and the public domain—has been even more dramatic. Strangers on the street largely afford to-be-shunned or avoided. ... many of us no longer dwell in public spaces the way we used to—we no longer casually grab the subway pole and rely on our habitual know-how to take up an appropriate distance to others. Moving about in public space is now more often than not an effortful endeavor (Van Grunsven, 2020).

By defamiliarizing the familiar, dislodging many of us from our habitual taken-for-granted access to a world of familiarity, the COVID-19 pandemic has (in principle) created the conditions for an appreciation of how our sense of agency and over-all well-being depend on a fluent, close-coupled match between our embodied

sensorimotor skills on the one hand and our practical socio-technological environment on the other hand:

If the unreflective activities that tend to support our more labor-intensive thematic forms of world-directedness now warrant thematic directedness themselves, this creates the condition for a specific kind of fatigue stemming from excessive self-monitoring and of reorienting oneself in a world that has lost some of its immediate action-guiding significance. Flow-like engagements are continuously interrupted by attitudes of distrust towards and detachment from the familiar. To put this in terms familiar to psychologists, the loss of world-familiarity brought about by the pandemic can be understood as a distinct source of *ego-depletion* (Van Grunsven, 2020).

A pandemic-enabled awareness of how our functioning and thriving as agents depends on a close-coupled match between our embodied sensorimotor skills on the one hand and the sociomaterial environment on the other hand can be utilized to design for world-familiarity; serving as an experiential resource that non-disabled technology designers can tap into to understand the normative significance of being embedded in a world-familiarity and the strenuousness that might go along with having to navigate an environment whose affordances resist effortless coupling with one's embodied skills and capacities. That said, we acknowledge that while many may have experienced the kind of loss of world-familiarity described here, that this experience of loss was not distributed equally. While, as discussed in the introduction, many disabled people and disability rights activists have welcomed the digitally-enabled forms of access that the pandemic world has embraced en masse, disabled people have still been among those bearing the brunt of the pandemic and the effects of various COVID-prevention measures (c.f., Wright, 2020). That world-familiarity is not an evenly distributed phenomenon makes it all the more important to introduce it as an explicit goal for technology development and design. In the next section we turn to Warm Technology as one example of what a design approach to promoting world-familiarity might look like.

10.4 Warm Technology: Designing to Support Fragile World-Familiarity

An alternative approach to technology design, termed Warm Technology (IJsselsteijn et al., 2020) has recently been formulated in the context of designing for and with people with dementia. Since loss of world familiarity is central to the phenomenology of dementia, the case of designing for dementia using the Warm Technology approach helps underscore the potential as well as the normative significance of using technology to support world-familiarity and, relatedly, well-being. Furthermore, reflection on how world-familiarity for people with dementia can be supported through digital technologies is particularly urgent during these pandemic times. As social distancing measures have had a particularly devastating impact on people with dementia, it is tempting to turn to digital technologies as quick technological fixes for this pressing social problem (Cheung & Peri, 2021). Our worry is

that the pandemic could motivate the development and adoption of digital interventions that fail to incorporate a robust reflection on how exactly digital technologies must be designed such that they genuinely support people in finding or retaining meaningful access to social and practices spaces. To make our case we take a closer look at how Warm Technology approaches the design for people with dementia.

Dementia is not a single disease. It is an overall term that refers to a cluster of symptoms affecting memory, thinking, language, motor abilities, and social abilities, which, taken together, are severe enough to reduce a person's ability to understand and deal with the everyday world. Central to the dementia experience is a loss of world familiarity, which comes in different guises. Dementia, as it progresses, is associated with a loss of temporal and spatial awareness, loss of episodic and semantic memory, loss of cognitive planning and control functions (e.g., not being able to coordinate one's behavior, such as cooking a meal, or making an appointment), loss of language abilities, and loss of sensory-motor functions and skilled behaviors. The familiar slowly becomes strange and confusing. One may get lost on well-traveled routes to and from home, or disoriented in familiar places such as a shopping mall or local park. One may forget words, and names of familiar objects, activities or events. Everyday appliances, such as a remote control or mobile phone, become increasingly opaque and inaccessible. Daily chores, rituals and habits become complex and disorganized. People that were once intimately familiar become mixed up with others or altogether hard to recognize. The trusted may become suspect. Attempts at sense-making – to integrate experiences over time and to form a coherent foundation of one's identity and understanding of the present moment – become unanchored from reality, transforming into a gap-riddled and incoherent patchwork of distorted memories, perceptual hallucinations, and confabulation. Eventually, one may lose all sense of understanding, of self-efficacy, of control over one's environment, and one's own body and mind. This is frequently aggravated by a necessary, sometimes forced, move to a care residence, with its dramatic shift in both physical and social contexts – moving from familiar surroundings to deeply unfamiliar ones. All this may result in feelings of alienation, apprehension, confusion, frustration, loneliness, anxiety, or apathy. These processes do not happen overnight – people live with dementia for years while enjoying a relatively good quality of life. Also, there are significant variations depending on the type and stage of dementia, individual differences, and availability of psychosocial and physical support. Even with progression of the disease, many worthwhile experiences are retained to quite advanced stages of dementia, including appreciation of music, of social company, and affective social touch.

In recent years, the health care technology space has witnessed the development of a wide gamut of digital technological interventions aimed at ameliorating some of the challenges caused by dementia. As we flagged earlier, we can expect that this trend will only accelerate as a result of the pandemic's ubiquitous social distancing measures. Some see this as a welcome “technology evolution in dementia practice,” arguing that “health policy makers, service providers and clinicians should take hold of these innovative opportunities and support the technological transformation of dementia practice in the coming years” (Cheung & Peri, 2021). But the

proof is in the pudding and will depend on the types of digital interventions pursued and the manner in which these interventions are designed. Typically, technological interventions used in dementia care settings include ambient assisted living, telecare systems, social robots, and internet of things technologies. The *Warm Technology* approach has emerged as a critical reaction to many of these developments. The underlying problem is that these standard ‘cold technology’ approaches tend to prioritize what is technologically possible instead of what makes sense from the viewpoint of the lived experiences of people with dementia, whose world-familiarity is increasingly fragile yet crucial to their well-being.

When designing Warm Technology for and with people with dementia, the importance of world familiarity is foregrounded in different ways. First, Warm Technology recognizes the diversity of needs, abilities and resources of people living with dementia. With or without dementia, older adults represent a growing and highly diverse group. Old age is not a uniform stage of life for everyone aged over 65, as some developmental models suggest, rather it is a rich, multiform, non-linear, culturally contextualized and deeply personal process. Furthermore, there is growing cultural and ethnic variation amongst seniors in Western countries. Some are tech-savvy or may have had professional careers that involved tech. Many are well-educated, well-traveled, and in relatively good health. Although clearly the dementia experience will play a role in one’s personal identity, experience and outlook on life, it does not define a person. As IJsselsteijn et al. (2020) write: “design efforts to support people living with dementia should not focus on the support, substitution or amelioration of functional decline, but on better ways of affirming old age – enabling people to remain open and attached to the world and to other people, and, as Lynne Segal (2013) so beautifully put it, ‘staying alive to life itself’” (p. 33). Technologies designed from a deficiency-first instead of person-first perspective tend to translate into interventions such as large red alarm buttons to be worn as a necklace, tracking devices enabling care-takers to monitor the whereabouts of wandering individuals with dementia, or mobility support (‘walkers’) designed as medical devices. Such interventions, which, promote a medicalized view of the individual tend to be experienced as stigmatizing and alienating. As Don Norman, himself in his mid-80s at the time of this writing, lamented in a critical essay on technology designed for seniors:

Despite our increasing numbers the world seems to be designed against the elderly. Everyday household goods require knives and pliers to open. Containers with screw tops require more strength than my wife or I can muster. (We solve this by using a plumber’s wrench to turn the caps.) Companies insist on printing critical instructions in tiny fonts with very low contrast. Labels cannot be read without flashlights and magnifying lenses. And when companies do design things specifically for the elderly, they tend to be ugly devices that shout out to the world “I’m old and can’t function!” We can do better. (Norman, 2019).

Second, and relatedly, when designing for world familiarity, Warm Technology puts the person’s lived experience at center stage, connecting to their personal and family history, their cultural background and upbringing, their local context and community, as well as diversity in literacy and skillsets, technological or otherwise. Familiarity with technology may differ substantially, in part because it will depend on the dominant technology of people’s formative years (i.e., one’s technology

generation – Docampo Rama et al., 2001). In terms of technology design, this may imply referencing familiar form factors and interaction metaphors from the formative years of the elderly person. A recent example of this is the StayTuned radio – a communication system designed by Marjolein Wintermans – den Haan (Wintermans et al., 2017). This ‘radio’ combines the WhatsApp messaging application with a familiar 60s radio exterior, allowing people to scroll through recorded voice messages of their loved ones using a simple turning knob on a familiar radio interface.

Third, Warm Technology acknowledges the importance of rich multimodal sensory experiences when interacting with the world. Instead of populating the environment with hidden sensors and actuators, touch-screens, virtual agents, or robotic devices, Warm Technology means designing for everyday interactions using everyday objects. This preserves the important affordances of objects and their intuitive relation to the dexterous and perceptual skillsets of a person – easy to recognize and to make sense of. In general, it also implies a preference in designing strong-specific, tangible systems over weak-general, virtual ones – typically steering clear from complicated, multi-layered, multi-purpose (‘integrated’) systems. In short, Warm Technology focuses on the affordances of familiar objects, and thereby adds to the world familiarity of designed technology interfaces.

Thus, Warm Technology is marked by two key constitutive elements. First, it is born from an emancipatory view of living with dementia. It is to de-emphasize disease and deficiency, and instead focus on the unique identity of the person, on the myriad of ways in which the person inhabits their world as a place of familiarity.

The second essential ingredient of Warm Technology, directly following from the first, is to work closely with people with dementia as part of the design process. Many innovations to date have been designed based on the possibilities of technology (a tech-push approach), or based on inputs from people *around* the person with dementia – for example, family members, informal carers or care professionals. Important and valuable as these perspectives are in their own right, they cannot substitute for the first-person perspective of the person with dementia. Research has shown that different needs, wishes, and requirements emerge depending on the perspective of those involved. The active and continued involvement of people with dementia is of key importance to the design of Warm Technology. In this context participatory practices are proposed and are needed (Suijkerbuijk et al., 2019).

At the same time though, we need to acknowledge that here too, a fundamental tension exists, as noted earlier, of “bringing people in” on the designer’s terms. That is, people with dementia are invited to take part in the design process, at the initiative of the designer, and within the value system and implicit assumptions of the design team. This means that the timing of inputs, their nature and expressive bandwidth are, at least in part, enabled and constrained within the design process that is determined by the designer. This observation falls within a larger discourse in research methodology literature on the relation between the researcher(s) and the researched. The privileged position of the researcher in relation to research

participants has been a recurrent theme, and perceived asymmetry is both an object of ethical as well as methodological concern.⁵

10.5 On the Importance of Instilling Mechanisms of Defamiliarization in Technology Design

In the previous section we saw that IJsselsteijn et al. (2020) argue for genuine participation of people with dementia in the design of warm technologies, such that the technological interventions designed for and with them align with their particular sensorimotor skills and personal histories, thus meaningfully contributing to their precariously maintained world-familiarity. Similarly, Shew stresses the importance of placing the perspectives and needs of disabled people at center stage: “Instead of imagining the desires of disabled people ... why don’t technologists simply ask disabled people what kinds of technological applications we want and need?” (Shew, 2020b, p. 47) Yet, as both Shew and IJsselsteijn et al. recognize, ‘simply asking’ people isn’t as simple as it seems. This is because the types of questions asked, the types of answers given and the importance and meaning attributed to those questions and answers are in part motivated and circumscribed by the wider value systems within which we are embedded. Since ableism is one of such value systems “that all of us participate in, including individual disabled people,” co-creation initiatives seem important but not sufficient in technology design efforts to combat ableism and to promote accessibility (Shew, 2020b, p. 46). Bell et al. (2005) argue, for instance, that there is a limit to “user-centered design techniques” when it comes to subverting entrenched pernicious value-systems, because of the emphasis placed on the “current needs and desires” of users. Focusing not on ableism but on patriarchy qua value-system, they maintain that:

Gender assumptions about labor may be built into technology and reinforce stereotypes about who in the home should do what Designers have an opportunity to alter these built-in gender assumptions and thereby support different patterns of behavior. This strategy runs counter to user-centered design techniques because it proposes to design not for users’ current needs and desires, but to shape alternative needs, desires, and behaviors through design (Bell et al., 2005, p. 168).

The specific strategy focused on shaping “alternative needs, desires, and behaviors” that Bell et al. are referring to is one of *defamiliarization*, which, compels designers “to examine *their automated perceptions of that which is so familiar* that it seems natural and so unquestionable (Bell et al., 2005, p. 151, our italics). By re-contextualizing and reframing “the affordances” of familiar everyday use-objects, such as “door handles, faucets, filing cabinets,” we can make them “strange” and

⁵This is not to say, however, that the researched do not bring their own agenda to the research situation.

“defamiliarize[e] the familiar” (Bell et al., 2005, p. 153, referring specifically to Donald Norman’s *The Psychology of Things*).

Bell et al. focus on literary, textual, ethnographic techniques of defamiliarization capable of offering “a lens to help us see our own design practices in a new light” (p. 154). Thus, they propose that defamiliarization is “available as a strategy to anyone with access to a pen and paper, or more likely, a keyboard and a monitor. Defamiliarization is not tremendously difficult to achieve and most of us have done it before. It is essentially a rich description which renders strange the familiar” (p. 169–70).⁶ This can bring into view the pernicious dimensions of our habitual ways of inhabiting our world of familiarity.

Alongside these ethnographic techniques, we have already presented the pandemic as an event that has viscerally exposed most of us to the experience of defamiliarization. To capitalize on this experience as a resource for access-promotion, we furthermore want to highlight the powerful mechanisms for defamiliarization that have been forged by disability activists themselves, contributing to the field of Crip Technoscience. Crip refers to the “anti-assimilationist position that disability is a desirable part of the world, and “technoscience,” refers to “the co-production of science, technology, and political life,” i.e. the ways in which our scientific and technological endeavors both form and are formed by shared conceptions of the good life and communal membership (Hamraie & Fritsch, 2019, p. 2). As we mentioned in Sect. 10.2, Crip Technoscience proposes to understand “access as friction” or “as a kind of attack” which “reveals access-making as a site of political friction and contestation” (Hamraie & Fritsch, 2019, p. 10). Furthermore, it foregrounds the long history of disabled agents of access-making, where disabled people have actively hacked, altered, tinkered with sociomaterial environments catered towards ‘able-bodied’ world-familiarity to not only make these environments more conducive to disabled forms of inhabiting the world, but also to explicate and critique entrenched habitual and often ableist ways of experiencing the world, promoting “practices of critique, alteration, and reinvention of our material-discursive world” (Hamraie & Fritsch, 2019, p. 1).

For instance, Collin Kennedy’s act of “protesting hospital parking prices by filling the pay-slot on a parking meter with spray foam,” defamiliarizes habitual taken-for-granted capitalistic norms of efficiency dictating what constitutes as a normal pace for moving through the world (Hamraie & Fritsch, 2019, p. 12). For another powerful example that illustrates this form of critical access-promotion through Crip Technoscientific acts of defamiliarization, consider “Deep Sea Diving ... in a

⁶Many qualitative traditions attempt to minimize the distance between researcher and research participant. A particular example, from design research with elderly communities, is the development of the cultural probe method as a way to rebalance this negotiation, and to subvert the roles of the designers and those “to be designed for”. Cultural probes are themselves designed to allow for more agency on the part of the participant – more expressive and creative ability, choice and freedom whether, when and in what ways to partake (See Gaver et al., 1999). Here too, defamiliarization techniques could play an important role, in particular to uncover value systems and default implicit assumptions in how to design for and with people living with dementia.

Wheelchair” – a TED talk in which artist and disability rights activist Sue Austin presents the various ways in which she has altered her wheelchair in order to claim her visibility in social space by challenging people’s implicit habitual ways of seeing what wheelchairs afford. Seeking for new narratives to reclaim her identity, Austin purposely “transform[s] perceptions by revisiting the familiar.” Among other things, Austin turns her wheelchair (or power chair, as she prefers) into a deep sea diving device. As viewers of Austin’s work watch her explore the ocean’s corals in her under-water power-chair, arms spread wide, she wagers that

In that moment of them seeing an object they have no frame of reference for or so transcends the frames of reference they have with the wheelchair they have to think in a completely new way. For me this means that they are seeing the value of difference, the joy it brings, when instead of focusing on loss or limitation, we see and discover the power and joy of seeing the world from exciting new perspectives. For me the wheelchair becomes a vehicle of transformation. ... Because nobody’s seen or heard of an underwater wheelchair before ... creating this spectacle is about creating new ways of seeing, being and knowing. (Austin, 2012)

Though ableism as a pernicious value-system has been materialized into the world through a wide range of technological artefacts and sociotechnical systems, it is also through the tweaking of artefacts and the disruption of sociotechnical systems that entrenched ways of seeing disabled people and perceiving our everyday world of familiarity can be called into question and new unfamiliar ways of imagining the world can open up. We wager that the mechanisms of defamiliarization offered by the field of Crip Technoscience, positioned as forms of access promotion, provide a powerful resource for technology developers and designers who follow the premise of our argument, namely that promoting accessibility (and resisting ableism) is a moral imperative in technology development. Finally, a commitment to Crip Technoscience’s mechanisms of defamiliarization can be reinforced by tapping into what we have presented as an important phenomenological feature of the pandemic; namely the sense in which the pandemic can be understood as a mass-scale event of defamiliarization, confronting many of us with the intimate but often taken-for-granted link between well-being and having access to a world of familiarity.

10.6 Conclusion

In his commencement speech “This is Water”, David Foster Wallace offers the following anecdote:

There are these two young fish swimming along, and they happen to meet an older fish swimming the other way, who nods at them and says, “Morning, boys, how’s the water?” And the two young fish swim on for a bit, and then eventually one of them looks over at the other and goes, “What the hell is water?” ... The immediate point of the fish story is that the most obvious, ubiquitous, important realities are often the ones that are the hardest to see and talk about (2005, p. 2).

Wallace calls on us to develop “simple awareness — awareness of what is so real and essential, so hidden in plain sight all around us, that we have to keep reminding ourselves, over and over: “This is water, this is water.” It is unimaginably hard to do this ... day in and day out” (2005, p. 8). This difficulty applies to everyone, including those of us who live our lives as technology developers and who, in this capacity, “are the unacknowledged legislators of our technological age” (Winner, 1990, p. 59).

What Wallace calls water, we have called world-familiarity and we have argued that inhabiting the world as a place of familiarity plays an integral role in our thriving as agents – the pandemic, which has pervasively disrupted people’s world-familiarity, has underscored as much. Of course, many disabled and chronically ill people have always been aware of this as they confront a world that is, for the most part, neither designed for them nor by them. That world-familiarity is deeply central to well-being is recognized in the Warm Technology approach, which aims to promote accessibility through technology development. However, because world-familiarity turns on the habitual, because, in Wallace’s words “it is unimaginably hard” “to keep reminding ourselves ...’ This is water,” designing for world-familiarity demands acts of defamiliarization, through which we critically examine whose world-familiarity we are in fact designing for to. As such, we have suggested that promoting accessibility involves a readiness to oscillate between two normative imperatives: (1) recognizing how human well-being depends on world-familiarity, which, in turn, can be materialized through design and (2) recognizing how world-familiarity can harbor pernicious biases that can be called into question through material gestures of *defamiliarization* (Bell et al., 2005). While the pandemic itself has offered many, if not all, of us a visceral experience of defamiliarization that can serve as a reminder in endeavors of access-promoting technological interventions, we also need tangible mechanisms and frameworks that can guide such projects. As such, we have presented Crip Technoscience as an important resource for defamiliarization – a resource that doesn’t frame disabled people as waiting to be included in ‘our’ world of familiarity, but that actively disrupts some of ‘our world’s’ basic organizing biases, assumptions and value-commitments.

By presenting these two perspectives as mutually required in efforts to design for accessibility, we hope to better enable technologists and laypersons alike to reflectively evaluate if and how a technological innovation may (or may not) be access-promoting, such that it can contribute to a more just post-COVID world; a world where we can all not merely survive, but thrive as precarious embodied world-dependent beings.

Acknowledgments This work is part of the research programme Ethics of Socially Disruptive Technologies, which is funded by the Gravitation programme of the Dutch Ministry of Education, Culture, and Science and the Netherlands Organization for Scientific Research (NWO grant number 024.004.031).

References

- Austin, S. (2012). *Deep sea diving ... in a wheel chair*. TED talk. Accessed on 17th Nov 2021. https://www.ted.com/talks/sue_austin_deep_sea_diving_in_a_wheelchair?language=en
- Bell, G., Blythe, M., & Sengers, P. (2005). Making by making strange: Defamiliarization and the design of domestic technologies. *ACM Transactions on Computer-Human Interaction*, 12(2), 149–173. <https://doi.org/10.1145/1067860.1067862>
- Bennett, C. (2020). *Toward centering access in professional design*. Doctoral dissertation. https://digital.lib.washington.edu/researchworks/bitstream/handle/1773/45406/Bennett_washington_0250E_21264.pdf?sequence=1. Accessed on Nov 2017.
- Cheung, G., & Peri, K. (2021). Challenges to dementia care during COVID-19: Innovations in remote delivery of group cognitive stimulation therapy. *Aging and Mental Health*, 25(6), 977–979. <https://doi.org/10.1080/13607863.2020.1789945>
- Docampo Rama, M., de Ridder, H., & Bouma, H. (2001). Technology generation and age in using layered user interfaces. *Gerontology*, 1(1), 25–40. <https://doi.org/10.4017/gt.2001.01.01.003.00>
- Dreyfus, H. L. (2007). The return of the myth of the mental. *Inquiry*, 50(4), 352–365. <https://doi.org/10.1080/00201740701489245>
- Gaver, B., Dunne, T., & Pacenti, E. (1999). Design: cultural probes. *Interactions*, 6(1), 21–29. <https://doi.org/10.1145/291224.291235>
- Gibson, J. J. (1979). *The ecological approach to visual perception*. Houghton Mifflin.
- Hamraie, A., & Fritsch, K. (2019). Crip technoscience manifesto. *Catalyst: Feminism, Theory, Technoscience*, 5(1), 1–34. <https://doi.org/10.28968/cft.v5i1.29607>
- IJsselsteijn, W. A., Tummars-Heemels, A., & Brankaert, A. (2020). Warm technology: A novel perspective on design for and with people living with dementia. In R. Brankaert & G. Kenning (Eds.), *HCI and design in the context of dementia, human computer interaction series*. Springer Nature.
- Ladau, E. (2015). *Why person-first language doesn't always put the person first*. <https://www.think-inclusive.us/post/why-person-first-language-doesnt-always-put-the-person-first>. Accessed on 5th Oct 2021.
- Norman, D. (2019). *I wrote the book on user-friendly design. What I see today horrifies me*. *Fast Company*. <https://www.fastcompany.com/90338379/i-wrote-the-book-on-user-friendly-design-what-i-see-today-horrifies-me>. Accessed on 1st Nov 2021.
- Rietveld, E., & Kiverstein, J. (2014). A rich landscape of affordances. *Ecological Psychology*, 26(4), 325–352. <https://doi.org/10.1080/10407413.2014.958035>
- Shew, A. (2020a). Let COVID-19 expand awareness of disability tech. *Nature*. <https://www.nature.com/articles/d41586-020-01312-w>. Accessed 17th Nov 2021.
- Shew, A. (2020b). Ableism, technoableism, and future AI. *IEEE Technology and Society Magazine*, 39(1), 40–85. <https://doi.org/10.1109/MTS.2020.2967492>
- Suijkerbuijk, S., Nap, H. H., Cornelisse, L., IJsselsteijn, W. A., de Kort, Y. A. W., & Minkman, M. M. N. (2019). Active involvement of people with dementia: A systematic review of studies developing supportive technologies. *Journal of Alzheimer's Disease*, 69(4), 1041–1065. <https://doi.org/10.3233/JAD-190050>
- van Grunsven, J. (2015). *Bringing life in view: An enactive approach to moral perception* (Doctoral dissertation, The New School).
- Van Grunsven, J. (2020). Perceptual breakdown during a global pandemic: Introducing phenomenological insights for digital mental health purposes. *Ethics and Information Technology*. <https://doi.org/10.1007/s10676-020-09554-y>
- Wallace, D. F. (2005). *This is water: Some thoughts, delivered on a significant occasion, about living a compassionate life*. Commencement speech given at Kenyon College on May 21st 2005.
- Winner, L. (1990). Engineering ethics and political imagination. In P. T. Durbin (Ed.), *Broad and narrow interpretations of philosophy of technology* (pp. 53–64). Kluwer Academy Publishers.

- Wintermans, M., Brankaert, R., & Lu, Y. (2017). Together we do not forget: co-designing with people living with dementia towards a design for social inclusion. In *proceedings of the design management academy 2017* (Vol. 2, pp. 767–782). International conference, Hong Kong.
- Wright, R. (2020). Who is “worthy”? Deaf-blind people fear that doctors won’t save them from the coronavirus. *The New Yorker*. <https://www.newyorker.com/news/our-columnists/who-is-worthy-deaf-blind-people-fear-that-doctors-wont-save-them-from-the-coronavirus>. Accessed on 17th Nov 2021.

Open Access This chapter is licensed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license and indicate if changes were made.

The images or other third party material in this chapter are included in the chapter’s Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the chapter’s Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.

