

The consequences of non-disclosure in higher education

Individuals who have a disability, chronic illness and/or neurodivergence can decide on whether or not they share that information and how much detail they provide about their conditions and needs, thus what they disclose. Disclosure statistics available from Higher Education Statistics Agency in the United Kingdom highlight that higher education still lags behind other sectors, when it comes to individuals disclosing their disabilities, chronic illnesses and/or neurodivergences. In research I have undertaken over the course of several years (e.g. Brown 2021, 2020a, 2020b), I have been able to show that there are largely three trends at play:

1. There are fewer disabled, chronically ill and/or neurodivergent people in academia as a sector than there are in other areas of life and work.
2. Many disabled, chronically ill and/or neurodivergent people drop out at different transition stages, such as at the level from undergraduate studies to postgraduate taught studies, or from postgraduate taught studies to postgraduate research studies, and then again from research studies to contractual positions.
3. Those disabled, chronically ill and/or neurodivergent people that do continue on this trajectory and stay within higher education, are less likely to disclose their conditions.

In reality, disclosure of needs to others is not an easy process for individuals, as they have to come to terms with personal experiences, potentially life-threatening diagnoses, and fear of stigmatisation. However, the consequences of non-disclosure are significant – for individuals and the sector, more widely. In my project "Disclosure dances in doctoral education", I specifically examined how doctoral students enact those two transition points from postgraduate taught studies to postgraduate research level and to contractual positions.

Many research participants were very clear about disclosure being a conscious and strategic choice, where they would tell their immediate supervisor(s), but nobody else, for example, although they themselves highlighted how problematic this specific disclosure is:

Non-disclosure and isolation

For people with disabilities, chronic illnesses and/or neurodivergences, both disclosing and non-disclosure are linked with a sense of isolation. Through the disclosure, they make themselves different and stand out in ways that they are not necessarily comfortable with. By not-disclosing, however, they feel isolated in their struggles with managing their symptoms and needs alongside the studies.

Non-disclosure and role models

Because so many people with disabilities, chronic illnesses and/or neurodivergences in academia stay hidden and unnoticed, the students follow into footsteps of invisibility and lack role models. Seeing a STEM (science, technology, engineering and mathematics) scientist in a wheelchair working in a lab would be enabling and empowering for students, as they could see themselves and that there are true routes through academia available to them.

The vicious circle of non-disclosure

The fewer academics and students disclose their needs, the less momentum there is for making environments accessible and inclusive as a matter of course because the "odd" adjustment can be put in place as and when needed. In turn, though, being made to stand

out leads to even higher levels of non-disclosure, and so we already find ourselves trapped in that vicious circle developing from non-disclosure.

Non-disclosure is therefore a much more profound issue than merely individuals not sharing their needs and accessibility concerns: it is a matter of social justice within education, but also a matter of self-preservation of the academy. The more significant the accessibility issues are in higher education, the more likely it is that we will lose an unfortunate large pool of exciting talent. The academy's priority therefore has to be the implementation of long-lasting policies and initiatives aimed at encouraging individuals to disclose. To this end, it may be helpful to consider disclosure as a cost-benefit analysis, where institutions and the sector need to revalue the benefits to such an extent that they outweigh the costs: access to support systems, opportunities to apply for special grants, funding of fellowships, and more equitable review processes would all be a welcome starting point.

References:

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