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Walking the Epistemic Tightrope: Autism, Participation and Knowledge Exchange in Cuba

Presentation

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Abstract

This paper examines a disability knowledge exchange project between the UK and Cuba through the lens of epistemic justice, exploring how participation, knowledge, and emancipation are differently constructed across contexts. Drawing on critical disability studies and critical autism studies, it interrogates dominant Global North models of participation, which are often individualised, procedural, and centred on consultation, in contrast to Cuban approaches that are more deeply embedded within collective structures, disabled people's organisations, and longstanding traditions of grassroots mobilisation. Rather than framing these differences as a deficit, the paper highlights the strengths of Cuban participatory practice, particularly its capacity to sustain collective leadership and social inclusion under conditions of material constraint.

The paper identifies an "epistemic tightrope" encountered in working within the Cuban context, which differed from previous experiences of decolonial collaboration elsewhere. UK partners were frequently positioned as contributors of neurodiversity-informed knowledge, while Cuban partners held significant forms of practical, embodied, and organisational expertise that were not always explicitly recognised as knowledge. These dynamics reveal how epistemic injustice operates within cross-cultural collaboration, shaping whose knowledge is made visible, whose frameworks are privileged, and whose expertise is required to adapt.

Autism and sensory practice emerged as key sites for negotiating these tensions. Sensory environments sit at the intersection of individual and collective experience, making them a powerful means of rethinking participation. Through collaborative sensory practices, the project moves beyond abstract notions of inclusion towards the co-creation of environments that support diverse forms of engagement, wellbeing, and belonging. The paper argues that sensory practice not only disrupts hierarchies of knowledge but also enables more epistemically just forms of participation, bridging Global North and Global South perspectives, individual and collective experience, and diverse ways of knowing.

Reflections on what was going on

Within UK-based autism research and knowledge exchange, participation is often framed through a rights-based and increasingly neurodiversity-informed lens. There has been a significant shift towards centring autistic voice, co-production, and epistemic inclusion, positioning autistic people as experts in their own lives (Milton, 2012; Pellicano et al., 2014). This reflects a broader move away from deficit-orientated paradigms towards approaches that recognise neurological difference as a form of human diversity (Walker, 2021).

However, as has been noted within critical disability studies, participation in Global North contexts often remains individualised and procedural, frequently tied to consultation rather than structural transformation (Cooke & Kothari, 2001). Participation can become something that individuals are invited into, rather than something collectively produced or embedded within social systems.

In Cuba, participation takes a different configuration. It is culturally grounded, politically shaped, and materially constrained by resources. As a result, what counts as participation and who defines it differs significantly across contexts. Participation is deeply embedded within collective structures, particularly through disabled people's organisations that operate at scale and in close relationship with state systems. Leadership is enacted through these structures, and participation is less frequently articulated as individual voice and more as collective mobilisation and social embeddedness.

Importantly, this should not be read through a deficit lens. Cuban disability organisations demonstrate a pragmatic strength: an ability to mobilise, organise, and sustain participation under conditions of constraint. Participation here is not simply an abstract ideal but an ongoing, practical achievement, shaped by resourcefulness, improvisation, and long-standing collective infrastructures.

At the same time, working within this context revealed a more complex dynamic than is often captured in decolonial accounts of collaboration. There was, at times, an expectation that we would bring particular forms of knowledge around autism and disability, especially those associated with neurodiversity-informed practice. Yet alongside this, Cuban partners held significant forms of knowledge grounded in practice, organisation, and lived experience that were not always explicitly elevated or named as expertise.

This created a kind of epistemic tightrope. Rather than a straightforward redistribution of authority, knowledge exchange involved navigating when to offer, when to step back, and when to recognise forms of expertise that were present but differently articulated. This differs from some decolonial approaches I have been involved in such as Canada (turtle island) and New Zealand (Aotearoa), where there is often a more explicit emphasis on centring local knowledge systems. In this context, knowledge was frequently enacted rather than declared, embedded in practice rather than positioned as theory.

This prompted a critical reflection: to what extent are dominant Global North models of participation overly individualised? And conversely, to what extent might highly

structured collective models risk obscuring individual differences, particularly in the context of neurodivergence?

Autism became a particularly productive site for exploring these tensions. Within neurodiversity-informed frameworks, autism practice focuses on individual experience, sensory processing, and non-normative communication, challenging assumptions about what engagement “should” look like (Milton, 2012; Walker, 2021). Participation, in this framing, involves not only inclusion but also the transformation of environments and expectations to accommodate diverse ways of being.

At the same time, critical autism studies have highlighted that even progressive frameworks can reproduce exclusions if they fail to account for intersectionality, cultural context, and material conditions (Goodley et al., 2014). This is particularly relevant in international collaborations, where Global North epistemologies can be implicitly positioned as transferable or universal, rather than situated and partial.

In Cuba, autism and other forms of neurodivergence are being incorporated into an existing emancipatory infrastructure that were not originally designed with neurodivergence in mind. This creates both opportunities and tensions. On one hand, there is potential for access to collective organisation, leadership, and political participation at a scale that is often difficult to achieve in more fragmented systems. On the other hand, existing emancipatory norms may not fully accommodate the heterogeneity of autistic experience.

Rather than positioning these as competing models, our project became a space of conceptual negotiation. We moved away from treating participation and emancipation as abstract principles and instead understood them as enacted through practice through what people do together, how spaces are organised, and how difference is navigated in situ (Ingold, 2013).

Importantly, these were not framed as accommodations or a lessening of CAS an emancipatory ideas. Instead, they became sites of mutual learning. Cuban partners contributed extensive experience in collective organisation and grassroots mobilisation, while UK partners brought perspectives from neurodiversity and autism practice. What emerged was a genuinely co-constructed space in which assumptions about participation could be questioned and reworked.

This process also highlighted issues of epistemic injustice. As Fricker (2007) argues, certain forms of knowledge are systematically devalued, particularly those associated with marginalised groups. In the context of autism, this includes experiential, embodied, and non-verbal forms of knowledge (Milton, 2012). In cross-cultural collaborations, these dynamics are further complicated by geopolitical inequalities, raising questions about whose frameworks are prioritised, whose knowledge travels, and whose knowledge is required to adapt.

Our project sought and continues to seek to challenge these dynamics by resisting a unidirectional model of knowledge transfer. Cuba’s structured, pragmatic participatory approach offers forms of collective disability leadership that are often underdeveloped in Global North contexts, while neurodiversity-informed approaches raise important questions about difference within these collectives. Bringing these

perspectives into dialogue required ongoing reflexivity and a willingness to remain on that epistemic tightrope, rather than resolving it, and to unsettle taken-for-granted assumptions about participation.

Why sensory

Sensory practice emerged as a focus for collaboration within the project due to a strong reciprocal relationship between people and the environment in Cuba. There is a more widely understood recognition that environments can create barriers or enable participation across all levels of society due to how harsh the environment can be with limited resources due to the embargos.

Additionally sensory experiences sit at the intersection of the individual and the collective in that we have individual experiences but in shared environments. This makes it a powerful entry point for deeper collaborative Cuba – UK work.

For autistic and other neurodivergent individuals, sensory environments are not neutral. When sensory needs are not accounted for, environments can become overwhelming, dysregulating, and exclusionary, with direct implications for stress, anxiety, and overall wellbeing. Equally, when sensory environments are attuned through consideration of things such as noise, lighting, pace, and spatial arrangement, they can support regulation, comfort, and a greater capacity for engagement. In this sense, getting sensory practice “right” is not simply about access; it is closely tied to health, wellbeing, and the sustainability of participation over time.

Unlike more abstract concepts, sensory practice is immediately tangible. It can be explored through doing rather than solely through discussion, aligning with practice-based and embodied approaches to knowledge production (Ingold, 2013). This enables participation to be enacted in real time, rather than simply theorised.

In our project, sensory practice creates a shared ground for collaboration. It allowed us to move beyond theoretical discussion and instead engage in the practical work of shaping environments and activities that supported diverse forms of engagement. This also means that wellbeing is not treated as an outcome to be measured after the fact but as something actively produced through the design and engagement of spaces.

Crucially, sensory practice disrupts hierarchies of knowledge. It does not privilege verbal articulation or formal expertise, creating space for embodied, experiential, and non-verbal forms of knowledge to be recognised (Pink, 2015). This is particularly significant in inter-neurotype contexts, where differences in communication can otherwise become barriers to participation.

At the same time, sensory practice aligns with existing strengths in Cuban contexts, particularly in relation to improvisation and resourcefulness. Working within material constraints has necessitated creative and adaptive approaches, and sensory-focused practices can often be developed using locally available materials. This makes them both accessible and sustainable, while still having meaningful impacts on comfort, engagement, and wellbeing.

In this sense, sensory practice functions as a bridge connecting individual and collective experience, Global North and Global South perspectives, and different ways of knowing. It enables participation to be reimagined not simply as inclusion within existing structures but as the co-creation of environments in which diverse forms of engagement and forms of wellbeing are genuinely possible.

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