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Neurodiversity and community-led rights-based movements: Barriers and opportunities for global research partnerships

We are a group of autism researchers and autistic self-advocates living and working within Europe, Asia, and Africa. In this Editorial, we initiate discussion on the topic of the neurodiversity movement and community-led rights-based movements within these contexts. We particularly reflect upon examples of the socio-cultural and political conditions that Asian and African movements need to engage with and respond to, plus share examples of indigenous scholarship and practice, drawing upon our individual perspectives and experiences as researchers and/or self-advocates. We do not intend to comprehensively represent the experiences of those within the communities under discussion, nor make points that are unique to these communities. We also acknowledge the sensitivity and complexity of these issues. This article is written in the spirit of curious and respectful conversation, and we do not claim to have all the answers.

The neurodiversity movement is a grassroots civil rights movement arising primarily in response to the marginalization of, and discrimination against, autistic people (Kapp et al., 2013; Shaw et al., 2022). Its proponents reject the default pathologisation of differences, which presumes that any deviation from the norm must be inferior or disadvantageous. This movement has been driven primarily by English-speaking White autistic people and allies living within pockets of Europe and North America (Botha & Gillespie-Lynch, 2022; Giwa Onaiwa, 2020; Kourti, 2022) and, as such, it reflects and responds to the socio-cultural and political circumstances and concerns of these communities. For example, it opposes intervention practices used within these communities that attempt to 'fix' autistic people in line with a normative agenda, and instead focuses on addressing the attitudes and environmental barriers that prevent autistic people from living a good life (Leadbitter et al., 2021; Shaw et al., 2021). It seeks to redress the dehumanisation of autistic people inflicted by research (Botha, 2021), redistribute power to autistic people through respectful partnerships and participatory methods (Pellicano & den Houting, 2022), and avoid reinforcing ableism through language (Bottema-Beutel et al., 2020). Whilst there are lively ongoing debates around issues of language and representation (e.g., Ellis, 2023; Kapp, 2023), the neurodiversity movement is bringing about significant positive shifts within these communities in public understanding and acceptance, and in research, policy, and practice.

The subject of community-led rights-based movements outside of Europe and North America has been given little attention, at least within English-language autism-centred academic discourse. The fundamental underlying values of the neurodiversity paradigm - equality, dignity, and respect for all people - could be said to be universally understood, with these core values recognised by many countries in national or international law, such as the United Nations Convention on the Rights of Persons with Disabilities (2006). The need for rights-based movements to ensure that these values are enshrined and enacted in relation to autistic people is also of relevance to all communities. The neurodiversity movement is one framework of understanding, form of activism, and set of practices that aims to do this. It may represent a movement that holds relevance and potential within some Asian and African communities (and there are already autistic self-advocates within these communities embracing this movement). However, the uncritical transportation and application of this wholesale framework from European and North American communities to those of Asia and

Africa must be avoided. Movements to decolonise knowledge production and global health research challenge the dominance and imposition of Euro-North American-centric knowledges, practices, and research paradigms (Chilisa, 2019; Kwete et al., 2022; Ndlovu-Gatsheni, 2015). The neurodiversity movement shares many of the same fundamental goals, namely: (1) reconstructing ingrained structures of power and privilege; (2) pushing back against biomedical model beliefs and practices; (3) raising the knowledges, truths and priorities of lived experiences to an equal status with insights generated from 'objective' scientific research; and (4) providing space for communities and individuals to identify their own concerns and find their own solutions (Botha, 2021; Chaudhuri et al., 2021; Gibson et al., 2021; Khan et al., 2021; Kwete et al., 2022).

Global research partnerships and multi-directional knowledge exchange are fundamentally important, particularly when they concern the urgent wellbeing needs of marginalised people. However, an approach that aligns with both neurodiversity and intellectual decolonisation agendas must acknowledge that Asian and African communities can have - and do have - their own theoretical frameworks, rights-based movements, and sets of practices that foreground indigenous philosophies and approaches (Goodley et al., 2019; Smith, 1999). These attend to the needs of communities' own socio-cultural, political, and linguistic conditions. For example, there is a body of uniquely South Asia scholarship within the context of disability studies that explores the intersection between disability/neurodivergence, family- and community-centred care, poverty, social class, gender, and neocolonialism (e.g., Addlakha, 2018; Staples, 2020; Vaidya, 2020). There is academic writing on disability rights movements in China (e.g., Huang, 2020), plus disability activism particular to Black communities (Schalk, 2022). These forms of scholarship and activism are often not noticed or valued by those in the West: they may look and sound different to white-dominated rights movements; they may take place on a small scale; and they may not be shared through the internet or in English (Milton, 2022; Schalk, 2022).

We now present examples of socio-cultural and political circumstances, drawing from the authors' experience within Ethiopia, India, and Hong Kong, and reflect upon how community-led, rights-based movements might – and do - address those circumstances. The neurodiversity movement has flourished within some Western communities because of the existence of communities of people with a shared diagnosis and identity, who have formed a common agenda and organised collective action. In Ethiopia, several factors (e.g., lack of autism knowledge, diagnostic services, and material resources) mean that families often only seek help when an autistic child has significant co-occurring intellectual, language or physical disabilities (Tekola et al., 2016). There are, therefore, fewer people who are diagnosed as autistic, and fewer still autistic self-advocates. In addition, in Ethiopia, there is a strong emphasis on interdependence, community, and family; recognition, inclusion and belonging within the local community is a primary concern (Abebe, 2019; Poluha, 2008). Identity is tied up in familial and community collective relationships and a movement focussed on the identity and rights of the individual might therefore seem socially and culturally unfamiliar. Family- and community-driven movements that address acceptance, inclusion and participation would be more aligned with cultures in Ethiopia and could address local social-cultural priorities. There are examples of such activism in practice. Zemi Yenus was a parent advocate based in Addis Ababa, Ethiopia, who practised radical acceptance of autistic children and campaigned successfully for their inclusion and participation within the local community (Yenus, 2012). Her work was firmly rooted in real-world local ways of doing, very visible within the local community and, in many ways, also well-aligned with neurodiversity-affirmative principles, even if that language was not used.

Within the context of India, there are autistic self-advocates, usually socio-economically privileged, educated in the West, and living within urban centres, who have built autistic social networks, accessed English-language neurodiversity-related discourse, and can see the potential of an India self-advocacy movement. However, there are socio-cultural barriers to kickstarting this movement. There

is stigma around autism that brings real world consequences for wellbeing, community inclusion, and livelihood (Divan et al., 2012). People with an obvious and visible disability may be treated with compassion, care, and charity, but kindness and understanding are not always extended to those with less immediately visible differences (Vaidya, 2020). This can make it difficult to be an openly autistic advocate. Moreover, within traditional Indian culture, identity and status are rooted in familial and community groupings (Staples, 2020; Vaidya, 2020). Stigma around neurodivergence, and its associated consequences, can therefore impact upon the whole family. A further consideration concerns language. Within some Western countries, access to a shared language has facilitated the development and dissemination of neurodiversity-informed thinking not only within and across countries, but also across academic, advocate, and lay communities. When Indian self-advocates and allies use neurodiversity-informed discourse, it sounds anglicised and can therefore be met with suspicion and rejection by the wider community. Together, these factors inhibit the formation of autistic communities and the ability to share alternative perspectives and fight for change. Sangath, an Indian not-for-profit organisation (Sangath, 2023), is attempting to address some of these factors by partnering with local self-advocates and an India-based design and innovation consultancy (Quicksand, 2023) to carry out a community engagement and participatory design process within Delhi and Goa. This work is in its early stages but aims to produce and disseminate digital and physical resources - in local languages and drawing upon locally familiar concepts – to improve the understanding, acceptance, and inclusion of autistic people.

A third example reflects upon socio-cultural and political circumstances within Hong Kong, an East Asian city and former British colony. Self-advocacy movements rely upon the political freedom to speak out against the status quo. In Hong Kong, political challenges render social changes particularly difficult to achieve. Tense relationships with China have made it risky for people of marginalized groups to speak out and engage in social movements. Particularly in countries under authoritarian regimes, democratic knowledge production practices that question power and aim to address inequalities, such as qualitative, inclusive, and participatory research, are perceived as inferior to traditional quantitative studies and are potentially subversive in a culture concerned with normality and conformity (Ho et al., 2018a). Chinese scholars and activists attempting to democratise research or conduct critical academic research have to exercise self-censorship and find their academic freedom compromised (Ho et al., 2018b). These factors make it increasingly difficult to engage in research or activism that goes against the grain, including that which challenges dominant pathology narratives about autism. Cultural values also influence attitudes towards autism. In Hong Kong, neoliberalism and the strive to become Asia's world city have created a competitive culture that places great emphasis on a child's academic performance. Hong Kong culture also strongly values social conformity. These socio-cultural norms can make it difficult, if not unrealistic, for parents to accept and celebrate their autistic child's difference and individual value (Kwok & Kwok, 2020) and most research and practice continue to adopt a deficit model and normative approaches to 'help' children fit in and achieve. The Red Swastika Society Tai Po Secondary School¹ has taken a brave and innovative approach to change this agenda by discarding a fixed rigid curriculum for an inclusive one that promotes differentiated, tailor-made learning, in recognition of the children's rights to inclusive education (Poon & Lin, 2011; Poon & Lin 2015). A small number of Hong Kong researchers have started to incorporate neurodiversity concepts in their work (e.g., Kwok & Kwok, 2020; Lam et al., 2021). The first author is an autistic self-advocate conducting research into autistic wellbeing and trying, in her own way, to advocate for better understanding and acceptance of autism through various means, including writing to a local newspaper to counteract the misrepresentation of autistic people (Cheng, 2018).

¹ There are cultural differences in the use of the word 'swastika' and its symbol. In Chinese and other cultures, it is a spiritual symbol denoting good fortune and infinity, and has no connection to Nazism (Thou, 2017)

To conclude, as the autism research field moves towards more respectful and equitable practices, there will be challenges along the way, especially when working across continents and communities. We present this discussion to reflect upon how the neurodiversity movement and other rights-based movements could and should engage with local circumstances to improve the lives of autistic people. Socio-cultural, political and language differences can easily impact upon international collaborations and impede research activity and improvements to practice. We need courage and integrity to engage in multi-directional conversations, to share our circumstances and perspectives but also to learn those of others; and to recognise and celebrate the shared values underpinning our work (Giwa Onaiwu, 2020; Kara, 2022).

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References

- Abebe, T. (2019). Reconceptualising children's agency as continuum and interdependence. *Social Sciences*, 8(3), 81. <https://doi.org/10.3390/socsci8030081>
- Addlakha, R. (2018). South Asia and disability studies: redefining boundaries and extending horizons. *Asia Pacific Journal of Education*, 38(1), 147-149, DOI: [10.1080/02188791.2017.1355883](https://doi.org/10.1080/02188791.2017.1355883)
- Botha, M. (2021). Academic, activist, or advocate? Angry, entangled, and emerging: A critical reflection on autism knowledge production. *Frontiers in Psychology*, 12, 727542. doi: [10.3389/fpsyg.2021.727542](https://doi.org/10.3389/fpsyg.2021.727542)
- Botha, M., & Gillespie-Lynch, K. (2022). Come as you are: Examining autistic identity development and the neurodiversity movement through an intersectional lens. *Human Development*, 66(2), 93–112. <https://doi.org/10.1159/000524123>
- Bottema-Beutel, K., Kapp, S.K., Lester, J.N., Sasson, N.J., & Hand, B.N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3(1), 18-29. <http://doi.org/10.1089/aut.2020.0014>
- Chaudhuri, M.M., Mkumba, L., Raveendran, Y., & Smith, R.D. (2021). Decolonising global health: beyond 'reformatory' roadmaps and towards decolonial thought. *BMJ Global Health*, 6, e006371. doi:10.1136/bmjgh-2021-006371
- Cheng, Y. (2018). *Rude and cold? Hong Kong's cruel myths about autism go against ideal of inclusive society*. South China Morning Post. Retrieved 4th February 2023 from: <https://www.scmp.com/comment/letters/article/2134483/rude-and-cold-hong-kongs-cruel-myths-about-autism-go-against-ideal>
- Chilisa, B. (2019). *Indigenous Research Methodologies, Second Edition*. Sage, Los Angeles.
- Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research*, 5(3), 190–200. <https://doi.org/10.1002/aur.1225>

- Ellis, J. (2023). Imagining neurodivergent futures from the belly of the identity machine: Neurodiversity, biosociality, and strategic essentialism. *Autism in Adulthood*. ahead of print <http://doi.org/10.1089/aut.2021.0075>
- Gibson, M.F., Sakamoto, I., & Monroe, H. (2021). *Decolonising Neurodiversity: Implications for Social Work Education*. Presentation at the CASWE-ACFTS Conference. Retrieved on 29th January 2023 from: <https://uwaterloo.ca/scholar/m23gibso/presentations>
- Giwa Onaiwu, M. (2020). “They don’t know, don’t show, or don’t care”: Autism’s White privilege problem. *Autism in Adulthood*, 2(4), 270–272. <https://doi.org/10.1089/aut.2020.0077>
- Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, 34(6), 972-997. DOI: 10.1080/09687599.2019.1566889
- Ho, P.S.Y., Kong, S., & Huang, Y.T. (2018a). Democratising qualitative research methods: Reflections on Hong Kong, Taiwan and China. *Qualitative Social Work*, 17, 469 - 481. <https://doi.org/10.1177/1473325018764133>
- Ho, P.S.Y., Jackson, S., Cao, S., & Kwok, C. (2018b). Sex With Chinese characteristics: Sexuality research in/on 21st-century China. *Journal of Sex Research*, 55(4-5), 486–521. <https://doi.org/10.1080/00224499.2018.1437593>
- Huang, S. (2020). International rights and local realities: Transnational allies of the disability rights movement in China. In A. C. Carey, J. M. Ostrove, & T. Fannon (Eds.), *Disability alliances and allies: Opportunities and challenges* (pp. 19-39). Emerald Publishing Limited, Bingley. <https://doi.org/10.1108/S1479-354720200000012004>
- Kapp, S.K. (2023). Profound concerns about “profound autism”: Dangers of severity scales and functioning labels for support needs. *Education Sciences*, 13(2), 106. <https://doi.org/10.3390/educsci13020106>
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59–71. <https://doi.org/10.1037/a0028353>
- Kara, H. (2022). *Indigenous research methods: Another reading list*. Blog post retrieved on 29th January 2023 from: <https://helenkara.com/2022/04/28/indigenous-research-methods-another-reading-list/>
- Khan, M., Abimbola, S., Aloudat, T., Capobianco, E., Hawkes, S., & Rahman-Shepherd, A. (2021). Decolonising global health in 2021: a roadmap to move from rhetoric to reform. *BMJ Global Health*, 6, e005604. doi:10.1136/ bmjgh-2021-005604
- Kourti, M. (2022). Autism, Race, Ethnicity and the Whiteness of the Neurodiversity Movement. Presentation at the Autscope Conference, Derbyshire, UK
- Kwete, X., Tang, K., Chen, L., Ren, R., Chen, Q., Wu, Z., Cai, Y., & Li, H. (2022). Decolonizing global health: what should be the target of this movement and where does it lead us? *Global Health Research & Policy*, 7, 3. <https://doi.org/10.1186/s41256-022-00237-3>

Kwok, K., & Kwok, D.K. (2020). More than comfort and discomfort: Emotion work of parenting children with autism in Hong Kong. *Children and Youth Services Review*, 118, 105456.
<https://doi.org/10.1016/j.childyouth.2020.105456>

Lam, G. Y. H., Sabnis, S., Migueliz Valcarlos, M., & Wolgemuth, J. R. (2021). A Critical review of academic literature constructing well-being in autistic adults. *Autism in Adulthood*, 3(1), 61–71.
<https://doi.org/10.1089/aut.2020.0053>

Leadbitter, K., Buckle, K.L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology*, 12, 635690. DOI: 10.3389/fpsyg.2021.635690

Milton, D., (2022). A personal account of neurodiversity, academia and activism. In D. Milton, & S. Ryan (Eds.), *The Routledge International Handbook of Critical Autism Studies* (1st ed.). Routledge.
<https://doi.org/10.4324/9781003056577>

Ndlovu-Gatsheni, S.J. (2015). Decoloniality as the future of Africa. *History Compass*, 13(10), 485-496.

Pellicano, L., & den Houting, J. (2022). Annual research review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychiatry & Psychology*, 63(4), 381-396.

Poluha, E. (2008). *The World of Boys and Girls in Rural and Urban Ethiopia*. Addis Ababa: Forum for Social Studies

Poon, F., & Lin, A. (2011). Creating a school program to cater to learner diversity: A dialogue between a school administrator and an academic. In M. R. Hawkins (Ed.), *Social justice language teacher education* (pp. 124-161). Bristol: Multilingual Matters.

Poon, F., & Lin, A. (2015). Building inclusive education from the ground up: The transformative experience of HKRSS Tai Po Secondary School (Hong Kong 2006–2013). In E. Rodríguez (Ed.), *Pedagogies and curriculums to (re)imagine public education: Transnational tales of hope and resistance* (pp. 141-155). Springer, Singapore. https://doi.org/10.1007/978-981-287-490-0_10

Quicksand (2023). *Quicksand; Design, Thinking and Innovation*. <http://quicksand.co.in/>

Sangath (2023). *Sangath: Healing Minds, Inspiring Lives*. <https://sangath.in/>

Schalk, S. (2022). *Black Disability Politics*. Duke University Press, USA.

Shaw, S.C.K., McCowan, S., Doherty, M., Grosjean, B., & Kinnear, M. (2021). The neurodiversity concept viewed through an autistic lens. *The Lancet Psychiatry*, 8(8), 654–655.
[https://doi.org/10.1016/S2215-0366\(21\)00247-9](https://doi.org/10.1016/S2215-0366(21)00247-9)

Shaw, S.C.K., Doherty, M., McCowan, S., & Eccles, J.A. (2022). Towards a neurodiversity-affirmative approach for an over-represented and under-recognised population: Autistic adults in outpatient psychiatry. *Journal of Autism and Developmental Disorders*, 52, 4200–4201.
<https://doi.org/10.1007/s10803-022-05670-4>

Smith, L.T. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples*. Zed Books, London.

Staples, J. (2020). 'Decolonising disability studies? Developing South Asia-specific approaches to understanding disability'. In N. Mehrotra (Ed.) *Disability studies in India: Interdisciplinary perspectives*. Springer, Singapore.

Tekola, B., Baheretibeb, Y., Roth, I., Tilahun, D., Fekadu, A., Hanlon, C., & Hoekstra, R.A. (2016). Challenges and opportunities to improve autism services in low-income countries: lessons from a situational analysis in Ethiopia. *Global mental health (Cambridge, England)*, 3, e21.
<https://doi.org/10.1017/gmh.2016.17>

Thou, C.K. (2017). *A Revisit - The Swastika: A Symbol of Buddhism or Nazism?* Buddhism and Daily Living – Mangala Vihara Dhamma Fellowship (MVDF) Blog. Retrieved 4th February 2023 from: <https://buddhismanddailyliving.wordpress.com/2017/02/18/a-revisit-the-swastika-%E5%8D%90-a-symbol-of-buddhism-or-nazism/>

United Nations (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved 29th January 2023 from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

Vaidya, S. (2020). Disorder, disability, difference: (Re)presenting autism in India. In N. Mehrotra (Ed.) *Disability studies in India: Interdisciplinary perspectives*. Springer, Singapore.
<https://doi.org/10.1007/978-981-15-2616-9>

Yenus, Z. (2012). Autism Activist: Zemi Yenus. Presentation for TEDx ADDIS retrieved on 29th January 2023 from: <https://www.youtube.com/watch?v=0k8QrkAd9TM>