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Advancing Meaningful Inclusion Through Design: An Architecture of Dis/Ability

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ABSTRACT

We heard a call to action after presenting at the 2023 World Congress of Architects in the stunningly creative city of Copenhagen: take notice of the "limiting virtues" of our built environment! As a successful interprofessional team representing public health, architecture, art, and neurodivergent communities, we demonstrate the potential of a collaborative approach to meaningful inclusion through a series of exemplar projects. This work relies on imagination, respect for genuine end-user engagement, and developing a common working language across the arts and sciences. Our approach demonstrates independence from traditional applications of accessible design in our investigation and exploration of novel tools to measure the impact of interventions, appreciation for the myriad ways in which built and natural environments relate to public health, community mobility, and independence as well as commitment to teach this as a new academic discipline. Our complementary lenses to the operationalization of accessible design challenge the traditional owners of this work to consider the true meaning of inclusion with thoughtfully articulated intended outcomes. We are informed by end-user need, aim to apply methodologic rigor in post-occupancy surveys with dedicated resources for iterative change based on the outcome, and employ genuine partnership with members of vulnerable and disabled populations not yet fully represented in the design process. This approach respects the value of diversity within public spaces with intentional consideration of design choices that magnify social exclusion and the cascade of loss that follows avoidance and lost opportunity. Locating affordances, acknowledging limitations, and making way for multimedia, multimodal communication from largely "unheard" and unacknowledged autistic populations anchors our collaborative approach. We encourage openness to language (both words and images) in which community members express their needs, facility in mapping the accessible environment, and explorations of the cognitive dissonance between disabled people and enabled people in the same spaces. We are confident there is tremendous potential to make significant progress in our collective but to date parallel efforts to advance the ways in which our built environment may be modified to support more successful and rewarding access by more people in more locations.

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1. Introduction

The common has not yet been achieved."
- Judith Butler [1]

The current intersecting crises of community and individual mental health, social justice, and civil rights challenge all of us to reflect upon how we live, work, play, and relate to each other within our public environments. We must question what it means to equitably share spaces intended to serve and support any individual, recognizing the existing limitations and inequitable affordances influencing community participation for many of us. We propose a scaffolding through which to consider and curate a means towards better understanding and leveraging opportunities to support those individuals harboring an uncomfortably complex relationship with our built environment. Our work specifically advances integration, respect, and appreciation for elevated and refined affordances for neurodivergent populations. Productive cross professional partnership through which design and engineering absorb the systematic investigation of mixed methods research underpinning implementation science harnesses a process to support more thoughtfully crafted environments for a wider swath of our communities. Essentially, our intention lies here: "when we don't notice the built environment, it's silently affirming our right to be there." [2]

In 2023, we presented at the World Congress of Architects in the stunningly creative city of Copenhagen to introduce studies of affordances and barriers for autistic populations within a series of built environments. One of us shared his work as an autistic artist and statistician, offering his expressions of sensory experiences in familiar public spaces using layering of photographs and heat maps to underscore the tension, disruption, and at times unexpected solace along walks through university campuses and cultural centers. He demonstrated a tangible means to relate feelings from which the rest of us could better appreciate his difficulty with community mobility. Two authors shared considered imaginaries of educational and playground spaces crafted through community based participatory design with autistic school students. The first author participated as the only physician and public health investigator at the Congress in her role supporting an inclusive design consulting firm dedicated to architecture for autistic and deaf people. Our complementary lenses to the operationalization of inclusive design broaden an understanding of an existing tension between intended versus actual experiences in environments and the means to appreciate a wider expression of these experiences by those we intend to serve. In sharing the literal platform with architects in carefully articulating attention to underdeveloped resources, limited funding and absence of best practices for neuroinclusive design, we found an easy and natural partnership to do more together. We share here our cross professional approach, supported by works in progress, and maintain strong conviction that our methods and innovation will support finalized exemplar builds. We reimagine the intersections of individual and collective experiences to better enable more people to realize greater productive use of places and spaces. Together, we seek to invent new strategies and tools to create essential built infrastructure informed by the broad range of physical and mental health strengths and vulnerabilities that influence community mobility and participation. Importantly, we respect the value of independence and the beauty of interdependence. We consider how to improve access, and how to go beyond access – recognizing that both approaches are essential.

2. How Public Architecture Disables People

Space is not neutral. It is inherently biased, containing a myriad of visible and invisible mechanisms that determine who is prioritized, valued, and enabled. Physical barriers such as steps, missing curb cuts, tall counters and controls, and unintelligible signage undermine some groups of people who are divergent from the idealized norm. Sensory and social hurdles such as excessive noise,

flashing lights, congested communal areas, and hidden rules of engagement (clear to some, but not all) limit others. Personal shortcomings of disabled people are typically blamed for these limiting consequences. It is more reasonable to recognize that buildings and spaces lacking clear and flexible affordances disable people. Locating the process of disablement within people and not their environment ultimately places the burden upon disabled people to vindicate their own human right to inclusion. Our built environment can and should support more people more fully.

Architectural tradition has long celebrated the youthful, able, standing, and often white male body. Ideal forms celebrated over centuries - Leonardo's Vitruvian Man (1490) or Le Corbusier's Modular Man (1954) - perpetuate notions of a "universal body" with harmonious proportions. These ideals continue to shape architectural education and practice. Professional handbooks such as Architectural Graphic Standards, updated at intervals over decades [3], create the illusion of standardized and measurable inhabitants. Such narratives and expectations reinforce what Hamraie calls "regimes of legibility and illegibility" and "access knowledge" that privilege certain bodies and minds over others [4] and contribute to a built environment that excludes difference.

Since the second half of the 20th century, disability has primarily intersected with architectural design through accommodations for physical impairments and less on autism or invisible disabilities [5]. Despite 61 million (25%) of US adults having a disability, many people cannot name a co-worker who is disabled, possibly because 80% identify with an unseen vulnerability [6], as detailed in Table 1 [7]. Often framed as complete solutions, most accommodations are centered on strategies to support physical access and on workplace modifications with a motivation to improve employee productivity and usefulness. Early accessibility research focused on design adaptations to integrate disabled veterans into schools and offices, giving rise to barrier-free design guidelines still in use today. With the passage of the Americans with Disabilities Act (ADA) in 1990, accessibility requirements for public buildings and spaces became codified into federal law. Although the spirit of the Act offers broad support, the guidelines detailed in the Design Standards cover a narrow definition of disability. No widely accepted recommendations exist for neurodivergence, cognitive disabilities, or mental illness, for example.

Table 1 Prevalence of disability and invisibility in the US population, 2022

	With a disability	With a hearing difficulty	With a vision difficulty	With a cognitive difficulty	With an ambulatory difficulty	With a self-care difficulty	With an independent living difficulty
All ages	13.4%	3.7%	2.5%	5.7%	6.7%	2.6%	6.0%
Under 18	4.8%	0.5%	0.8%	4.8%	0.6%	1.1%	-
18 to 64	11.0%	2.0%	2.1%	5.2%	4.4%	1.7%	3.9%
65 and over	33.1%	13.6%	5.9%	8.0%	20.8%	7.1%	13.3%

The notion of "universal design," which originator Ron Mace defined in the 1980's as "design that's usable by all people, to the greatest extent possible without the need for adaptation of specialized design" [8] is often dubbed the "common sense" solution to inviting inclusion. It outlines principles of equitable use, flexibility, simplicity, perceptibility, tolerance for error, low physical effort, and appropriate size and space. Yet paradoxically, this approach to making spaces for "all" correlates to a "disability-neutral" platform [9] that effectively dismisses disability as immaterial. The one-size-fits-all implication of universal design simplifies the constellation of factors that render spaces disabling. Recently, thoughtful contributions to design discourse by disabled designer-scholars Aimi Hamraie and David Gissen, scholar Jos Boys, artist and design researcher Sara Hendren, and neurodivergent

author Nick Walker, among others, have privileged the perspectives and narratives of disability and divergence, celebrating the often-excluded "unruly bodies" [10] and "misfits" [11] and their "frictioned negotiations" [12] of access and experiences within our built environment. Disability is not something to be accommodated by architecture but instead demands a complete rethinking of our disciplinary assumptions, biases, and approach to community and the built environment. Describing this radical shift of focus, Boys quotes Leopold Lambert and Minh-Ha Pham: "We can begin to explore the political – sometimes violent – relations of bodies, objects, and environment that are produced and maintained through standard design practices and knowledge. How might a collaborative relation of body and environment create the potential for a more non-hierarchical architecture? How might it build one that frees all bodies from the abstract concept of a 'normal' body?" [13] Sara Hendren encourages us to acknowledge the "hidden assumptions on which our everyday environment is built" and a collective pivot to "actively engineer public spaces" to foster interdependent living [14].

Moving beyond the checklist-approach and the architect as savior model requires a multi-disciplinary outlook not captured in the typical teaming model of the profession. As a start, meaningful inclusion requires genuine partnership between disabled communities and builders, architects, engineers, and urban planners. It also demands a commitment to identifying common goals for meaningful change and investment in evaluating the impact of presumed affordances, adaptations, and reinvention to allow a dynamic and evolving co-design process. Likely, success will be measured in a series of parameters that embrace functional as well as joyful opportunity and confirmation by autistic people that they feel included [15].

3. Case Studies

3.1 Case Study 1: Improved Community Mobility by More People to Support the Full Range of Human Experience: the perspective of a physician and public health researcher

Consider: joy as an emergency medicine physician largely stems from magnificent multidisciplinary collaboration through which care is elevated and comprehensive – sometimes with something as straightforward as social work for support in accruing resources, and other times with a cadre of teams to minimize the impact of life-changing injuries. There is a rhythm to this work, weaving in and out as our skills are needed, striving to complement one another's strengths at the bedside and giving our respective insights to the evolving clinical problem in front of us. The opportunity to consult one another is an occasion to learn, teach, advocate, and hold ourselves accountable for the decisions we make.

Such cooperative efforts are largely absent in inclusive design efforts. As Heylighen *et al* notes, "the uptake of inclusive design in general seems to be hampered by perceptions that it has no business case, sacrifices aesthetics, increases costs, involves a more complex design process, is not an end user need, is design for disabled people, and slows down time to market. Furthermore, more practical barriers are identified, such as a lack of skills or tools to practice it, a lack of knowledge to assess inclusivity, competing or conflicting requirements and the client's influence or the company's culture." [16]. We propose that the integration and shared responsibility of auditing environments and problem-solving accessibility and usability of public spaces by users, public health investigators, designers, engineers and contractors would offer a sophisticated and elevated approach to inclusion. The enthusiasm for honoring diversity and leveraging our built structures to support marginalized communities in education, leisure and employment is clear. However, without the framework imparted by a rigorous methodologic research approach at the design stage, these efforts have lacked meaningful impact and precious resources are lost. Fully inclusive design is rarely a primary specification in the execution of new infrastructure and developments and is often not even a subsidiary priority – a significant failing. Inclusion as a goal is often tacked on afterwards, promised as a later phase, or not considered at all. This approach has not yielded needed change.

We know the potential for rewarding and successful access to our communities exists. Contrast the fully accessible Crann Centre in Ovens, County Cork with the delivery of five wheelchair accessible swings in Cork City, Ireland. The design of the Crann Centre facilities was guided by Universal Design concepts within the Aspen Institute 2Gen model of care, providing for both disabled children and disabled parents. Three guiding principles (pre-defined outcomes) of this work are "Can I get there? Can I play? Can I stay?" for all members of the family, of all ages and abilities. The Crann Centre playground is the only one of its kind in Ireland, reinforcing the impression that accessibility requires specialized design for a certain minority of the population. The Cork City swings are an initiative to support more widespread use of existing playgrounds. Families may apply for a key that unlocks a wheelchair-accessible swing. This is a gated swing that allows a wheelchair to lock in place within its mechanism. Kids (and adults) may safely swing facing (positioned) away from the playground where other children are clustered around the traditional equipment. The former sketch empowers a community around play. The latter enforces exclusion. Good intentions and good engineering left out doing good in Cork City. The purpose, and challenge, is creating a meaningful social and physical experience for more people - for people using wheelchairs, who are blind, who have depression - and for people who would thrive by interacting with them. A public health perspective (our perspective) would have encouraged careful consideration of the hoped for outcomes in advance so the quality of the experience would be thought through, as well as the facilitators to access and planning for such a resource.

At the time of this writing, a notable project is underway with momentum and vision approaching our described ideal. A US healthcare system recognized limited capacity to meet the needs of developmentally and cognitively impaired individuals in crisis. Resources have been appropriated to build a new model of health care to support this population. The architectural team made room at the table for public health, physician, and program developer partnership. The evolution of both the physical site and planning for treatment course are stronger, more deliberate, better informed, and novel because of our mutually respectful dialogue and awareness of how best to leverage our specific talents to translate population needs into design that is research-based, scalable, safe, and thoughtful.

Importantly, this work touches almost everyone when we consider the benefits that more inclusive design promises. We recognize the impact of clear signage and wayfinding, acoustic baffles in open atria, natural lighting and wider corridors, and environments with more choice as a welcome change for many and as essential for some. Just as curb-cuts for wheelchairs prove useful to delivery carts and strollers navigating from street to sidewalk, we see brilliance in designing other 'curb-cut' strategies that help our environments meet us where we are.

3.2 Case Study 2: A Sense of Safety and Belonging in the City: the perspective of an autistic artist

Artistic imagery provides a mechanism to study and share experiences of public places that transcends narrative descriptions, as noted by Neilson [17]. Autistic people report that sensory and social overload, the hidden logic of wayfinding, anxiety-provoking transitions and insecurity make public space "terribly chaotic and unpredictable" as noted by Kinnaer *et al* [18]. Architecture can be less or more disabling, by design, obscuring affordances and opportunities. Visual studies of public places, routes and pedestrian crossings in Cork City and elsewhere in Ireland expose sensorily calming, stimulating, and overloading spaces in a medium where other people can both see and share the sensory experience of place. They have helped map out a set of refuge spaces and a safe personal network of connections between them, connecting home with the necessary activities of daily living.

These images, examples of which are shown in Figures 1 and 2, identify how autistic needs are subsidiary to monetization and private enterprise in public places. The destinations we need for work, play and leisure are often both uncomfortable and disconnected from easy access by uncomfortable streets. Sensory disorientation and sensory confusion are often engineered into retail and hospitality venues to create uncertainty and anxiety in shoppers [19]. Most people resolve their anxiety by

transferring their uncertainties into a purchase or transaction. Shopping malls, airports, and inconsiderate working environments are all examples of the social and economic choices by which society excludes autistic people from full participation. It is easy to avoid sensory distress by not going out, but avoiding sensory distress comes with a large penalty, reducing the number of friendship, educational, and job opportunities.

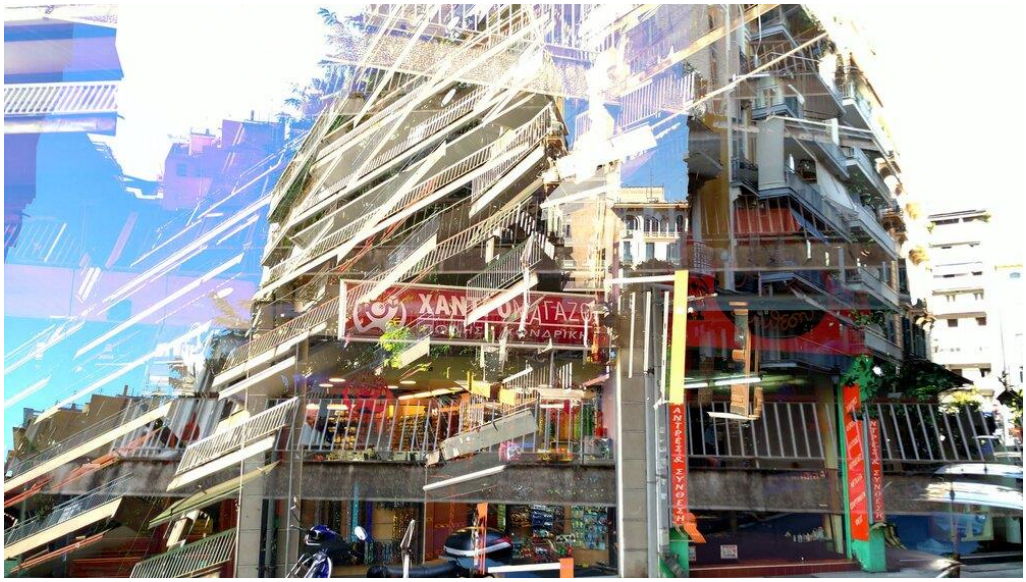

Fig. 1. Composite image of Kasritsiou in Thessaloniki by Stuart Neilson

Fig. 2. Composite image of Trafalgar Square by Stuart Neilson

3.3 Case Study 3: Public Space, Joy, and Disability: the perspective of two architects

What does it mean to design spaces that offer increased accessibility not in terms of more fluid ingress and greater occupant productivity, but in terms of more opportunities for joy, creativity, and self-expression? Two current interdisciplinary initiatives in New York City try to answer this question. The first is a multi-phase project to reimagine New York City's playgrounds as places that appeal to and function for all children, including disabled and neurodivergent children. This work is part of a larger project called the Neurodiverse City, conducted in partnership with the non-profit organization Design Trust for Public Space by the authors and WIP Collaborative, a collective of women designers.

The project is co-designed with neurodivergent New Yorkers and community advocacy partners [20]. The first phase of the playground portion of the project is an existing-conditions audit to clarify how neurodivergent children and their caregivers experience recreation in existing play spaces and what might improve the time spent in these areas designed for exploration, socialization, and physical activity. Recruiting participants for the audits is multilingual, as seen in the flyers for the audit on the Lower East Side of Manhattan shown in Figure 3. While designing the survey process the team consulted with public health experts, playground equipment manufacturers, parks-department officials, landscape architects, disability advocates, and self-advocates. Deciding where to audit, how to connect with disability communities, what questions to ask and how to ask them are not tasks that belong to architecture alone. The process requires an open mind and a responsiveness to critical feedback. Architects often want to jump to the problem-solving phase, relying on a best-practices approach coupled with personal experience as the most reliable guide. But an inclusive architecture requires an inclusive process, and a multi-disciplinary and disability-informed approach requires slowing down and being more intentional. In addition to interviews and observations at playground sites as illustrated in Figure 4, the project also includes an online survey that is being broadly distributed in conjunction with the community partners.

Fig. 3. Flyers to recruit audit participants by Verona Carpenter Architects

Fig. 4. Playground audit

The second initiative is *Dis/Abling Architecture,* a Columbia University graduate-level seminar and studio recently taught by the authors in collaboration with the renowned and disabled dancer Jerron Herman. This unlikely and convivial teaming led to a richness of dialog and design that can be a model for other classrooms. The seminar portion of the class was open to students outside the architecture school, encouraging cross pollination of ideas between academic disciplines. Students went beyond designing for traditional disability access and instead imagined and demonstrated an architecture rooted in disability as a source of joy and creativity. Students studied and interacted with disabled artists, dancers, and thinkers, including Kayla Hamilton, Christopher Nunez, and Troels Heiredal, and read texts by disabled and neurodivergent authors. The studio focused on design for play to move away from ideas of productivity that traditionally shape studies of inclusion. Play was defined broadly as artistic or performative, recreation, leisure, wandering, and pleasure. One successful student project, illustrated in Figures 5 through 7, critiqued the popular urban planning notion of the "15-Minute City" as overly able-bodied and neuro-typical, proposing instead an urban block full of "Stations" that provide moments of pause and comfort within environments typically designed for continuous flow. These stations, the student designers stated, "are reminders that efficiency should not come at the cost of accessibility and that the rhythms of human movement vary widely."

Fig. 5. Stations Catalog and Base Map, Dis/Abling Architecture student project, Aimee Yang and Do Yeon Kim

Fig. 6. Multi-sensory tactile model, Aimee Yang and Do Yeon Kim

Fig. 7. Dis/Abling Architecture studio final review with tactile model

4. Learning from Case Studies: Rethinking Methodology

Expanding integration of more people into the structured, unstructured and interstitial elements of the places in which we work, play, learn, and live requires intention, ingenuity, inspiration, and new

perspective on the relationship of people to place. Collaboration and genuine partnership with the full range of stakeholders through all stages of planning and development, including post-occupancy reviews, must be valued. Disabled individuals, caregivers and educators, and self-advocacy groups are available and must be active and respected participants in consultation. An early body of literature has emerged to introduce the means and methods that facilitate participatory design workshops with stakeholders, leaning on awareness and appreciation of a range of platforms, media, and communication tools to enable productive dialogue [21-23]. Disability gaps in education, democracy, income and employment are notoriously stubborn and resist nearly every effort to narrow them [24]. All too often outreach and discourse with stakeholders is conceived by technologists and requires users to familiarize themselves with complex images and technical language outside everyday experience. A subset of people with the background, education and commitment persist long enough to fully participate. Other people communicate in moods, emotions, gestures, markings, and throw-away comments that are lost to such highly specialized consultation exercises. Instead of placing the language burden on disabled people, designers must learn to receive feedback and entertain a dialogue using a range of human exchange. Communication methods contribute to how each of us is the sum of layered identities; acknowledgment of intersectional identities over singular embodiments is an important clarification here.

Traditional assessment and audits of spaces and buildings largely respond to mobility needs and safety concerns. We acknowledge these essential qualities of a space and encourage additional consideration of a role for transition spaces, legible sequencing of layouts, an awareness of the ways in which lights, sounds and textures may influence certain areas either as supports or hindrances, with thoughtful wayfinding and clear signage. This may begin with the application of computer science methods to the study of motion, chaos, light, and sound in a given space. Our experiences have demonstrated this unravels a cascade of novel demonstrations of how and why certain locations may present as unpredictable, unapproachable, or even frightening, thereby limiting engagement by some users. Image composites, made from a video attempting to replicate a natural visual sweep of a place, form accumulated sensory impressions that are closer to perception than a single photographic snapshot. Exemplar studies show the motion intensity of a walk in a city highlighting where our eyes might be drawn, if we attend to anything and everything that moves, instead of (as most people seem to accomplish with ease) attending only to tasks and social interaction without distraction. Motion composites and motion heat maps expose the desire lines people follow, and (sometimes unexpected) objects and movements that attract (or distract) attention in a place. Composites also reflect the dynamism of people, animals and objects in the environment, trying to portray the full range of motion and completed action as a kind of story in one image.

There is an obligation to consider inclusion within new builds and re-imagining existing locations. The knock-on costs of retrofitting accessibility into existing designs, temporary closures for redevelopment, and poor-quality melding of accessibility into an inaccessible design are very high, leading to the impression that disability is expensive and a burden to architects, planners, and society. Disabled people and their families are obliged to become experts in design, logistics, finance, and law, merely to attain the same opportunities as enabled people. This expertise is acquired at a great cost in time, energy, and money – costs which enabled people expend on opportunities to engage in learning, leisure, and social contact. The failure to center diversity in design pushes accessibility into the background with every change, whether the technological possibilities opened up by glass curtain walls or laminated timber; or the social distancing space requisitioned (at the expense of access) in the COVID-19 pandemic; or the changing legal and financial landscape of public-private partnerships. Compelling disabled people to be the experts in providing for their own needs creates an imposing, full time chore.

5. Conclusions

We are confident there is tremendous potential to make significant progress in our collective but to date parallel efforts to advance the ways in which our built environment may be reconceived to support more successful and rewarding inclusion for more people in more locations. A cross-disciplinary and inclusive approach requires identifying disabled and neurodivergent stakeholders, involving them from inception to conclusion, and developing a common language among architects, public health researchers, scientists, and disabled people. It means unlocking funding sources dedicated to this interdisciplinary work, creating novel tools to measure outcomes and impact of interventions, and a commitment to teach a new academic discipline informed by historically under-represented partners. To affect significant change across project types, including public space projects, design practices and design teams must include more disabled people, more neurodivergent people, and support these individuals so that they can grow into leadership roles. The potential for genuine, productive, and successful inclusion with interdisciplinary collaboration is truly exciting. May the next Congress offer more examples of shared change.

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