

## Participatory, Emancipatory, Activist Research

The most salient characteristic of activist research is the belief that it must go farther than knowledge production; it must create transformative action.

[\*From Theorizing in the Ivory Tower to Creating Change with the People: Activist Research as a Framework for Collaborative Action\*](#)

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## Activist Research as a Framework for Collaborative Action

It turns out that there is an emerging research framework—activist research—that is inclusive of multiple disciplines including educational research (Cushman, 1999; DeMeulenaere & Cann, 2013; Fine & Vanderslice, 1992; Knight, 2000; Malone, 2006; Nygreen, 2006), anthropology (Hale, 2006; Speed, 2006; Urla, & Helepololei, 2014) social movements and other social science research fields (Chatterton, Fuller, & Routledge, 2007; Choudry, 2014). A review of the theoretical frameworks, methodologies, findings, ethical issues, and challenges has allowed me to identify three characteristics that delineate activist researcher from other types of research: (1) combination of knowledge production and transformative action; (2) systematic multi-level collaboration; and (3) challenges to power.

The most salient characteristic of activist research is the belief that it must go farther than knowledge production; it must create transformative action. Knowledge production is the epitome of all research, even for studies that seek to expose inequities and call out oppressive systems and structures, but activist research goes further by committing to bringing about change with and for the participants (DeMulenaere & Cann, 2013; Hale, 2001, Fine & Vanderslice, 1992; Nygreen, 2006). Who is changed and how they are changed is a key aspect of activist research. DeMulenaere and Cann note that critical research is not necessarily activist research if it fails to include social transformative change, “at the spaces and sites of research...” (p. 557, 2013). They stress that if the only change that takes place is through reading of the published findings, then the study would not be considered activist research.

Hale contends that researchers who engage in cultural critique are committed to the research institution while activist researchers have dual commitments to the people and their political struggle and the academy (2006, p. 100). And it is this dual commitment that transforms the methodology beginning with the research topic and ending with the production of knowledge that is not only useful but transformative (Hale, 2001). Thus, activist research is an emerging research framework that shifts the focus from traditional knowledge production to commitment to working with others to produce transformative change. Traditional research methods such as ethnography, action research, and feminist research are situated within an activist research framework, leaving the means intact, but striving to change the ends.

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Activist research in education does not seek to transform the participant but to work with the participants to bring about transformative change in education policy, practices, structures, and institutions.

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Like cultural critique, research in education often fails to bring about social change (DeMeulenaere & Cann, 2013) and can reproduce myths of cultural and cognitive deficiency (Nygreen, 2006). Activist research uses transformative action to change educational practices, structures, and institutions. Nygreen notes that, “activist research is politically engaged: it assumes education is inherently political—rooted in and shaped by political process and relations of power—and that education change is a political struggle” (2006, p. 2). When education research is decontextualized from its political roots, the problem is often seen as the individual child, teacher, or urban community, and the goal becomes to fix them with the right intervention. Nygreen makes clear, however, “many of the contextual factors that shape teaching and learning in under-resourced urban schools are rooted in political-economic structures and practices that extend far beyond the impoverished neighborhoods of these schools” (p. 5). Activist research in education does not seek to transform the participant but to work with the participants to bring about transformative change in education policy, practices, structures, and institutions.

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Some might question if it is ethical to engage in research that seeks transformation as a result, implying that neutrality in research should remain the goal. An activist research framework dismisses the idea that education research can or should be neutral but instead assumes that it is inherently political. The third aspect of this framework includes challenges to power; thus, neutrality or objectivity is not possible if one engages in activist research. As mentioned earlier, transformative change is not about forcing or demanding that the participants themselves change. Educational research situated within an activist framework acknowledges that political structures create systems of oppression for low-income children and students of color, and seeks to change those through policy and practice. As with any lofty goal, there are limitations in desiring transformative change but that does not mean the pursuit is any less worthy than those that guide traditional research.

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Activist research embraces collaboration at every step of the research process. Hale (2001) notes beginning with the research question and objectives, activist research is organized collectively with the people who are subject to the conditions under study. He suggests that prior to the selection of a research design, the researcher must undergo “a process of dialogue and collective work with the subjects of study...” (p. 14). The goal is to ascertain what knowledge or problem the people want to gain or work toward solving. Instead of the researcher identifying the goals and the selecting participants who share the same goals, the objectives “coincide at least in part with what actors in the process under study think it is important to know and to understand” (p. 14).

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In traditional research, the researcher collects and analyzes the data. Even in qualitative participatory research that uses naturalistic forms of data collection, the researcher is often the sole interpreter of the data. Although we may ask our participants to review our analysis as a form of member checking, rarely do we have them collect, interpret, and analyze the data. In activist research the participants actively engage in data collection, interpretation and analysis.

Fine and Vanderslice state that the strategy of turning the participants into researcher created a major turning point for the staff, “by becoming researchers they changed their thinking about students, the community, and one another” (p. 210).

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The use of systematic multi-level collaboration was instrumental in creating the conditions needed to make restructuring the school a valid possibility.

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The final salient feature of activist research is the nexus between transformative action, systematic, multi-level collaboration, and challenges to power structures. As the researcher works with the participants to design a research project that leads to transformative action the power structure that limits and or oppresses those participants is challenged during the research process or with the research findings. Malone (2006) argues that her identity as an environmental education researcher and an environmental activist creates a “professional commitment and responsibility to support and empower community members to be active in social and environmental change” (p. 378). However, she notes that the traditional notion of empowerment, where the researcher makes the participant aware of their lack of power, is problematic. “Empowerment requires the appropriation of power for participants beyond knowledge of the source of their disempowerment” (p. 378).

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*Environmental education researchers as environmental activists*

In addition to challenging power, Fine and Vanderslice (1992) highlight how activist research works across multiple levels and sites of power and practice. They stress the importance of constructing theory at the school level (practice) and the district level (power):

Activist research involves the dialectical gathering and sharing of information across sites of power and practice, so that no one side of the institution is even engaged in an image of possibility without the rest of the system at least on deck to listen, and be part of the transformative process. To initiate activist research at the school-level alone could be irresponsible, in so far as we could easily “take” the schools toward images of possibility that the district, union, or state would never tolerate. Similarly, to initiate activist research at the district (state/union) level alone could yield unduly narrow images. Districts, as the seat of policy setting, monitoring and power, do not know, intimately, where they need to change, give up monitoring, and share power until they hear from schools—the site of practice. (Fine & Vanderslice, 1992, p. 205)

As the participant researchers negotiated ideas for school restructuring, they were sent to the district and as the district proposed ideas they were sent back to the school, thus the levels of power and practice worked together as new questions and new ideas surfaced. Challenges to power must be explicit and encompass multiple sites if they are to support the participants desire for transformative action.

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Activist research can serve as a foundation for developing critical conscious in youth or an outlet for engaging in critical civic practice, or both.

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In addition to exposing and challenging the political battles waged through education policy and reform efforts, activist research can provide youth with the experience needed to develop their critical consciousness and critical civic practice. Critical civic praxis is defined as “a process that develops critical consciousness and builds the capacity for young people to respond and change oppressive conditions in their environment” (Ginwright & Cammarota. 2007, p. 699). Based on the work of Freire, critical consciousness is achieved when the person realizes how oppression has limits their agency and ability to engage in resistance. Through critical consciousness, “the individual’s subjectivity transforms to foster new possibilities and capacities to see and act differently, proactively in the world—perceptions and actions geared toward promoting justice” (p. 699). Activist research can serve as a foundation for developing critical conscious in youth or an outlet for

engaging in critical civic practice, or both.

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To summarize, I have reviewed three salient characteristics of activist research: transformative action, systematic multi-level collaboration, and challenges to power.

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Perhaps it is best to think of activist research as a framework for conducting collaborative research that makes explicit challenges to power through transformative action. Activist research can employ many different research methods including ethnography, participatory action research, and community based research. Activist research can involve an academic researcher but does not require one, and the work happens in the community and is initiated by those working for their own liberation. Research that is critical, participatory, and social justice oriented is not automatically classified as activist research if it fails to create transformative action.

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If the goal of research is to change the world, then the framework for conducting research must change. Research that produces knowledge and awareness about oppression will not change the lived reality of the oppressed. Those who traditionally have research done to or for them, will not be changed by research articles that are only accessible in academic journals. Research that maintains the status quo will not be sufficient to improve the future of marginalized youth and adults. If change is the goal, the way we conceptualize research must be restructured to work for change. This does not mean that activist research is a cure to all that ails society and will fix every problem facing today's youth. Those who engage in activist research face challenges to reliability, validity, and acceptance from the larger research community (Hale, 2006) and although they strive for transformative action there is no guarantee that their work will bring about the outcomes they desire. Nonetheless, activist research provides a framework of possibilities for taking research out of halls of academia

and into the hands and hopes of the people.

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## Emancipatory Research

Perhaps the most important message arising from the emancipatory approach is the freedom of expression it offered to its participants.

[“I Don’t Feel Like a Gender, I Feel Like Myself”: Autistic Individuals Raised as Girls Exploring Gender Identity](#)

A recent editorial in the major international journal *Autism* called for researchers to ‘acknowledge the need to address the everyday realities of autism’ by engaging with autistic people at all steps of the research process, including – but not limited to – establishing directions for research (Pellicano et al. 2018, 82). This ‘partnering’ of researchers with autistic people, together with a recognition of potentially unequal power dynamics between researchers and research participants, is characterised as participatory research (Waltz 2009; Fletcher-Watson et al. 2018)

However, **meaningful inclusion of autistic voices in research tends to be the exception rather than the rule** (Chown et al. 2017). This is methodologically and epistemologically problematic (Milton and Bracher 2013). Thus, drawing on an emancipatory as well as a participatory framework for autism research can increase the inclusion of autistic voices and contribute to a revision of the non-autistic voices. For example, Waltz (2009) claims that the accuracy of the findings is likely to improve when increasing the involvement of the participants in the process, because their insight will provide important information about their needs, priorities, and challenges, amongst other parameters. Research produced in this way is therefore of ‘higher quality ... (and more) relevant and applicable’ (Jivraj et al. 2014, 782). This statement applies to autistic people, researchers, and participants. For example, autistic researchers suggest that well-being for an autistic person would mean adapting the lifestyle to an individual’s own personal needs and desires, rather than being forced to mimic behaviours that can be confusing to them (Milton and Bracher 2013), a finding that may come less easily to a non-autistic researcher. The insight of autistic people is of importance if the research community is to have access into autistic ways of thinking (MacLeod, Lewis, and Robertson 2014), which we, and others,

argue produces better research. As a result, **an emancipatory framework can provide crucial contributions to the current understanding of autism.**

*Doing it differently: emancipatory autism studies within a neurodiverse academic space*

an emancipatory approach refers to the inclusion of the participants within the research process in such a way that they benefit from it and it expresses their opinions and experiences.

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According to Stone and Priestley (1996) in one of the first descriptions of emancipatory approaches within disability research, an **emancipatory approach refers to the inclusion of the participants within the research process in such a way that they benefit from it and it expresses their opinions and experiences.** An emancipatory framework aims to challenge power structures within the research process (Stone and Priestley 1996) and aims for the equal representation of all ideas and beliefs. It is important to make space in our work for competing discourses as far as is possible.

**In emancipatory research the participants are not passive objects, but actively form the final product** (Waltz 2009). Emancipatory research, therefore, in contrast to participatory research, aims not only to record and present the issues of a particular group by involving them in the process, but also **to initiate changes that will work for the benefit of the people of the community involved in it** (Waltz 2009). Therefore, in order for a research process to be emancipatory, a number of criteria have to be met. The agreement upon this framework from the participants is the first important aspect, and engagement with the process for the whole research team from initial conceptualisation to the final product is considered crucial as a shared goal.

Emancipatory research has its roots in investigating marginalised social groups such as ethnic minorities and has been extensively used in feminist research (Stone and Priestly 1996). It also entered the field of disability and mental health research when people with disabilities started to request their rights in the decision-making processes that were related to them (Danieli and Woodhams 2005). Its presence in the field of autism research is, however, relatively new and sporadic (Milton and Bracher 2013; Woods et al. 2018). The nature of the social and communication difficulties of autistic people make researchers sceptical in terms of the ways they might be able to include autistic people in the current research process (Waltz 2009).

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Meanings of space are central in an emancipatory research practice.

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The innovative emancipatory design proved effective in giving voice to a group who have had little presence within the academic and medical large and inter- nationally based participant sample. This article highlights both the importance of approaching autism from an intersectional perspective that takes greater account of context, and the unique contributions that autistic individuals can make to current understandings within autism research.

This project endeavored to follow the main principles of emancipatory research, an approach akin to participatory re- search, whereby participants are active stakeholders within all aspects of the research process.<sup>19</sup> Throughout this study, participants were encouraged to be coresearchers, directing the research agenda, setting their own questions and commenting upon the analysis and findings. In this way, it was hoped that they would derive personal benefit from the research. We aimed not only to record and represent their experiences, but also through dissemination to initiate broader change for the benefit of the whole community.<sup>20</sup> Emancipatory research has only recently and very sporadically been used in the field of autism research. The social and communication difficulties associated with autistic individuals have caused researchers to be cautious, perhaps overly so, about consulting them, despite evidence from autistic and nonautistic researchers that this can be done effectively.<sup>23,24</sup> This relative absence of representation of autistic individuals deprives the research community of the insights of autistic people, and as Ne'eman has observed, have put autism behind other areas of disability self-advocacy.

[\*"I Don't Feel Like a Gender, I Feel Like Myself": Autistic Individuals Raised as Girls Exploring Gender Identity\*](#)

**We believe that participatory research should always be the baseline of any autism research project, whoever it is led by.** We agree that it is important to value the voice of the 'other' as a primary source of knowledge production rather than a secondary source within the context of power structures around epistemology.

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There are important benefits for research communities and participants alike in adopting an emancipatory research approach. Waltz has claimed that the accuracy of results is likely to improve by directly involving participants, because their insights can provide important information about their needs, priorities, and challenges, which may be overlooked by non-

disabled researchers. Likewise, autistic researcher Milton has reflected on the production of knowledge in autism studies and the fact that it is largely based on interpretations from non-autistic researchers, neglecting the autistic perspective. Yet the insights of autistic participants are of the utmost importance, if research communities are to have access to their unique ways of thinking and reflect their priorities. An emancipatory approach was also deemed appropriate since this research was inspired by the personal experiences of the first author, who is autistic. The first author met most of the participants online, through her journey to awareness of her own challenges.

However, in keeping with its emancipatory philosophy, **the negotiation of consent was treated as an ongoing consensual process rather than one event.** Through the dialogues both during and after the data collection and analysis, participants had multiple opportunities to raise questions or concerns.

*[“I Don’t Feel Like a Gender, I Feel Like Myself”: Autistic Individuals Raised as Girls Exploring Gender Identity](#)*

For research to be considered emancipatory, it is not sufficient that the research process and production are emancipatory, but **dissemination of the research findings should also fulfil this function.** Considering the dissemination of research findings, and that the findings themselves are produced in an ‘accessible’ format, should be a concern of any researcher who is doing emancipatory research.

*[Doing it differently: emancipatory autism studies within a neurodiverse academic space](#)*

More autistic-led, participatory, and emancipatory research is needed to increase our understanding of how best to break down the barriers that constrain opportunities for autistic individuals and to understand autism not as a biological deficit, but as a form of “neurological queerness.”

The data for this study were collected by the first author, endeavoring to comply with the principles of emancipatory research throughout. The initial conception of the project was influenced by the community from which the participants were recruited, and the first author was a part of the autism community before the beginning of the process. This was an important factor behind their motivation to participate and share sensitive areas of their lives, as many of them confirmed at various times.

**Perhaps the most important message arising from the emancipatory approach is the freedom of expression it offered to its participants.** Through this, notwithstanding the mentioned points, participants not only reflected upon these aspects of their identities, but also highlighted the need to go beyond them and see the “dancer” and the “artist.” Just as autism research risks neglecting the experiences of autistic women, research such as this study, with its focus on “identities of disadvantage,” potentially risks neglecting the

individual experience. Our participants ensured that this did not happen, and instead offered empowering accounts of the development and expression of their different identities, negative and positive.

[\*“I Don’t Feel Like a Gender, I Feel Like Myself”: Autistic Individuals Raised as Girls Exploring Gender Identity\*](#)

...it is important that we avoid essentialising autistic communities, voices, and views. It is important to recognise that people have different perspectives and approaches, which may all be equally valued and important. This suggests the importance of intersectional approaches for emancipatory autism research

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An arts-based approach can further the emancipatory model through Practice as research.

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## **Making the future together: Shaping autism research through meaningful participation**

We know that there is a gulf between the autism research that gets done and the research that people in the autism community want.

[\*Shaping Autism Research in the UK\*](#)

So, how do we go about building the community of practice we need to deliver these participatory methods? Some basics are already well known – for example, the importance of using respectful language to talk about autism and the need to create an enabling environment in which autistic people can contribute. Our series went beyond these basics, and [\*identified five topics which are essential parts of developing a more participatory and collaborative research model\*](#) in which autistic academics and autistic people in the community lead and / or partner in research projects.

[\*Shaping Autism Research in the UK\*](#)

- Respect – how to respectfully represent lived experience in research
- Authenticity – how autism communities can shape a research agenda
- Assumptions – best practice in autistic leadership and community advocacy

- Infrastructure – how to support and encourage autistic academics and activists
- Empathy – how to build effective working partnerships

Source: [Making the future together: Shaping autism research through meaningful participation – Sue Fletcher-Watson, Jon Adams, Kabie Brook, Tony Charman, Laura Crane, James Cusack, Susan Leekam, Damian Milton, Jeremy R Parr, Elizabeth Pellicano, 2019](#)

Participatory research methods connect researchers with relevant communities to achieve shared goals.

Participatory research enables meaningful input from autistic people in autism research. It is one important way to overcome barriers to effective translation and to ensure that research yields relevant benefits (Long et al., 2017).

By participatory research, we mean incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented (Cornwall and Jewkes, 1995). A key principle of participatory research is the recognition, and undermining, of the traditional power imbalance between researcher and participant (Nelson and Wright, 1995).

Another key feature of participatory research is inclusiveness including adapting the research environment, methodology and dissemination routes to permit the widest and most accessible engagement, or engagement from specific groups (e.g. non-speaking autistic people and people with additional intellectual disabilities – see Long and Clarkson, 2017). Participatory research is ethically informed by the values of the community, for example, in the selection of research questions and study objectives. Moreover, input from this community can improve the quality of research methods, contextualise findings within real-world settings and thereby enhance the translation of findings into practice (Carrington et al., 2016; Grinker et al., 2012; Parr, 2016; Parsons and Cobb, 2013). However, there is evidence that this engagement is not yet prevalent in the field.

[Making the future together: Shaping autism research through meaningful participation – Sue Fletcher-Watson, Jon Adams, Kabie Brook, Tony Charman, Laura Crane, James Cusack, Susan Leekam, Damian Milton, Jeremy R Parr, Elizabeth Pellicano, 2019](#)

The participatory approach is a crucial element in all future autism research. A body of literature exists on its principles, practices, and significance.<sup>26–33</sup> Anything that will truly help needs to be co-designed, developed, and evaluated with the involvement of autistic people. It has positive implications for the wider research agenda, in particular when established non-autistic autism researchers collaborate meaningfully with autistic scholars. We need approaches that value and center autistic voices, experiences, and expertise.

As participants, autistic people can correct misperceptions regarding concepts developed by autistic communities, researchers, and scholars, including neurodiversity and the neurodiversity paradigm,<sup>34–36</sup> the double empathy problem,<sup>37</sup> autistic inertia,<sup>38</sup> monotropism,<sup>39</sup> hyperfocus,<sup>40</sup> and autistic space.<sup>41</sup> We can offer insights on the

therapeutic and empowerment value of self-help activities and the positive aspects of engaging in intense interests, as well as introducing emerging ideas such as sensory trauma,<sup>42</sup> the co-creation of extended autistic families, and community-based mentoring.<sup>43</sup> These concepts have implications for clinical research, including early intervention,<sup>44</sup> and can lead research to new, more effective directions.

[Autistic Perspectives on the Future of Clinical Autism Research | Autism in Adulthood](#)

## Navigating Open Scholarship for Neurodivergent Researchers

The power structure that dominates psychology and social sciences is from white, male and able-bodied people who treat neurodivergent people as an *object* of the conversation, not the *subject*. As argued by Jackson (1998, p.8), “Each person is at once a subject for himself or herself – a *\_who\_* – and an object for others – a *what*. And though individuals speak, act, and work toward belonging to a world of others, they simultaneously strive to experience themselves as world makers”. Once we consider that scientists are human, and neurodivergent people can be included in this research, then we can co-create projects that allow us to discover the truth about diversity from different perspectives. This is more commonly discussed in qualitative research but rarely even considered in quantitative research. In addition, with different perspectives, there is an emphasis on moving away from the typical White, Educated, Industrial, Rich, Democratic (WEIRD) samples that account for 80% of study samples but only 12% of the world population, despite the fact that this movement does not acknowledge the neurodiversity movement or neurominorities (e.g. autistic, ADHD, dyslexic). In addition, there is a lack of patient involvement in how to make the research more likely to improve the quality of life of neurodivergent people. The need to address this issue and to ensure disabled and marginalised individuals are directly included in research and policy-making decisions that affect them can be expressed by the commonly used slogan “Nothing about us without us”. Emancipatory and/or participatory approaches such as participatory action research (e.g. Bertilsdotter-Rosqvist et al., 2019; Fletcher-Watson et al., 2018; Grant & Kara, 2021; Leadbitter et al., 2021; Strang et al., 2019; Strang et al., 2021) have considerable potential for facilitating this type of collective knowledge creation and driving social change that benefits neurodivergent people in areas that may contrast with many mainstream research approaches.

A recent movement has become important in education: open scholarship. This reflects the idea that knowledge of all kinds should be openly shared, transparent, rigorous, reproducible, replicable, accumulative, and inclusive (allowing for all knowledge systems). Open scholarship includes all activities that are not solely limited to research such as teaching and pedagogy. One key foundation of open scholarship is accessibility, a key facet that also belongs to the neurodiverse movement (e.g. Brown & Leigh, 2018; Brown et al., 2018). Accessibility and inclusion is where your content, activities and all their components are accessible to all people with disabilities, learning differences, mental health conditions or other health conditions that may affect their learning or engagement with the materials and activities, research activities, clinical training, and teaching (Victor et al., 2021a). It highlights the importance of embracing diversity and making everyone feel welcome and

valued (see [information sheet](#)). Discussions have been, however, scarce regarding not only how open scholarship can advance the neurodiverse movement, but also how it can benefit from it. It is thus a priority to build community to discuss how the neurodiversity movement can be included in open scholarship, as the lived experience of neurodivergent individuals (including encountered barriers) may help to enhance accessibility, allowing open scholarship to be truly open (Whitaker & Guest, 2020). This in turn may help to dismantle the harmful stereotypes about disabled individuals (Devendorf et al., 2021), providing more specific provisions for neurodivergent and/or disabled researchers (e.g. virtual conferences; see Levitis et al., 2021). Furthermore, including this population in academia will help promote work-life balance, by denormalising overwork and practices that lead to burnout.

There has been a recent shift towards the use of Universal Design for Learning (UDL) (i.e., an approach to teaching highlighting that academics/tutors should be proactively, not reactively, inclusive by making adjustments to their teaching without students having to disclose their disability to student disability services) in higher education (Burgstahler & Cory, 2010). UDL has several benefits: by offering a more flexible and inclusive practice, there is no need to disclose one's disability, irrespective of student status (Clouder et al., 2020). In addition, making the assumption about the student's intention based on your interpretation of their behaviour can be damaging for neurodivergent students' self-esteem. University staff should recognise the different manners in which students may communicate and contribute, whilst being open to collaborating with students to find suitable approaches. Put simply, it can be described as neurodiversity involvement for pedagogy.

[Navigating Open scholarship for neurodivergent researchers | FORRT – Framework for Open and Reproducible Research Training](#)

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