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## Care as Active Architectural Practice

Jos Boys

How might we understand care and care work as something that starts from our own bodyminds, <sup>1</sup> both as architectural or other kinds of workers and through our various ordinary lived social, spatial, and material experiences and encounters? What does it mean to conceptualize architecture as an explicitly embodied practice? What kinds of work do we each do that perpetuates or challenges which bodyminds are valued and which marginalized or ignored? <sup>2</sup> What are the everyday, unnoticed social, material, aesthetic, and spatial practices that perpetuate one particular normality—including one version of care or its lack? How can we critique normative practices that reproduce the world to the benefit of some rather than others? And what kinds of collective and personal shifts can move architectural, social, and individual practices toward valuing the vital richness of human and non-human bio- and neurodiversity?

In this article I explore “care” by opening up difficulties in how architecture as a discipline talks to and about itself; most particularly around who and what gets left out, how such gaps

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<sup>1</sup> Margaret Price, “The Bodymind Problem and the Possibilities of Pain,” *Hypatia Special Issue: Conversations in Feminist Disability Studies* 30, no. 1 (2015), 268–84.

<sup>2</sup> See Jos Boys, “Invisibility Work? How Starting from Dis/ability Challenges Normative Social, Spatial and Material Practices,” in H el ene Frichot et al., eds., *Architecture and Feminisms* (London: Routledge/AHRA, 2017), 270–80, here 270.



**fig. 1** Matrix feminist design collective cofounder Anne Thorne with her son, negotiating a North London underpass in the 1980s. Image used for the front cover of the Matrix book *Making Space: Women and the Man-Made Environment* (London: Pluto Press, 1984). Photographer: Liz Mullen

come to be both unnoticeable and unconsidered (not worth considering), and the effects this has on how architecture is inculcated and practiced. I have previously suggested that the Western architectural canon has a tendency for slippage away from the difficult implications for design processes of actual, diverse, and complex embodiments. This slippage can occur through reliance on general concepts such as user or community (or even care) when these rely on commonsense notions of “the people as a whole,” unproblematically sharing characteristics, attitudes, or interests in common—concepts that, by obscuring relational and

differential effects of power, ultimately hide as much as they reveal. It can come about through theoretical frameworks that locate care away from actual messy bodyminds, projecting it instead into the “body” of the built environment; for example, in notions of a “sense of place” where this is assumed to be based on a shared communality, which is then literally read into certain kinds of “familiar” spaces, rather than through engagement with different kinds of bodyminds or their complex and sometimes conflicting histories, trajectories, needs, preferences, and desires. <sup>3</sup>

<sup>3</sup> See Jos Boys, ed., *Doing Disability Differently: An Alternative Handbook on Architecture, Disability, and Designing for Everyday Life* (New York: Routledge, 2014), 127–28.

<sup>4</sup> See Jos Boys, “Space, Place and ‘Careful’ Designing for Everyday Life,” in Charlotte Bates, Rob Imrie, and Kim Kullman, eds., *Care and Design: Bodies, Buildings, Cities* (London: Wiley-Blackwell, 2016), 155–77; and Jos Boys, “Crippling Spaces? On Dis/abling Phenomenology in Architecture,” in Bryan E. Norwood, ed., “Phenomenology against Architectural Phenomenology,” special issue, *LOG* 42 (2017), 55–66.

<sup>5</sup> And, of course, considerably affected by the lack of power of architects and other built environment professionals within larger economic, political, and social contexts.

<sup>6</sup> See <https://disordinaryarchitecture.co.uk/> (accessed February 12, 2022).

<sup>7</sup> See the prototype online Matrix archive at <http://www.matrixfeministarchitecturearchive.co.uk/> (accessed February 12, 2022).

<sup>8</sup> Understanding access as a matter of justice is central to much contemporary disability activism and scholarship, with associated concerns that it will be co-opted by nondisabled people and undermined. For more on design justice, see Sasha Constanza-Chock, *Design Justice: Community-Led Practices to Build the World We Need* (Cambridge, MA: MIT Press, 2020), 52, 68, 100.

Finally, the Western architectural canon’s slippage away from the difficult implications posed by the multitude of human embodiments can occur through valuing “care-full” design; that is, creative approaches that explicitly express care in how buildings are made material. Again, instead of analyzing how caring happens (or could happen) through and in the *occupation* of built space, this kind of care predominantly comes to reside in the designers’ own intentions and actions and is thus judged through their perceived sensitivity and “carefulness.” While this is not wrong – and can produce beautiful buildings and spaces – it acts to blur other ways of conceptualizing an architecture of care. <sup>4</sup>

This is not meant to underplay the considerable difficulties in finding ways to design that can support the complex – and often contested and contradictory requirements of – human and nonhuman bio- and neurodiversity. <sup>5</sup> In fact, starting from a commitment to embodied practice, to the valuing of non-normative bodyminds, and to human and planetary flourishing is ridiculously idealistic and radical and ultimately demands a complete rethinking of the modes of education and practice around the built environment. Despite this, I will start things rolling by discussing some small-scale provocations and interventions that stem from exploring care as an active practice. These are based both on the work of The DisOrdinary Architecture Project <sup>6</sup> – of which I was cofounder in 2008 with disabled artist Zoe Partington – and on occasional references to Matrix, a feminist design collective I helped cofound in London in the 1980s. <sup>7</sup> Key themes center on developing new kinds of terminology and alternative design methods and on reframing access and inclusion as social, spatial, and material justice. <sup>8</sup>

## **Toward a New Language: Fitting and Misfitting**

DisOrdinary Architecture is an informal platform that brings together disabled artists with built environment students, educators, and practitioners (both nondisabled and disabled) for creative

and critical dialogue and action that coexplores how disabled and other nonnormative bodyminds offer a valuable and generative force in design, rather than being merely a technical and legalistic “problem” for designers. Informed by the vital contemporary work of disabled artists, activists, and scholars, we explore how disability (and other identities) can be reframed, not in simplistic binaries but as a complex, intersectional, situated, and dynamic patterning of enabling and disabling practices and spaces. This means there is no such thing as simple, “universal” access design solutions, added on at the end of a process of designing for “normal people” in order to include those who have already been excluded 9 — what Jay Dolmage calls “retro-fitting.” 10 Instead, we need to start codeveloping collective and emergent design practices deeply informed by disabled and other nonnormative people’s experiences and expertise, a process that looks for shared affinities in how we occupy space but also accepts tensions and contradictions by introducing variety and multimodality. 11

In talks and workshops with built environment students, educators, and practitioners, DisOrdinary Architecture often starts from participants’ own embodied assumptions and experiences. Building on the work of Rosemarie Garland-Thomson, 12 a feminist disability studies scholar, we refuse the artificial binaries of “able-bodied” or “disabled” by instead using the concepts of “fitting” and “misfitting.” Rather than characteristics of ability (or gender, race, class, or sexuality) being located “in the body,” these are always relational — dependent on the dynamic intersections between particular bodyminds, spaces, objects, and encounters. To “fit” is to find the normal world unproblematic, to be able to operate smoothly in it, without needing to take much notice of it. As Tanya Titchkosky writes,

*“Language recommends that we conceive of the able-body as something that just comes along ‘naturally’ as people go about their daily existence. People just jump into the shower, run to the store, see what others mean while keeping an eye on the kids, or skipping from office to office and, having run through the day whilst managing to keep their noses clean, hop into bed. All of this glosses the body that comes along while, at the same time, brings it along metaphorically. Speaking of ‘normal bodies’ as movement and metaphor maps them as if they are a natural possession, as if they are not mapped at all.”* 13

As Garland-Thomson explains, such fitting occurs in “a world conceptualized, designed, and built in anticipation of bodies considered in the dominant perspective as uniform, standard, majority bodies.” 14 In contrast, misfitting occurs whenever your needs, preferences, or desires are unmet (whether unnoticed,

9 Tanya Titchkosky, “To Pee or Not to Pee? Ordinary Talk about Extraordinary Exclusions in a University Environment,” *Canadian Journal of Sociology* 33, no. 1 (2008), 37–60, here 48.

10 Jay Dolmage, “Mapping Composition: Inviting Disability in the Front Door,” in Cynthia Lewiecki-Wilson and Brenda Jo Brueggemann, *Disability and the Teaching of Writing: A Critical Sourcebook* (Boston: Bedford/St. Martin’s, 2008), 14–27.

11 See M. Remi Yergeau et al., “Multimodality in Motion: Disability and Kairotic Spaces,” *Kairos: A Journal of Rhetoric, Technology, and Pedagogy* 18, no. 1 (2013), <https://kairos.technorhetoric.net/18.1/coverweb/yergeau-et-al/> (accessed February 20, 2022).

12 Rosemarie Garland-Thomson, “Misfits: A Feminist Materialist Disability Concept,” in “Ethics of Embodiment,” special issue, *Hypatia* 26 (2011), 591–609.

13 Tanya Titchkosky, *Disability, Self and Society* (Toronto: University of Toronto Press, 2003), 103.

14 Garland-Thomson, “Misfits,” 595.

marginalized, misinterpreted, or deliberately excluded) by the design of built space and by its other occupants. You become (however momentarily) “the odd one out”:

*“In one moment and place there is a fit; in another moment and place a misfit. One citizen walks into a voting booth; another rolls across a curb cut; yet another bumps her wheels against a stair; someone passes fingers across the brailled elevator button; somebody else waits with a white cane before a voiceless ATM machine; some other blind user retrieves messages with a screen reader. Each meeting between subject and environment will be a fit or misfit depending on the choreography that plays out.”*<sup>15</sup>

<sup>15</sup> Garland-Thomson, “Misfits,” 595.

<sup>16</sup> See, for example, Margaret Price et al., “Disclosure of Mental Disability by College and University Faculty: The Negotiation of Accommodations, Supports, and Barriers,” *Disability Studies Quarterly* 37, no. 2 (2017), <http://dsq-sds.org/article/view/5487> (accessed February 20, 2022). See also Margaret Price, “Everyday Survival and Collective Accountability” (University of Utah Disability Studies lecture, University of Utah, School for Cultural and Social Transformation, March 23, 2021), <https://transform.utah.edu/dslecture-2021/> (accessed February 20, 2022). Similar studies of built environment education and practice have not yet been undertaken.

<sup>17</sup> Sara Ahmed, *Queer Phenomenology: Orientations, Objects, Others* (Durham, NC: Duke University Press), 25.

<sup>18</sup> Sheila Rowbotham, *Woman’s Consciousness, Man’s World* (Harmondsworth: Pelican, 1973), 35.

<sup>19</sup> Boys, “Invisibility Work?,” 270.

<sup>20</sup> Challenging existing overwork processes in built environment education and practice are becoming more common. See, for example, the United Voices of the World Section of Architectural Workers: <https://www.uvunion.org.uk/en/sectors/architectural-workers/> (accessed February 20, 2022).

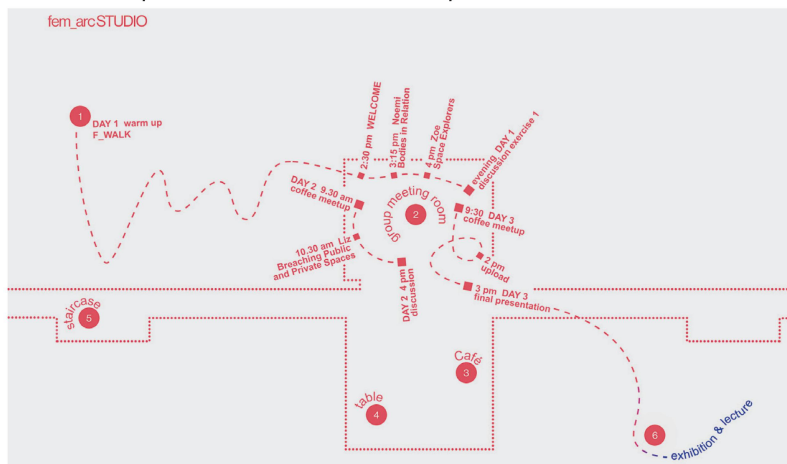
So we ask our DisOrdinary Architecture workshop participants – and you the reader – to think about how smoothly you fit within your social and built surroundings. When and how often do you have to negotiate a failure to take notice, a lack of care, or experience thoughtless assumptions about who you are or what your needs are? This might only be about noticing uneven floor surfaces, awkward steps, and a lack of lifts when you are looking after a baby in a pushchair. <sup>fig.1</sup> Or it might be about negotiating the complexities of being the only woman or person of color at a formal meeting; or it might be about hiding (“passing” or “masking”) the experiences of chronic pain or sight loss or neurodivergence as an architectural student, educator, or practitioner because disclosing is likely to adversely affect your studies or employment and because fighting for even reasonable adjustments is so often itself exhausting and unproductive.<sup>16</sup>

As Sara Ahmed writes, bodies take shape as they move through a world that either directs (orientates) them toward or away from themselves.<sup>17</sup> The experience – and unpleasant discomfort of – being directed away from yourself is one of the mechanisms through which power and privilege continually enact everyday discriminations, by undermining nonnormative ways of being – what feminist Sheila Rowbotham tellingly describes as “lumber(ing) around ungainly like in borrowed concepts which do not fit the shape we feel ourselves to be.”<sup>18</sup> Together with Julia Dwyer, I have written elsewhere about how we are each implicated in experiencing, perpetuating, and/or contesting unequal and normative practices through both our personal and professional lives.<sup>19</sup> This is underpinned by commonsense assumptions that constitute the “normal” body as an unencumbered, mobile, autonomous, white, and well-resourced subject, as well as the preference in architectural education and practice for body-minds that are similarly unencumbered, but also obsessive and endlessly energetic and focused.<sup>20</sup> Nearly forty years ago,

Matrix – through both its practice and book-writing group – also asked how built environment practices and built space design were gendered so as to create and perpetuate just such uncomfortable misfitting for women. <sup>21</sup> What has changed since then and by how much?

<sup>21</sup> Matrix (1984), *Making Space Women and the Man-Made Environment* (London: Verso, 2022), 1–11.

Analyzing our own assumptions about whose bodyminds are noticed and valued in conventional design processes and whose experiences are misrepresented or invisible also illuminates missed creative and critical opportunities. During the COVID-19 pandemic, for example, DisOrdinary Architecture worked with Fem\_ArcSTUDIO from Berlin as part of a workshop series in which students challenged existing power structures in the built environment and explored new design tools. **fig.2** COVID-19 shifted conventional relationships of public/private, inside/outside, visible/invisible, and included/excluded for “normal”



people by creating unpredictability and uncertainty in such everyday acts as going to the shops or the park. Such disruptions of “smoothness” demanded new creative skills in navigation and negotiation – an expertise many disabled people would say they already have just by living in the *normal* world. By working with disabled artists, students creatively and critically investigated their changed everyday practices as a means to explore how to design differently. <sup>22</sup>

**fig.2** Map of fem\_arcSTUDIO's online collaboration with DisOrdinary Architecture, November 2020. Source: fem\_arcSTUDIO, <http://studio.fem-arc.net/>

DisOrdinary Architecture artists also aim to open up invisibilities in designing for access, asking that built environment students, educators, and practitioners take more notice of how space is experienced not just differently but differentially. In her seminal article “Lying Down Anyhow: Disability and the Rebel Body,” disabled artist Liz Crow explores how the act of lying down in public (an essential access requirement for her as someone with chronic pain) becomes a story of external constraints, as societal assumptions about what is “proper” behavior are enacted and she is endlessly assumed to be homeless or drunk and moved on. <sup>23</sup> Both through her own practice and in DisOrdinary workshops, Liz has coexplores how built space might better offer informal places of rest.

<sup>22</sup> “Developing an Embodied Practice with DisOrdinary Architecture,” *Fem\_ArcSTUDIO 1*, November 2020, <http://studio.fem-arc.net/> (accessed February 20, 2022).

<sup>23</sup> Liz Crow, “Lying Down Anyhow: Disability and the Rebel Body” (2013), in Jos Boys, ed., *Disability, Space, Architecture: A Reader* (Oxford: Routledge, 2017), 42–47. Also available online at <http://www.roaring-girl.com/work/lying-anyhow-disability-rebel-body/> (accessed October 23, 2021).

## Difference as a Creative Generator

For a DisOrdinary design project at the University of Westminster, London in 2017 entitled “Tilted Horizons,” Liz Crow and Julia Dwyer asked students to explore the effects and potential of lying down in public spaces. <sup>24</sup> *fig.3* This project started from the expertise that creative disabled people already have in negotiating spaces and encounters not made for them and in opening up new spaces of accessibility:

*“[T]he experience of misfitting can produce subjugated knowledges from which an oppositional consciousness and politicized identity might arise. So although misfitting can lead to segregation, exclusion from the rights of citizenship, and alienation from a majority community, it can also foster intense awareness of social injustice and the formation of a community of misfits that can collaborate to achieve a more liberatory politics and praxis. ...*

*So whereas the benefit of fitting is material and visual anonymity, the cost of fitting is perhaps complacency about social justice and a desensitizing to material experience.”* <sup>25</sup>

Misfits, then, are potential design experts, and starting from difference can be a creative generator, as well as a challenge to normative design assumptions. By revealing how inequitable social relations are organized through differential access to space and resources, nonnormativity disrupts and reorders these relations – offering alternative social and spatial typologies, as well as different ways of working. For example, The DisOrdinary Architecture Project uses nonconventional drawing/mapping techniques – developed out of diverse disabled artists’ own creative practices – to investigate experiences of embodiment that often disappear in conventional (visually oriented) orthographic techniques. This might be by changing our bodies to draw differently *fig.4* or by reframing the development of a design brief as an embodied process. <sup>26</sup>

With Architectural Association (AA) tutors Manijeh Verghese and Inigo Minns, Deaf artist Aaron Williamson worked with students to explore how his creative practice could critique the normative forms of production of architectural projects. <sup>27</sup> This is one of several current DisOrdinary Architecture collaborations that start from the positive qualities of Deaf Gain, starting from the spaces that learn from the social, spatial and performative character of sign language. <sup>28</sup>

Another project aims to challenge the very nature of architectural education. Called Architecture Beyond Sight (ABS), it is a foundation-level one-week residential intensive study program to enable blind and partially sighted people to study architecture. It was originally commissioned in 2018 by the then dean

<sup>24</sup> “Disabled Artists Making Dis/Ordinary Spaces,” Liz Crow and Julia Dwyer, 2018, <https://vimeo.com/showcase/4562223/video/215407274> (accessed February 20, 2022).

<sup>25</sup> Garland-Thomson, “Misfits,” 597.

<sup>26</sup> *Narratives of Difference: A Collaboration between Rachel Gadsden, Judit Pusztaszeri and Students of the School of Architecture and Design, Brighton University*, dir. Tim Copsey for The DisOrdinary Architecture Project, posted as “Brighton University Case Study,” Vimeo, March 6, 2019, <https://vimeo.com/showcase/4562223/video/321870384> (accessed February 20, 2022).

<sup>27</sup> *Disrupting Behaviors: A Collaboration between Aaron Williamson, Manijeh Verghese and the Students of the Architectural Association, London*, dir. Tim Copsey for The DisOrdinary Architecture Project, posted as “Architectural Association Case Study,” Vimeo, July 17 2019, <https://vimeo.com/showcase/4562223/video/348571812> (accessed February 20, 2022).

<sup>28</sup> Todd Byrd, “Deaf Space,” in *Boys, Disability, Space, Architecture*, 241–46. The term *Deaf Gain* originated with Aaron Williamson. See, for example, H-Dirksen L. Bauman and Joseph J. Murray, eds., *Deaf Gain: Raising the Stakes for Human Diversity* (Minneapolis: University of Minnesota Press, 2014), xv. The DisOrdinary Architecture Project is also developing a foundation course called “Vibrant Spaces” for Deaf people wanting to study architecture and a Deaf Space–informed temporary festival pavilion for Theater Foramen in Germany.

of the Faculty of the Built Environment at the Bartlett School of Architecture, University College London, and has run once with fifteen participants (and again in August 2022, post-pandemic). Program development and implementation has been disability-led throughout, starting with a one-year development process,



with the course itself led by blind and partially sighted architects, makers, and artists. Like conventional foundation courses, studies are centered on conceptual thinking, design making, spatial and atmospheric mapping, and interpretation and design communication. But tutors and students also codevelop ways of designing beyond the visual, including audio description, large-scale sketching, and tactile and performative communications. This, in turn, suggests methods that all architectural students and practitioners could use to design differently.

**fig. 3** "Tilted Horizons," a design project codeveloped by disabled artist Liz Crow and architect Julia Dwyer, who invited interior design students from the University of Westminster, London, to explore the conditions of, and adapt existing spaces for, lying down. Screenshot from video by Tim Copsey, 2017



29 **fig. 5** ABS thus works at multiple levels. It provides blind and visually impaired people with the confidence, skills, and portfolio to apply for further educational opportunities conventionally unavailable to them; it challenges normative assumptions

**29** *Architecture beyond Sight*, dir. Tim Copsey, posted as "Architecture beyond Sight 2018," Vimeo, October 24, 2018, <https://vimeo.com/showcase/4562223/video/296974975> (accessed February 19, 2022); and Anna Ulrikke Andersen, *Architecture beyond Sight* (dir., 2019), <https://annaulrikkeandersen.com/2019/08/23/architecture-beyond-sight/> (accessed February 20, 2022).

about what disabled people are capable of creatively; it opens up alternative ways of designing space beyond the norms of standard orthography; and it models best practices for providing truly accessible design education. As one of the participating blind students writes,

**fig. 4** Exploratory device for drawing differently, developed by students at the Royal Academy of Design, Copenhagen KADK, for the *Alternator* project, created by disabled artist David Dixon. Photograph: Jos Boys, 2018

*I went on the Architecture Beyond Sight course at the Bartlett School of Architecture in London, with no expectations and I've gained far more than I could ever have imagined. ... We had been asked to make a box inspired by our time at the British Library, I've ended up making two, one made of driftwood, that's texture and smell links back to the library's architectural links to ships and there for the sea. ...*

*On Saturday [the day after the workshop finished] I woke up and realised I've spent years making art accessible for others but no one has ever made anything accessible for me in my entire life, this was a very emotional realisation.*

*I realised that being excluded or only getting half the information had become the norm. As recently as last year I was told it didn't matter if I learnt things properly because I couldn't see anyway, it was at that moment that I decided I needed to find a new way of learning because these tutors only see my visual impairment, they don't see me as an artist who exhibits and does art residencies unlike the tutors [sic] attitudes this week.* 30

**30** Fae Kilburn, "Architecture Beyond Sight," *Disability Arts Online (DAO)* [blog], August 6, 2019, <https://disabilityarts.online/blog/fae-kilburn/architecture-beyond-sight/> (accessed February 19, 2022).



To me, this is the closest DisOrdinary Architecture has come, to date, to implementing care as active practice.

## Access Is Love

As Leah Lakshmi Piepzna-Samarasinha writes in their seminal work *Care Work: Dreaming Disability Justice* (2018), the first Creating Collective Access network started in the United States in 2010, aiming to break away from normative “access as a service begrudgingly offered to disabled people by non-disabled people who feel grumpy about it” to “access as collective joy and offering we can give to each other.”<sup>31</sup> Since then, many disabled activists and scholars, such as *Sins Invalid* (2017), the Disability Visibility Project,<sup>32</sup> and Aimi Hamraie’s Critical Design Lab<sup>33</sup> — all always working intersectionally — have been exploring ideas of collective care, developments that can vitally inform built environment education and practice if the discipline just takes time to listen. Care is here framed as responsive, reciprocal, emergent, dynamic, and adaptive. It is not split along caregiver/care receiver, active/passive, normative/non-normative divides or



“solved” through mechanical design solutions added onto the end of a design project conceived originally for bodies not needing care. As Piepzna-Samarasinha asks,

*“What does it mean to shift our ideas of access and care (whether its disability, childcare, economic access or many, many more) from an individual chore, an unfortunate cost of having an unfortunate body, to a collective responsibility that’s maybe even deeply joyful?”*<sup>34</sup>

Mia Mingus also explores such an understanding through the concept of access intimacy:

*“Access intimacy is that elusive, hard to describe feeling when someone else ‘gets’ your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level. Sometimes it can happen with complete strangers, disabled or not, or sometimes it can be built over years. It could also be the way your body relaxes and opens up with someone when all your access needs are being met. ...*

*It doesn’t mean that our access looks the same, or that we even know what each other’s access needs are. ... Sometimes access intimacy doesn’t even mean that everything is 100% accessible. Sometimes it looks like both of you trying to create access as hard as you can with no avail in an ableist world.*

<sup>31</sup> Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Vancouver, BC: Arsenal Pulp Press, 2018), 16–17.

<sup>32</sup> Alice Wong, ed., *Disability Visibility: First Person Stories from the 21st Century* (New York: Vintage Books, 2020), xv–xvii. See also the “Access Is Love” project, <https://disabilityvisibilityproject.com/2019/02/01/access-is-love/> (accessed February 17, 2022).

<sup>33</sup> See <https://www.mapping-access.com/lab> (accessed February 20, 2022); and Aimi Hamraie, *Building Access: Universal Design and the Politics of Disability* (Minneapolis: University of Minnesota Press, 2018), here xiii–xiv.


**fig. 5** A partially sighted “Architecture Beyond Sight” participant explains her one-week foundation design project to one blind and one sighted tutor in an “under-the-table” crit. Photograph: Jos Boys, 2019

<sup>34</sup> Piepzna-Samarasinha, *Care Work*, 33.

Sometimes it is someone just sitting and holding your hand while you both stare back at an inaccessible world.”<sup>35</sup>

Accessibility understood like this is an always emergent, partial, and shared activity. Of course, such a way of articulating access causes problems for conventional architectural forms of thinking and doing. It is less focused on the “bright new shiny thing” of the next building or project and more on the slow and particular, on diverse people finding creative ways to occupy space through negotiation and adaptation.

### Care as Repair, Adaptation, and Maintenance

Kim Kullman’s research on the Ed Roberts Campus, a well-known disability-led building in Berkeley, California,<sup>36</sup> offers clues about how interpreting care as repair, adaptation, and maintenance can challenge normative built environment practices.  The original building design for the campus grew out of a campaign by mainly physically disabled people – a particular historical moment of disability activism<sup>37</sup> – but its ongoing value to diverse disabled people means that it has adapted to the needs of more recently self-advocating groups, such as autistic people and those with environmental sensitivities. For these newer generations of disability activists, impairment is not so obviously framed around identity categories such as wheelchair users, blind or deaf people, or focused on “barriers” that can be designed out. Kullman suggests that the people with environmental sensitivities he talked to were much more concerned to explore the intersections between their vulnerabilities and the requirements of other disabled people in the building – recognizing tensions and multiple needs as a means to develop improvements – rather than by first defining the “needs” of different impairment groups and then somehow adding these together to produce a “universal design.”

This research also highlights the vital role of ongoing service support in managing these tensions productively and illustrates how building maintenance and caretakers – mostly learning-disabled people at the Ed Roberts Campus in a supported employment scheme – respond to complex differences positively and creatively. This is ongoing detailed work that is often framed as problematic – as a “wasted” resource in conventional building services and management – because it takes time and connection to support individual adaptation of, for example, building-wide ventilation, heating, and lighting systems. This project’s continuing commitment to meeting diverse needs is a great illustration of both access as collective care and care as embodied practice. To conceive of built space like this requires moving access out of its normative location as an “add-on” technical and

<sup>35</sup> Mia Mingus, “Access Intimacy: The Missing Link,” *Leaving Evidence* [blog], May 5, 2011, <https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/> (accessed February 26, 2022).

<sup>36</sup> Kim Kullman, “Politics of Dissensus in Geographies of Architecture: Testing Equality at Ed Roberts Campus, Berkeley,” *Transactions of the Institute of British Geographers* 44, no. 2 (June 2019), 284–98, <https://doi.org/10.1111/tran.12276>.

<sup>37</sup> The building is named in honor of Ed Roberts (1939–1995), a pioneer of the disability rights movement in the United States. After his death, a disabled group came together to develop an inclusive campus for organizations that provide services to disabled people.

<sup>38</sup> See Mia Mingus, "Access Intimacy, Interdependence and Disability Justice" (Paul K. Longmore Lecture on Disability Studies, San Francisco State University, April 11, 2017), <https://sfpirg.ca/wp-content/uploads/2017/08/Access-Intimacy-Mia-Mingus.pdf> (accessed October 31, 2021).

<sup>39</sup> Yergeau et al., "Multimodality in Motion," <https://kairos.technorhetoric.net/18.1/coverweb/yergeau-et-al/pages/index.html> (accessed December 8, 2022).

legal solution, "out of the realm of only logistics and into the realm of relationships and of understanding disabled people as human beings, not burdens."<sup>38</sup>

In addition, centering care in this long term and adaptive way requires a generosity of investment (of both capital and revenue) in spaces, resources, and services, not just one accessible toilet but several with different facilities, corridors spacious enough for comfortable passing, doors wide enough to get through easily in a mobility scooter or with children or when carrying packages. This demands a major shift from normative allocation (where a grand commercial foyer is value for money but a lift is "too expensive"). And it requires multimodality as a core design principle. Multimodality—the layering of multiple access requirements—needs to be underpinned by what Yergeau and colleagues call an ethics of accessibility, requiring responsible and respectful attention paid to the differences people bring to a situation "that allow[s] the broadest possible range of people to make meaning in ways that work best for them."<sup>39</sup> Yergeau particularly discusses how multimodality needs to be more than just the additive combination of different elements (particularly if this retains a "retrofitting" mentality). We need always to be exploring how those access layers can be commensurable, however varied, without a differential quality of experience. Committing to multimodality, then, is a deliberate redistribution of resources toward those who currently face barriers and away from those who already occupy space smoothly.

### **Toward Care as an Active Practice**

In the 1970s and 1980s, I was one of many feminists trying to better understand how space was gendered rather than neutral (the common assumption) at a time when sexism was not a concept in everyday use, let alone in architectural discourse. Matrix worked to enable women and other disadvantaged groups to imagine and actively be involved in creating new building types (e.g., women's centers and refuges and radically different forms of shared childcare). It did this by developing equitable design methods (e.g., explaining the arcane language of architectural drawings, working with easily manipulated physical models, and by creating straightforward techniques for understanding scale); by aiming to break down boundaries across construction and design so as to bring more women into the built environment sector; and by creating multiple sites of discussion and development. The DisOrdinary Architecture Project continues in that vein, starting this time from disability-led creative arts practices to develop a similar range of tactics to help us better under-

stand how our built surroundings disable (not just in relation to impairment but also beyond it) and how we might begin to productively “crip” not just built space but — as Matrix did — the normative modes of practice across built environment disciplines that (re)produce inequalities. We agree that “when disability activists enter ... the profession of architecture, they show ... that architects do not just design buildings, they also design curricula, licensing requirements, research, and fields of discourse that give meaning to their work.”<sup>40</sup> This means everything from rethinking employment and continual professional development practices, to building in ways of engaging with the creativity of disabled people across all aspects of the discipline, to exploring alternative design methods and forms of representation.

Again, the intention here is ridiculously idealistic. But it starts with each of us and our own embodied practices and moves toward an ongoing, slow, but increasing accumulation



of changed mindsets and new kinds of actions, an accumulation that can snowball into a real paradigm shift. For built environment professionals, educators, researchers, and students this means recognizing and acting against the normative assumptions of privilege (we are already privileged in being able to read this). The intent is not to create feelings of guilt, blame, or embarrassment or to ask “What shall I do?” or “What is the solution?” (ques-

tions that nonnormative people have been fielding for many, many years). It is instead about listening to those most impacted by social, spatial, and material inequalities, finding ways to be an ally across diverse forms of misfitting and discrimination, and intervening when needed to call out inequalities. For the built environment industries, it is about paying attention to the sheer oddness of designing for “normal” people and then adding on access “solutions” for those you have already left out. It also means critically reflecting on current ways of working within architecture as a discipline. This could include challenging professionalism as “neutral” consensus, compromise, and balance instead of looking to social, spatial, and material justice. It could be about rethinking design techniques that are still stuck in the limitations of

<sup>40</sup> Matthew Allen, “Designing for Disability Justice: On the Need to Take a Variety of Human Bodies into Account,” Harvard Graduate School of Design, February 10, 2021, <https://www.gsd.harvard.edu/2021/02/designing-for-disability-justice-on-the-need-to-take-a-variety-of-human-bodies-into-account/> (accessed March 4, 2022).

**fig. 6** Internal view of the Ed Roberts Campus, University of California, Berkeley, 2011. Designed by Leddy Maytum Stacy Architects. Photograph: Tim Griffith

41 David Graeber, *The Utopia of Rules: On Technology, Stupidity, and the Secret Joys of Bureaucracy* (Brooklyn: Melville House, 2016), 89.

orthography. Wherever you focus, caring, in this understanding, is to explore how – within the very real constraints of contemporary architectural education, theory, and practice – normative practices and spaces might be critically and creatively rethought and redesigned. As David Graeber writes, “the ultimate, hidden truth of the world is that it is something that we make, and could just as easily make differently.” 41