

Divergent Review: Consideration of Recent Autistic Research

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CNST-710-A.2023SP: Research and Program Evaluation

March 14, 2023

Author Note

I identify as autistic. It was certified during clinical sessions with a leading diagnostics professor in the region where I was residing. She called it a disorder, and businesses still refused low cost accommodation requests. I know it to be an inseparable part of the way I interface with my environment, so I am overjoyed to have found the recent surge in research coming out of predominately english speaking countries (other than the US) which is adding actual voices of the people being studied to the literature. Research designed and led by autistic people has long refuted prevailing wisdom in public discourse and clinical practice. The groundswell in recent years lends hope to the notion of reaching critical mass in terms of usurping pathologization of natural human neurodiversity as normative experience. Nihil de nobis sine nobis.

Divergent Review: Consideration of Recent Autistic Research

For this literature review the search was focused on journal articles which, when viewed together, begin to represent evidential support for the need to provide for the unique experiences and perceptions of a worldwide, cross-cultural, minority of autistic people in a variety of contexts and environments. We'll begin with findings from UK researchers Williams, Corbin & Hart (2023), who reported on improving sensory environments of in-patient facilities for children. Richdale et al. (2023) from Australia examined variability in sleep quality, fatigue, and social well-being on depression in adolescents and young adults. Finally, the thesis of a Japanese doctoral candidate who has studied in the USA, and more recently the UK, Umagami (2023) presents mixed method research exploring loneliness in autistic adults. These apparently disparate research topics will be bound together by my own experience and observations as an autistic person in academia. In downloading and reading representative portions of 38 articles rejected for this review I suffered the overwhelming influence of rote regurgitation of DSM criteria for Autism Spectrum Disorder. All 3 resources cited here focus instead on emerging emphasis in the literature regarding autistic inclusion, eschewing the inherently cis-normative, hetero-normative, white-normative, binary-gendered pathology paradigm in favor of assessing skills and needs with cultural humility. My overriding question was, how do I more effectively advocate for autistic needs to holders of authority in granting accommodation?

Williams, Corbin & Hart (2023) detail many factors influencing wellbeing in autistic children: social stigma, interpersonal victimization, bullying, intersectional issues relating to race and gender, parental behavior and wellbeing, and barriers to education, diagnostic, and support services, with emphasis on sensory environments. The authors go on to assert effective framing

of autism as being primarily shaped by sensory processing differences, even citing 1943 research from Kanner (once the popular namesake of this “disease”) in demonstration of such claims throughout the literature. With complex variability in responses to sensory stimuli, difficulty coordinating movement, muscle tone and postural differences, it is no wonder that disinterested observers might label such presentation as woefully divergent and needing intervention.

What is often missed in such short-sighted reductions are the impacts of experience beyond the 5 primary senses (sound, vision, smell, taste, touch): interoception, proprioception and vestibular systems. Harsh influences relating to pressure, temperature, thirst, pain, balance within space, and orientation of body parts to each other are overlooked without skillfully focused curiosity. Williams, Corbin & Hart (2023) explain that when we consider the mechanics of monotropism, observed as deep singularity of focus common to autistic people, the sensory load an autistic person can handle is considerably less than the loads that might easily be borne by people with more typical presentations. The authors’ most striking assertions were in relation to masking, or camouflage of behavior with socially acceptable alternatives to one’s natural embodiment. Links were drawn from masking behaviors in compliance with social demands to anxiety, depression, autistic burnout, and suicidality even in this research focused on children. On top of mood regulation and concentration difficulty, the need for extended rest and low stimulation environments going unmet was cited as frequent cause for overload. Interventions need to hold space for spiky skill sets resulting from imbalanced sensory impacts on autistics.

Richdale et al. (2023) dive right into the deep end, beginning their article with statistics showing 37% of autistic people, spanning ages from childhood to old age, with co-occurring depression diagnosis. This was linked directly to reduced quality of life, loneliness, and suicide

risk. Suicidal behavior is noted at higher levels in autistic populations, lending weight to the need for broad understanding of warning signs and presentation of autistic depression. With added high levels of insomnia, a known contributor to depression, autistic populations are especially well advised to focus on mediating impacts of insomnia, fatigue, and lacking social support. The authors also note that addressing insomnia before depression develops may act as protection against depression and development of other forms of psychological distress.

In the fourth chapter's Discussion section of the dissertation provided by Umagami (2023), entitled "*Trapped in a no-win situation*": *exploring the Unique Experiences of Loneliness in Autistic Adults*, we begin to see assertions boldly contradicting prevailing social stigma. The author asserts that autistic adults *do* desire social relationships and that they encounter barriers to building those relationships. The autistic imperative to retreat from social interaction is a necessary way to manage navigating, and recovering from, social spaces. One notable mitigating factor against loneliness was self-acceptance of an autistic identity, including consideration of redefining what socially comfortable means to a newly diagnosed person.

Here again, sensory environment struggles were noted as a barrier to social connections and indicative of increased loneliness. Anthropomorphism, or special connections with non-human agents, was suggested as a possible alleviating factor in autistic loneliness. Especially prominent was the divide separating reports of autistic people opting out of social interaction owing to sensory constraints from those commonly reported as perceived unwillingness to engage in social participation. The self-care invoked by an autistic person bowing out of a poorly accommodating context often gets interpreted as lacking desire to maintain a given social connection. Broad acceptance of autistic difference and knowledge of these implications may be

taken so far as to suggest that if the barriers to accepting those invitations were less foreboding, anyone in relationship with an exhausted autistic might know to offer help with taxing duties like chores, errands, travel, etc. in order to allow space for more readily accessible self-regulation, more freely accepted invitations, and thereby decreased loneliness and related suicidality in their autistic relations (Umagami, 2023).

When survival depends on accommodated needs, and little else, there is not much room for individual effort paying dividends in resolving related issues. Disabled people, and particularly autistic people, need freedom from the work of surviving *before* their efforts are evaluated on any par with ableist, neurotypically conforming, notions of normative behavior. With a disability so closely related to executive function, implications of reduced difficulty due to episodic memory failures, not to mention decreased negatively perceived autistic behaviors in general, questions are raised about why generally lacking social service supports are not prescribed along with every new autism diagnosis.

I embody a highly applicable skill set for clinical work with neurodivergent populations. In the reviewed literature, desire for increased social connection is often blocked by context or environmental factors. Sensory overload caused by typical building designs, and the ways sound echoes and reverberates through them, are frequently unavoidable, and yield entirely undesirable autistic experiences. Raising an alarm over the impact the active noise floor has on my own understanding of a conversation is only rarely met with action to move the conversation into a more inclusive environment. Incorporation of these findings into clinical practice is an almost trivial matter in spaces holding such concerns with care. Lived autistic experience matching recorded levels of othering affords evidential support in providing services for autistic people.

References

- Richdale, A. L., Chetcuti, L., Hayward, S. M., Abdullahi, I., Morris, E. M. J., & Lawson, L. P. (2023). The impact of sleep quality, fatigue and social well-being on depressive symptomatology in autistic older adolescents and young adults. *Autism Research*. <https://doi.org/10.1002/aur.2899>
- Umagami, K. (2023). *Towards a better understanding of loneliness in autistic adults: examining measurement tools and lived experiences* (Dr. Laura Crane, Ed.) [IOE, UCL's Faculty of Education and Society]
- Williams, G., Corbyn, J., & Hart, A. (2023). Improving the Sensory Environments of Mental Health in-patient Facilities for Autistic Children and Young People. *Child Care in Practice*, 29(1), 35–53. <https://doi.org/10.1080/13575279.2022.2126437>

Recommended Reading

- Milton, D. E. M. (2012). *On the ontological status of autism: The 'double empathy problem'*. *Disability & Society*, 27(6), 883-887
- Murray, D. (2020, February 17). *Monotropism -- An Interest Based Account of Autism*. London, UK: National Autistic Taskforce
<https://www.researchgate.net/publication/338127881>
- Pearson, A., & Rose, K. (2021). A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice. *Autism in Adulthood*, 3(1). <https://doi.org/10.1089/aut.2020.0043>
- Verhulst, I., MacLennan, K., Haffey, A., & Tavassoli, T. (2022). The Perceived Causal Relations Between Sensory Reactivity Differences and Anxiety Symptoms in Autistic Adults. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0018>
- Walker, N. (2021). *Neuroqueer Heresies: notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Fort Worth, TX: Autonomous Press, LLC
- White, R. C., & Remington, A. (2018). Object personification in autism: This paper will be very sad if you don't read it. *Autism*, 23(4), 1042–1045.
<https://doi.org/10.1177/1362361318793408>
- Yergeau, M. (2018). *Authoring Autism: on rhetoric and neurological queerness*. Durham: Duke University Press