EXPLORING AUTISTIC SPACE

The Aspects and Implications of Spatial Autistic Autonomy

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DSAB 601: Psychosocial, Cultural, and Political Aspects of Disability

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January 18, 2023

Defining Autistic Space

The vast majority of the physical and social world has been constructed by neurotypical people, for neurotypical people. Historically, this non-autistic population has paid little attention to the spatial, sensory, and communicative needs of autistic people. Furthermore, these needs have been pathologized and defined as individual issues for autistic people to learn how to cope with independantly and discretely (Chapman, 2021). This status quo space is “Neurotypical Space,” where autistic sensitivities are understood to be personal medical problems, rather than consequences of systemic barriers addressable through cultural and environmental change (Sinclair, 2010, Being Autistic in NT Space section).

In Neurotypical Space, interpersonal interactions are meant to follow neurotypical standards. For example, most face-to-face communication relies heavily on non-verbal cues and implicit meanings. Autistic people frequently find these methods of communicating difficult to understand (Davidson, 2010). They also experience rejection for not complying with arbitrary social expectations, such as maintaining eye contact or refraining from self-stimulatory behavior like hand flapping. Autistic displays of care and empathy can be misinterpreted as rude, and many autistic people report being frequently ridiculed in response to their attempts to clarify what they don’t understand (Parsloe, 2015, p. 347).

Additionally, most autistic people also experience discomfort or distress from common environmental stimuli (Davidson, 2010; Steele & Ahrentzen, 2016). These include simple visual elements like fluorescent lighting, harsh paint colors, and visual

clutter. Acoustics also play a major role in the accessibility of a physical space for many, and others might be hyper-sensitive to odors. At a larger scale, disorienting spatial layouts and nonintuitive wayfinding can be overwhelmingly stressful. This list is only a small sampling of the sensory stimuli prone to causing overstimulation, and the specific array of elements that act as disabling barriers will vary for each autistic person.

Neurotypical society at large is not oblivious to the existence of autistic people, and Neurotypical Space includes both “Places for Autistics” and “Autism Spaces.” Jim Sinclair (2010) categorizes Places for Autistics as “situations in which autistic people are in the majority, but [neurotypical] people are still in charge of creating structure and setting the agenda… according to [neurotypical] people’s perceptions of what autistic people need” (Sinclair, 2010, Autistic Space vs. Places for Autistics section). Examples of these include special education classrooms and sheltered workshops. In Autism Spaces, autistic people are not necessarily the majority population, but they are the primary focus of attention. Most autism-themed conferences and non-profit organizations can be considered Autism Spaces, where control typically rests with autism “professionals” and parents (Bertilsdotter Rosqvist et al., 2015, p. 601). Ironically, Autism Spaces are frequently rife with the types of environmental stimuli and neurotypical social expectations that pose the biggest challenge for autistic people in occupying Neurotypical Spaces (Bertilsdotter Rosqvist et al., 2013, p. 374; Sinclair, 2010, Brief History of ANI section).

In contrast, “Autistic Space” is created and controlled by autistic people, for autistic people (Botha et al., 2022, p. 2281; Sinclair, 2010, Autistic Space vs. Places for

Autistics section). These are places where autistic sensitivities are respected, autistic ways of functioning are valued, and autistic methods of processing are celebrated. In Autistic Space, the implied rules of neurotypical socializing are rewritten and then clearly documented for community members to reference. The disabling barriers imposed by neurotypical society are mediated to the greatest extent possible. The social model of disability is supported by Autistic Space, where biomedical understandings of autism are challenged by the mere existance of autistic socialization, community, and friendship (Bertilsdotter Rosqvist et al., 2013, p. 373).

Online Autistic Space

Many autistic people first experience Autistic Space on the internet. In 1997, The New York Times reported that “in cyberspace, many of the United States’ autistics are doing the very thing the syndrome supposedly deters them from doing — communicating” (Blume, 1997, pa. 2). Several elements inherent to digital platforms contribute to their suitability for autistic community building. Most unneccessary stressors are avoided due to the ability to remain in one’s own comfortable personal space. Interaction with people online does not necessitate interaction with the agitating environmental stimuli of public places, including the sounds, smells, and touches of other people (Sinclair, 2010, Virtual vs. Physical Spaces). Furthermore, non-verbal cues are nearly eliminated, and asynchronous access provides ample time to respond at one’s own pace (Bertilsdotter Rosqvist et al., 2013, p. 368; Seidmann, 2021, p. 2278). People can carefully curate their presentation of self (Seidmann, 2021, p. 2278), while also maintaining anonymity if they are struggling with self-stigma (Parsloe, 2015, p. 340).

In physical Neurotypical Space, when autistic people decide that they would prefer to stay on the sidelines instead of directly participating, it is often received poorly. Online, autistic people have the power to take as much time as they would like to observe and orient themselves prior to actively engaging.

The precise formats utilized — email lists, forums, blogs, and social media platforms — have evolved and expanded over the last three decades. Each type has unique aspects and cultural functions. On forums, autistic participants find community and develop an autistic culture and collective identity (Parsloe, 2015, p. 340). It is possible to filter conversations by topic and engage in only the desired arenas. In the blogosphere, Autistic bloggers emphasize the importance of having control over their own space which "is achieved through codes of clear behavioral rules and adaptation of the environment to autistic needs" (Seidmann, 2021, p. 2288). They share their experiences as a form of self-expression, often in order to promote social change (Seidmann, 2021, p. 2288). Bloggers highlight the notion that their blogs are a safe space. This is important to many of the people who find respite in these online oases because Neurotypical Space feels far from safe (Seidmann, 2021, p. 2282).

Offline Autistic Space

In 1992, three autistic adults, Jim Sinclair, Xenia Grant, and Donna Williams, traveled to spend a weekend together for the first time (Sinclair, 2005, First Encounters section). They had made contact with one another through a parent-led newsletter and connected about the difficulties they experienced as autistic adults who were designated "high-functioning" (a label they disagreed with) by parents and

professionals. Sinclair (2005, 2010) describes the first afternoon that they all spent time together as a revolutionary affair, where they could all “be autistic” together. Inspired by the brief weekend of Autistic Space they had stumbled into at Xenia’s apartment, the three immediately founded Autism Network International (ANI) and its own online list (ANI-L). ANI was established specifically as an autistic-led organization, presumed to be the first to ever exist (Silberman, 2015, p. 440; Sinclair, 2010, Introduction section). In *Neurotribes*, a narrative history of autism, Steve Silberman (2015) explains that “ANI-L acted as an incubator for Autistic culture, accelerating its evolution” (p. 448). During the following few years, ANI made attempts “to create little islands of autistic space at [neurotypical]-run conferences” (Silberman, 2015, p. 449) but found that these neurotypical-led Autism Spaces would never truly accommodate the needs of autistic attendees, particularly those with the greatest support needs.

In response, ANI made the move to create an offline dedicated and intentional Autistic Space: Autreat, an annual retreat-style conference, was held from 1996 to 2013 in the northeastern United States (Autism Network International, 2013). Influenced by Autreat, other Autistic Space retreats have been developed. The most notable is Autscape, which continues to be held annually in the United Kingdom since its inception in 2005 (*Autscape*, 2022; Buckle, 2020). Organizers of both Autreat and Autscape attempted to include as many positive elements of online Autistic Space as possible. The primary method of accomplishing this was through establishing explicit rules about behavior and boundaries and by curating an event culture of acceptance (Buckle, 2020; Sinclair, 2010). At both retreats, name tags and color-coded tags are worn by attendees,

used to unambiguously communicate their interactional needs at any given moment. A red card signals that a person would like to be left completely alone, a yellow card warns that they would only like to be approached by friends, and a green card announces that the bearer would like to interact but is having trouble initiating (Buckle, 2020, p. 112). This approach means that there is never a need for anyone to guess what anyone else needs based on their body language. Attendees have noted that the red badge allows them to comfortably spend time in common areas observing without fear that anyone will try to engage (Sinclair, 2010, Spontaneous Interaction section).

Another valuable element to establishing physical Autistic Space is careful control of the physical environment. This can be challenging because “the kinds of sensory stimuli that are hurtful to some autistic people may be necessary for others” (Sinclair, 2010, Why Autistic Space Is Different From NT Space section). However, both conferences have adopted a policy of limiting potentially offensive stimuli, such as odors and sounds, as much as possible. All attendees are expected to abide by many rules that have been determined for the well-being of everyone. Venues are also selected based on their ability to meet a long list of requirements, such as the availability of a self-meal preparation space for those with limited diets. To further combat the stress of leaving their own safe home environments, retreat attendees receive a packet ahead of time that lists information about the event in painstaking detail. By including photos of venue lodging and common spaces in advance, retreat organizers hope to lessen the disorientation people may feel when arriving at a new place with new people (Buckle, 2020; Sinclair, 2010).

In terms of conference lectures and workshops, Sinclair (2010) states that “the concept of ‘one size fits all’ does not work in autistic space” and thus “the general principle is to provide opportunity but not pressure” (Sinclair, 2010, Contact A La Carte section). This philosophy is in keeping with the overall goal of providing the autistic attendees with full autonomy. Although each individual is responsible for explicitly communicating and meeting their own needs (independantly or with the assistance of an arranged companion), they often find that it is easier to do this in Autistic Space where they are not managing all of the extraneous expectations of Neurotypical Space (Sinclair, 2010, Receiving And Giving Assistance section).

The cultural shift in Autistic Space can be so successful that neurotypical attendees are often disoriented and experience a social confusion and discomfort reportedly similar to the experiences of autistic people in Neurotypical Space. For example, “one [neurotypical] attendee described feeling unsure of how to behave and how to relate to people, confused about how to interpret other people’s behavior, and anxious that he might offend people without realizing it” (Sinclair, 2005, Freedom From Pressures and Expectations section). Autreat and Autscape, as temporary isolated sanctuaries, reveal how disabling standard Neurotypical Space can be.

Almost Autistic Space

Beyond Autreat, Autscape, and their short-lived cousins, there are few other formal examples of what might be deemed “authentic” Autistic Space offline. Some attempts have been made to establish spaces with social norms similar to those found at Autreat and Autscape. One instance of this is Ability-Inclusive Sensory Theatre (AIST), a

“genre of Theatre for Young Audiences which creates highly intimate theatrical productions in which narrative structures are organized around sensory engagement” (Mattaini, 2020, p. 42). These performances are flexible and audience-centered, providing a high-degree of agency to participating children, who are typically autistic. This is different than more commonplace Sensory Friendly productions — adaptions of existing work in which rules for audience etiquette are relaxed while dramatic movements, colors, lights, and sound are dulled — which merely “make room in Neurotypical Spaces for people with autism” (Mattaini, 2020, p. 44). In contrast, the fundamental premise of an AIST performance is based entirely on the needs and joy of neurodivergent children, without attempting to be a therapeutic fix.

The major reason that AIST does not fufill Sinclair’s (2010) and other autistic theorists’ definitions of Autistic Space is because AIST has yet to meaningfully include autistic people in its creation, but Mattaini (2020) notes that several AIST production companies are actively working toward this goal (p. 45). Despite the lack of Autistic organizers involved in AIST performances, this unique type of theatre more closely resembles Autistic Spaces than Places for Autistics or Autism Spaces. One piece of evidence that supports this is that neurotypical companions at AIST performances often find it to be a challenging experience, as they are asked to relinquish all controlling behaviors and let the children interact freely and naturally (Mattaini, 2020, p. 51). During each AIST performance, social norms are constructed by the autistic children present, creating a unique culture at every show (Mattaini, 2020, p. 50).

Praises for Autistic Space

For all marginalized populations, one of the most fundamental prerequisites to successful enactment of deep societal improvement is the provision of space to gather. Positive interactions with peers build community connectedness, which can lead to political activism and eventually result in systemic change. In the disability community at large, the Independent Living movement was conceived at UC Berkeley, where Ed Roberts and several disabled classmates were forced to live together at the university hospital due to lack of accessible student housing. This group, dubbed the "Rolling Quads," spent their nights sequestered together strategizing about self-advocacy (Shapiro, 1994). Although the choice of venue was not on their terms, the fact remains that without all that shared time spent together in the same physical space, the Disability Rights movement would not have unfolded in the same fashion.

Likewise, online and offline Autistic Spaces foster autistic community, culture, and coalition building. Through collective identity, autistic people find a sense of belongingness and connectedness (Botha et al., 2022). Studies have shown that positive experiences with Autistic Spaces are correlated with increased self-worth and confidence (Bertilsdotter Rosqvist et al., 2013; Parsloe, 2015). Autistic people find valuable friendships with other autistic people online and at autistic retreats like Autscape. Some autistic people have stated that attending retreats "keeps them going year-round" (Bertilsdotter Rosqvist et al., 2015, p. 373). Autistic Space may be the first place that an autistic person is granted true control and autonomy. A supportive environment with like-minded peers also provides a platform for autistic people to ask

questions to better understand themselves and the world around them (Blume, 1997, pa. 8). Within this context, they can work to overcome the self-stigma imposed by near constant existance in Neurotypical Space. The experience of occupying Autistic Space — where sensory needs are accommodated and communication expecations and styles are modified — also demonstrates that there are alternatives to neurotypical conventions, bestowing hope for a more inclusive future.

Criticisms of Autistic Space

While Autistic Spaces aim to provide a haven for those who have been excluded from the default Neurotypical Spaces of the world, they should not be mistaken as entirely inclusive environments. When The New York Times reported on the surprising growth of autistic communities online in 1997, only 34.6% of U.S. households owned a computer (Bureau of Labor Statistics, 1999). Even more dramatically, only 17.9% of Black U.S. households owned a computer. Yet for households where someone had attended graduate school, 65.6% owned a computer (Bureau of Labor Statistics, 1999). These statistics point to an unbalanced demographic of internet users at the time when autistic culture was first growing online. To this day, marginalized racial and socioeconomic classes have disproportionality less reliable access to the internet (U.S. Census Bureau, 2017). Offline, a similar dynamic plays out for physical retreat type spaces, as the ability to attend depends on access to funding. While Autreat and Autscape do not discriminate on the basis of support needs, people with higher support needs may find themselves intentionally or incidentally excluded from other Autistic Spaces (Sinclair, 2010, Autistic Differences section).

Even for the autistic people who are welcomed into Autistic Space, high expectations may lead to dramatic disappointments. Sinclair (2010) warns that "being autistic in shared Autistic Space may be easier than being autistic in [Neurotypical] Space or in one's own personal space — or it may be harder… it simply has some different difficulties" (Sinclair, 2010, Being Autistic Together section). Some people enter an Autistic Space to find that that specific group is not the right fit for them, which can be very alienating and push them farther away from the community. Sinclair (2010) explains that ANI's early core group shared several characteristics that influenced their group dynamic and culture, as well as the boundaries implemented at Autreat. They all had a tendancy to be sensory-defensive rather than sensory seeking, and thus they developed "customs and rules that place greater emphasis on protecting people's boundaries than on allowing complete freedom of self-expression" which may be uncomfortably restrictive for "people who need intense stimulation, and/or who struggle with impulse control" (Sinclair, 2010, Introduction section).

While neurotypical people are not the target audience of Autistic Space, explicit exclusion of all neurotypical people has shown to have negative consequences. In response, some internet forums explicitly forbid "neurotypical-bashing" because it quickly devolves into a toxic mindset of "us vs. them" (Parsloe, 2015, p. 346). When accepted into Autistic Space, curious neurotypicals can ask questions and gain better insight into the needs of autistic people. Furthermore, by keeping the space open and accepting to everyone, a potential "ghettoizing" effect is reduced (Bertilsdotter Rosqvist et al., 2013, p. 377).

The Future of Autistic Space

Autistic Space and Neurotypical Space are both neuro-separate spaces, regardless of whether their occupying population includes people of other neurotypes (Seidmann, 2021). Autistic Spaces developed as havens and critical community building spaces for autistic people because Neurotypical Spaces tend to be architecturally discriminatory and socially unwelcoming. While the benefits of Autistic Space are undeniable, the positive experiences they nurture should not be restricted to digital space and specialty retreats, particularly because these are isolated bubbles not accessible to all autistic people. There is a potential path forward in creating "Neurodiverse Space" — a neuro-shared space — which is intentionally designed by and for people of all neurotypes, with explicit inclusion of those who have been historically excluded from Neurotypical Space.

For the successful realization of Neurodiverse Space, both the architectural and the social factors will need to be addressed (Davidson, 2010, p. 310). Even if a room is designed with the utmost consideration in reducing potentially triggering sensory stimuli, it may still feel like a hostile environment to some autistic people if they are still expected to engage in a stereotypical neurotypical manner. Changing social norms to accept autistic communication styles may seem like an insurmountable task, but it is not without precedent. It has become relatively commonplace to identify one's pronouns in an introduction — which many people do regardless of their status as trans or genderqueer, simply to normalize the practice of explicitly sharing pronouns. Although it is still far from being a ubiquitous ritual, the speed at which this shift has occurred

demonstrates how malleable cultural norms can be. It is possible to imagine a future where a variation of Autreat's red-yellow-green card system is more widely employed in public spaces, or it becomes customary for events unrelated to autism to have "no odor" and "no touching" policies.

Still, architectural accessibility regulations do not currently account for the needs of autistic people (Toronyi, 2021, p. 134). The built environment will require modifications to be less sensory aggressive and more inclusive. This is an area of research that is currently in a nascent stage, but it is swiftly showing signs of development with some promising projects on the horizon (Black et al., 2022, p. 1905; Tola et al., 2021). As this field gains traction and garners public attention, it will be critical that autistic people are autonomous stakeholders. One of the most crucial elements of both online and offline Autistic Space is that control rests with autistic people. If the responsibility for scope of sensory building upgrades rests with neurotypical people, Neurodiverse Spaces may be more akin to Places for Autistics or Autism Spaces than a new true neuro-shared space. As the disability rights rallying cry demands, "nothing about us without us!"

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