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Access Denied. 30 Years on, We Are Still Failing the Meaningful Inclusion of Neurodiverse Populations in Research

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Abstract: Over the past two decades, there has been a much-needed shift within research to ensure that neurodivergent populations, including people with intellectual disability, mental health or autism, have a voice and are given opportunities to speak up about the issues affecting them as experts by experience. Whilst inclusive research has become the norm, in practice, it remains unsatisfactory to get access to disabled people. Within this paper, three doctoral researchers discuss their shared experiences with gatekeepers in restricting access to neurodiverse participants. The paper draws attention to the potential dangers and consequences of making decisions based on evidence that limits the nature of participation. The article provides tips and recommendations for researchers and stakeholders, including policymakers, under three themes: culture, creativity and courage, on how they can help break down these barriers to ensure that those difficult-to-reach groups are able to have a voice in research.

Keywords: gatekeeping; disability; participatory research; inclusive research; autism; mental health

Introduction

Recruitment plays a critical role in research to enable collaboration with neurodivergent people, such as people living with an intellectual disability, autism and various mental health conditions. Therefore, the first-hand experiences of current recruitment practices from three doctoral students can add to our knowledge base and inform research students, supervisors, gatekeepers and policymakers about the barriers and opportunities of involving neurodivergent people. The article first clarifies our position on the terminology used in the studies. Then, the authors briefly introduce the three doctoral projects, the participants and the various recruitment practices leading to the shared experiences and recommendations under three themes: culture, creativity and courage.

A note on the terminologies used in the studies

The notion of correct or respectful terminology and language remains an ongoing challenge in the contested field of disability studies (Fitzgerald and Paterson 1995; Valeras 2010; Kinderman et al 2013; Shakespeare 2016; Gernsbacher 2017). We also know that participants have a range of preferred identifications outside of the conventional terms used by policies and professionals, primarily their given name, but also expressions such as partners, clients, members, autistic, Aspie, and neurodiverse, if they care about such theoretical debates about language at all (McDermott and Turk 2014; Kenny et al. 2016; Crocker and Smith 2019). Like many of our participants who would not consider their differences as a disability, we argue that expressions of equality and pragmatic sentiment will not solve the many issues facing disability studies as language does not mirror the world or passively reflect an objective reality (Halliday 2003; McClimens 2007). For this article, hidden cognitive and mental disability (in short, hidden disability) and neurodiverse individuals (or

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neurodiversity) are used interchangeably, including a broad range of behavioural, mental and neurological conditions such as intellectual disability, mental health conditions and autism. Whilst neurodiverse individuals are preferred by the majority of people living with such conditions, disability remains the official term used by legislation and policies such as the Equality Act 2010. The researchers believe that whilst these participants are habitually placed in different groups based on pathological motifs, experiences that are common to all members exist within this group of people. Therefore, it can be significant to explore needs and opportunities from a shared cultural experiences standpoint to find new pragmatic solutions to real-world issues.

The changing landscape of participation in disability research

Traditionally, autistic people and people with intellectual disabilities and mental health conditions have been 'researched on' and have not been "active participants in the creation of knowledge relating to their own experiences" (Milton and Bracher, 2013. P. 63, Hamilton et al. 2017). This has been challenged as leading to an understanding of people's experiences from non-disabled points of view, with services being developed around what other people think 'disabled people' need (Rudd and Hwang, 2021). Over the past three decades, there has been a much-needed shift in disability-related activities to ensure that people living with various conditions are given opportunities to speak up about the issues affecting them as experts by experience informing policies, strategies and the direction of services based on what people want (Department of Health 2001, 2009, 2023).

The developing interest in approaches where participants are partners rather than subjects has become prominent in research since the 1980s. There are a growing number of quality examples of participatory and inclusive research in the field that recognise that in order to ensure that research is relevant and meaningful, we need to focus on first-person experiences and put people with disability at the centre of inquiries (Esan et al. 2012; Milton and Bracher 2013; Bradbury-Jones & Taylor 2015; Turk et al., 2019; Danker et al. 2019; Roche et al, 2020). More recent works from scholars like Gunin and colleagues (2021), Marco-Crespo and others (2018), Wilson and colleagues (2020), Goldschmied Z (2020) and O'Brien (2019) go one step further, arguing that contemporary evidence must not only be collaborative with the participants but consider other signifiers when grouping people together beyond their medical diagnoses such as culture, age, local communities, and everyday activities. This 'contemporary research and experience' position builds on the facts that young and old living with various hidden mental or cognitive disabilities have a wide variety of competencies associated with their contextual knowledge of their local environment and contact with their communities.

Whilst the number of inclusive and participatory research has increased over the past three decades, there is enough literature to suggest there are still significant barriers restricting the involvement of neurodiverse people (McClimens and Allmark 2011, Frankena et al 2015). This paper argues with the sentiment of Atkinson and Walmsley (2010), Nind and Vinha (2014) and Walmsley and Johnson (2003) that the involvement of people with disabilities remains an area of research fraught with difficulties. One such area is the issue of gatekeepers denying access to participants, which will be explored in this paper.

Access to participants in research from neurodivergent communities

Gatekeepers can be defined as "…. individuals who have the power or influence to grant or refuse access to a field or research setting" (Berg and Lune, 2004, 218-219). Although an important aspect of the gatekeeping role is to protect participants who are considered more vulnerable from unsolicited contact from researchers (Walker et al. 2005, Crook et al 2016), supported by various policies and legislation like the Mental Capacity Act 2005, gatekeepers are also in the position to refuse access or adversely affect participant involvement from neurodiverse communities (McClimens 2008; Robson, 2011; McFadyen and Rankin, 2016; Egid et al, 2021). This has been particularly evident in research within particular communities, such as children and young people and people living with intellectual disabilities, autism or mental health conditions.

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The specific role that gatekeepers play in protecting access to neurodivergent adults and children, as outlined within these three doctoral research projects, is complex. Historically, gatekeepers have long been evident in many aspects of disabled people's lives. For example, gatekeepers are often managers working in settings such as schools, residential homes, and universities, with people who are seen as vulnerable in some way. There is a wide range of literature available on the topic of gatekeeping that discusses in great length the hierarchies or tiers of gatekeepers to be negotiated by researchers (Ware 2004; Kelly et al. 2007; Nind 2008, Ouellette-Kuntz et al. 2013; Whitlock et al. 2020).

This article adds to the rich field of recruiting potentially vulnerable participants and connecting ethical debates by revisiting what has positively changed and where we see the opportunities to improve this important aspect of research further. We believe that the topic of disabled people's involvement in research remains a high priority as we know that failed attempts to undertake research with neurodiverse populations due to gatekeepers restricting access have also led to gaining professionals', parents' and carers' views instead (Balen et al., 2006; Coyne, 2010). Whilst Patient and Public Involvement (PPI) has become a standard element of public funds, Sales and others (2021) warn us that PPI itself is an under-researched area. It remains open to debate on how to ensure that people can provide their views on what and how research should be carried out.

The perceived and real vulnerabilities of the participants in everyday life

On the one hand, a body of evidence has found autistic people and people with intellectual disabilities and or mental health problems to be at increased risk of negative life events and traumatic experiences such as financial difficulties, abuse, problems in employment, stigma, lack of acceptance and bullying (Howlin et al, 2004; Callanan 2010; Graetz, 2010; Billstedt, Gillberg and Gillberg 2011; Hoover, 2015; Camm-Crosbie et al. 2019; McLeod et al. 2019; McLeod, Meanwell and Haubaker, 2019; Wilson et al. 2023) which would make them potentially more vulnerable than other research participants. It is probably understandable, then, that gatekeepers and professionals tend to adopt the position of focusing on participants' vulnerability and protection as their primary role. Conversely, people with disabilities are also expected to demonstrate autonomy and independence in many aspects of life supported by current drives in policy, guidance and advocacy. Studies of quality of life for people with hidden disabilities are characterised by a lack of employment, further education, meaningful everyday activities, social relationships and dependence on families and carers as discussed by scholars like Howlin et al, 2004; Graetz, 2010; Gillberg et al. 2011 or Richman 2019.

To offer some examples, autistic students have reported the burdens associated with reporting their disabilities to obtain Disabled Students Allowance (DSA) funded support at universities and the subsequent burden associated with 'managing' their disability and support at university whilst communicating and advocating their needs (Goode, 2007; HEC 2020). People with intellectual disabilities have similarly reported their difficulties with self-advocacy whilst facing the hegemony of large non-profit organisations representing their rights (Mitchell 2006). Children's experiences of managing their mental health follow similar trends. Three in five (62%) young people did not receive any support for their mental health from their school, and almost 48% of young people were disciplined for their behaviour that was related to a mental health condition (Mind, 2021). Recent evidence suggests that a 15-year-old comprehension of what mental health is and how it is exhibited is multifaceted and complex (Wickström & Lindholm, 2020) with self-reporting of mental health issues is increasing, whilst the numbers of well-being and severe psychiatric diagnoses considered to be stable (Fattore et al. 2009; Petersen et al., 2010; Baxter et al., 2014). So, on the one hand, individuals are seen as personally responsible for 'managing' their own neurodiverse conditions, whilst there are increasing calls for their involvement in service development and research, but the services gatekeeping practices remain suboptimal with often denying access to research.

Listening to the voices of people living with hidden disabilities then is critical when trying to understand their lived experiences of joy, quality of life, inclusion, help-seeking behaviours and

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managing their own health and wellbeing. Learning from the participants through meaningful involvement in research is even more significant when our aim is to identify the skills, abilities and solutions for adaptive and positive actions which can assist people to effectively cope with the stressors and burdens of everyday life (Hellström & Beckman, 2021). After all, young and old are experts in their own lives, and their experiences need to be explored to ensure we fully understand the richness of their well-being practices, challenges, everyday practices, and lived experiences.

Background to the three PhD research and the recruitment of the participants

It is common among all these mental and cognitive conditions in the three doctoral works that participants have previously been defined as a 'highly neglected group', 'vulnerable population' and 'hard to reach' population in research (Preece, 2002; Beresford et al., 2005; Beadle-Brown et al. 2012). There are several explanations for this – for example, Milton and Bracher (2013) argue that a commonly held misconception is that autistic people cannot meaningfully participate in research. Macleod, Lewis and Robertson (2013) believe that this misconception may be rooted in difficulties with social, communication, sensory issues and mental health challenges associated with autism. Lack of capacity, communication problems and reduced cognitive abilities are often cited for people with intellectual disabilities (Thomson *et al.* 2014; Northway *et al.* 2015). Issues of consent and susceptibility commonly emerge in research with children (Coad and Evans, 2008).

Anita's ethnographic study explores the experiences of autistic people and people living with intellectual disabilities or mental health problems.

Anita's PhD research set out to explore the everyday life of people with hidden cognitive or mental disabilities. The design of the ethnography involved months-long collaboration with the participants and significant people in their lives, including carers, family members, service providers and professionals. Anita following their everyday activities altogether for over a year. Participants were central to the project to accommodate their needs and wishes. Anita is a learning disability nurse and social worker whose practice and research are in constant dialogue with the people themselves. The boundaries of gatekeeping roles and access to information were complex and often blurred, characteristic of ethnographic projects. Anita has followed convenience and snowball sampling recruitment practices relying on the gatekeepers, the networks of the gatekeepers, the participants and the connections of the participants. Data collection included direct observations, interviews and conversations with the participants and significant others, as well as the collection of artefacts, emails, photos and official documents.

Ellis's project is about the mental health experiences of autistic undergraduate university students.

Elli's PhD research discussed within this article sets out to examine the mental health experiences of autistic university students longitudinally and takes a participatory approach. The aim is to inform the development of a good practice guide for UK universities to help inform future services and support. At the beginning of the project, a group of autistic adults who were current or recent university students formed a Participatory Group to advise and guide the research, ensure that it was accessible and meet the needs of the autistic community. The first part of the research design is a survey hosted online that aims to seek the experiences of UK undergraduate autistic students. To recruit participants for the online longitudinal survey, contact was made with disability and/or wellbeing departments across 128 UK universities listed within the *What uni* league tables. A few additional universities known to the researcher have also been approached.

Bethans's research investigates the lived experiences of young people through their recovery in the community after being discharged from CAMHS.

Bethan's PhD research explores the journey of recovery of children and adolescents who have received support for their mental health conditions from inpatient and community services and how this influences their recovery. The aim is to understand community support for young people in order to improve services and influence future service provisions to support recovery. The first phase of the project, a consultation focus group, allowed participants to express their views and insights into

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how they would like to be recruited and have their views expressed. This inclusive approach allows researchers to understand and adapt to suit their needs and capture their voices. It was also envisioned to include participants in the entire research process and recruit young people from a variety of services. Bethan found that achieving an adequate number of participants in the proposed project has been difficult, further justifying the need for this paper.

Learning points and recommendations from the doctoral works

The three doctoral projects have covered a wide range of recruitment practices and populations considered to be vulnerable by traditional research and policy practices. The experiences and potential solutions are organised under three themes: culture, creativity and courage. Gatekeepers are any organisations or individuals who hold access to the neurodivergent population, including the potential participants and their families and carers.

Culture – Contacts, Responses and the Silent Bodies

The first difficulty faced by the researchers has been finding a specific named contact and/or contact details. This experience got more challenging with the size of the organisation and was worse for universities. The information available on websites was often inaccurate. Therefore, for Ellie, contact varied across the universities, with some being targeted to a specifically named contact, and where this was not available, contact was made with generic emails such as 'wellbeing@'. This process was time-consuming and frustrating. In Ellie's case, there was no response from 97 universities out of the 128 targeted institutions.

Bethan spent time on directories for councils, services and organisations within the region and beyond to locate contact details, which often meant a generic email address. Many such emails would bounce back due to the service being unavailable, the address not being up to date or the organisation not updating their details. Bethan also reached out to schools to recruit participants, with schools being the most predominant support networks within a young person's life and those in which they have the most contact. In Bethan's project, around 250 organisations were approached, including over 65 schools within the area. Typically, these would be emails directly to a reception or other relevant team. Only 14 organisations, including two schools, had any type of response, many of which said they could not assist.

In Anita's case, due to the significantly smaller numbers of organisations and a targeted culture, making contact was less problematic. As an ethnographic project, the study relied more on the ethical committee, professional networks, the gatekeepers of the services, parents and carers, as well as the availability of the participants. Initially, two professionals were approached who were well-known to the researcher. After agreeing to support the project, they either directly recruited the participants by sharing the relevant documentation or recommended the researcher to their contacts, starting the snowball effect. The project eventually recruited 65 people as gatekeepers, including the participants, promoted the project to other people and services. In Anita's case, no response or limited participation due to gatekeeping came about differently. There was a marked difference between recruiting people with mental health problems, their families and carers and involving autistic people or people with intellectual disabilities. People with intellectual disabilities, their families, and carers were the most forward coming in participating in research. People with autism and the organisations gatekeeping them were also open to participation, however, this group was markedly more fragmented. The hardest-to-reach population was people with mental health conditions. They were also the participants who often dropped out during the research.

Top 6 Tips for doctoral students and supervisors

1. After initial contact and email, aim to build rapport via a face-to-face approach, physically or virtually. Networking and budling trust remain a key ingredient to success.

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2. Help gatekeepers with ideas, well-prepared materials and a variety of sources, including style, delivery and formats.
3. Make the supervisors visible and available for the projects. Supervisors are there to nudge you and encourage you gently. Supervisors also add an extra layer of trust for the gatekeepers.
4. Have a plan 'B' for unexpected turns in the recruitment process. Be creative and do not rely on one method or your initial ideas. Build in extra time for adapting your recruitment practices.
5. Document and collate all organisations that you contact with their response. Do not forget that no response is as significant data and a type of response that carry important information.
6. Be creative in offering an incentive for the Gatekeepers. For example, Anita has offered voluntary work. Ellie, after initial difficulties in the first round of recruitment described within this article, organised a Webinar to discuss the mental health experiences of autistic university students and invited universities to attend. Several universities subsequently offered to promote the survey in its second attempt.

Courage - Ethical Committees, Rejection and the Missing Masses

A main issue for Anita and Bethan, and to a lesser extent, Ellie, has been the response and attitude of the ethical committees. In Ellie's case, although ethical approval was agreed promptly from the University of Warwick, four universities asked for specific ethical approval from their own institution's ethics committee, which was eventually granted by all universities. One university, even after the additional ethical approval, decided that they could not send the details of the study in targeted emails to autistic students due to GDPR. Within this same university, a decision for support was made by a senior manager but was later refused by a less senior manager. A second university asked for further details to gain specific ethical approval from their university and then did not respond further. The two remaining universities sent out targeted emails after ethical approval was gained from their institution, and an excellent response was gained.

For Anita, issues of ethical committees started much earlier. It took over five months just to pass the first gatekeeper, the two ethical committees of her former University, as the project crossed two Faculties. One Faculty did not feel confident in approving a project that included people from a potentially vulnerable population. The other committee did not appreciate the variety of participants and the theoretically unfamiliar underpinning of the project, namely semiotics. Amongst the many issues, the ethical committees suggested that an ethnographic approach was overwhelming for disabled people. They questioned the capacity of people with intellectual disabilities but not with autism or mental health to the extent that Anita, a registered learning disability nurse and social worker, was not allowed to explore participants' capacity to participate. The ethical committees also commented extensively on language, terminology, methodology and philosophical underpinning to 'protect a potentially vulnerable population'.

Bethan has also waited over five months for the project to be approved by the ethical committee due to two main reasons. First, the perceived heightened risk of children with mental health issues included in a project and Bethan's ability to work with them. Second, a break in the work of the committee and confusion in leadership postponed further the approval. The ethical committee, like in previous instances, also felt it appropriate to comment on the use of commas, numbering and semi-colons. Due to issues with gatekeepers in recruiting children, the project had to go through a second ethical approval process in order to include professionals as participants. This resulted in a further four-month delay in data collection due to similar reasons that we have already briefly explored. Altogether, Bethan has waited over 8 months to pass the first gatekeeper, the ethical committee.

Rejection is not only a characteristic of ethical committees but many other gatekeepers along the road. Whilst it remains mostly unknown why organisations reject assistance, a small number of gatekeepers have provided a reason. For Ellie's project, reasons were related to GDPR (6), University policy not to circulate research (3), being asked to take part in many research projects (3), being sent to another department for consideration but not actioned (3), lack of time (1), alternative contact but no response (1).

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In Anita's and Bethan's projects, vulnerability remained the most used excuse. From Bethan's research, we learnt that rejection was typically related to the organisations not working with under-18-year-olds or not working with young people 'anymore' or not with this type of mental health problem (discharged from CAMHS). Such responses from schools and community mental health services left Bethan and her supervisory team to wonder what organisations are working with these young people who require the most intensive support after their stay within an inpatient facility. Of the 14 organisations who responded at all, only a few made recommendations to contact other services they feel may be suited. Such contacts were followed up and were welcomed with the same rejections and ignorance.

Anita's project worked with people with different conditions and age ranges (intellectual disability, autism, mental health between the ages of 16 and 70), which made the project even easier target for the 'experts'. In our present fragmented world, where every condition and various age ranges have its own organisation, it seems to be an easy response to rejection. The separation and competition between various groups and their supporting bodies, often within the same 'broad condition' like Asperger Group and Autism Group, was visibly present. When organisations supported the project, many still insisted on their presence during focus groups or other data collection practices. In terms of the participants, there was a difference between people with mental health problems and autistic people or people with intellectual disabilities. The former were significantly more concerned about stigma and the potential negative consequences of participation, whilst the latter were generally proud and wanted to share their experiences.

Top 6 Recommendations for Gatekeepers

1. Have a clear path and policy, quality assurance protocol and a named person for research recruitment purposes with a can-do attitude.
2. Create a research culture by embedding the participation of employees in research in the organisational culture, activities and curriculum.
3. Promote inclusion via training and advocacy for staff and students led by disabled people.
4. Allow research students to have access to the audiences needed to fulfil their research. They passed the ethical committee and have an institution behind them.
5. Ensure that decision-makers have the relevant training and understanding of research guides and participation, including policies and legislation like the Mental Capacity Act.
6. Put processes in place that enable our neurodivergent population to decide for themselves about participation requests. Trust your clients, in this case, disabled people.

Creativity – resilience, flexibility and the Predicted Unpredictable

Ellie has sent an email to outline the research along with various promotional and information documents, together with a link and QR code so that participants could directly access the online survey independently of the gatekeepers. Be ready to contact your gatekeepers more than once. Most universities were initially contacted in May 2022, prior to the launch of an online survey in August of the same year. This was to ensure that adequate time is given should universities require further ethical approval from their own ethics board. This approach is also in line with recommendations that suggest early engagement with gatekeepers to minimise the potential of restricting access (Lennox et al 2005; McFadyen and Rankin, 2016; Egid et al., 2021;). Non-responders were followed up on two occasions during a five-month period. In Anita's case, the variety of documents created was enriched with an easy-read pack co-created with people with intellectual disabilities. After an initial email contact, a face-to-face meeting was always requested to build rapport and give gatekeepers and participants the opportunity to ask questions or just simply get to know the researcher. Phone calls and emails were attempted at least twice after initial contact before the researcher moved on to other informants. Adequate time was provided to appreciate that gatekeepers are busy people. Bethan also offered a variety of materials, including a poster, information sheet, and further information detailing the study. Bethan contacted organisations via email, telephone and

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face-to-face. Whilst Bethan, like Ellie and Anita, has sent emails, followed up on the requests and tried to build rapport, the response remained disappointing.

It was suggested in the initial email from Ellie that universities could promote through targeted emails or through inclusion into a newsletter or by displaying a promotional poster in communal areas. It should also be noted that participants were also recruited through other means, such as networks within charities such as Autistica or The National Autistic Society. These networks were much more open to sharing and supporting the recruitment of participants. Anita shares Ellie's experiences that whilst organisations, professionals, and the people themselves with the various conditions responded differently to the request to participate, non-profit organisations and self-advocacy groups were more open to research than official or professional bodies such as the NHS or Local Authorities. Once Anita passed the bureaucracy of the ethical committees, it was key to meet with the gatekeepers of the organisations and also with the individuals alone or in the presence of the gatekeepers. As the project was an ethnography involving the researcher participating in the everyday life of people with a disability, the project had access to various people connected to the participants, such as paid and non-paid carers, professionals, family members, lay people, and others with mental health problems, autism and or an intellectual disability through the activities of the primary research participant.

In all three projects, creativity was a key ingredient in the recruitment process and beyond. Creativity can mean expanding the circle of participants, creating additional materials, and developing new sampling strategies or widening our data collection methods. In Bethan's case, the focus group was expanded to interviews, a short survey and virtual data, whilst the group of participants had to change from children with mental health issues only to include carers and professionals. Anita remained flexible in recognising the opportunities as they arose on the field and accommodating the unanticipated and unexpected experiences. Data collection and the range of data types changed as participants introduced novel 'evidence' such as posters on the wall, club membership cards, emails, or comments of professionals on the research poster at a conference. Ellie has shown resilience and creativity in her second year of promoting the survey by organising a free webinar with autistic students and recent graduates to discuss their mental health experiences throughout the university and inviting all the contacts from her original mailing list. Several of the contacts have subsequently agreed to promote the survey in its second year, in 2023. Therefore, offering something in return, whether this be a training session, other voluntary work or some insights into the research, can be beneficial. If anywhere, here, in the attempt to find young people with mental health conditions accessing community services, autistic undergraduate students and people with hidden disabilities living their lives in the community show the nature of research: what we plan and where it takes us are often two different things in real-world research, removed from the comfort and misleading certainty of laboratories, clinician's rooms and fancy pie charts.

Top 6 Learning points for policymakers

1. Make mandatory training on the Mental Capacity Act (2005), GDPR and other guides with a significant effect on recruitment for members of ethical committees and other gatekeepers who manage access to potentially vulnerable people.
2. The government and relevant organisations should create and/or promote a site where research recruitment calls can be displayed.
3. Be a role model by promoting research through the participation of your employees and students and not only through the activity of research itself but also through the promotion of a few selected researchers and organisations.
4. Create a forum or department including a named person responsible for recruitment where researchers can get support if they are disadvantaged by gatekeepers potentially discriminating against people with disabilities.
5. Include evidence and statement of research support in REF and other metrics, asking organisations to submit statistics of requests for research received and their responses.

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6. Develop good practice guidance for gatekeepers to promote the meaningful involvement of disabled people.

Discussion

Whilst we believe all three researchers followed the best research recruitment practices as much as possible based on the literature, the guidance of the hosting institution and the voices of people with hidden disabilities, the results have been disappointing. Of the 128 UK universities that were contacted by Ellie, only 11 responded and agreed to promote the survey amongst their autistic students. Of these 11 organisations, some universities sent targeted emails to the students known to them with a formal diagnosis of autism, whilst others included an article in their newsletter or displayed a poster. The universities who agreed to send out targeted emails, by far, elicited the best response. For Bethan, only one large organisation and one smaller non-profit organisation prompted support after targeting over 250 potential gatekeepers. Anita has used her network to target gatekeepers which resulted in far the best responses but also much smaller numbers. Contact made via trusted networks elicited positive responses, whilst random targeting of organisations hardly brought any success or even hostility.

Recruitment of participants to take part in PhD research was problematic for all three research students despite several attempts to engage with appropriate gatekeepers. Gatekeepers within universities and organisations were in the position to enable access yet they mainly limited the opportunities for potential participants to make such a decision. Only a small number of gatekeepers gave reasons. The most frequent answer remained no response at all. No response remains particularly frustrating for doctoral students and supervisors and should be alarming for policymakers as it questions the available evidence and how much neurodivergent people are involved in offering solutions and setting directions. Some of the findings of these three projects correspond to earlier experiences, like McFadyen and Rankin (2006) who found that even after ethical approval was agreed upon, access was refused by gatekeepers. Being passed to colleagues in other departments or contact details being passed on to the researcher also have been reported previously by Nind (2008), who found tiers of gatekeepers to navigate.

Gatekeepers play a necessary role in protecting vulnerable people from potential harm, but this appears to be a contradiction within universities and organisations that have two primary roles: 1) to advance research and 2) to support the autonomy and voice of people living with a disability. This also appears to be counter-productive in an era when disabled students and people living with a disability in the community, when accessing services, feel under pressure to self-disclose and 'manage' their condition and support needs which is often an additional burden for people living with a disability.

McFadyen and Rankin (2016) followed up on the issue and investigated why gatekeepers refused access to vulnerable adolescents. They themed responses and found that those who were granted access were motivated for evidence-based practice, interested in research, knew about the study and had a positive attitude. Ellie's experiences certainly agree with this as one of the best responses and support came from one of the UK's top Russell groups and, indeed, one of the world's top research universities. All three projects found that gatekeepers, including the ethical committees, used similar reasons and assumptions for refusing access, such as the potential participants wishing not to take part, lack of understanding of the research, poor communication within the environment, inconvenience for the participants and organisations, protection of vulnerable people, professional jealousy, generally negative attitude, or the lack of doctoral training and qualification.

The researchers' experience suggests, based on hundreds of rejections without any explanations, that many other potentially unknown reasons remain for the lack of response, collaboration and support. The researchers urge high-profile gatekeepers and policymakers such as university leaders, public and professional bodies and national non-profit organisations to reconsider the current research practices and to step up for the rights of neurodivergent people participating in and creating research. We need further actions to ensure that people living with a hidden mental and cognitive

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disability have the right and the opportunity to decide about participation. We must continue to promote real-world research by shifting from a culture where a few self-prompted people act and speak up on behalf of the 'disabled' to the meaningful involvement of a wide range of disabled people.

Conclusion

The participation of neurodiverse people in research is important in ensuring that it is relevant, accessible and, crucially, that our understanding of their experiences is told by the people themselves living with an intellectual disability, mental health conditions or autism rather than by third-party observers only and their hand-picked representatives. Experiences gained from three PhD projects in recruiting participants with autism, intellectual disabilities and mental health conditions from UK universities, non-profit organisations and professional bodies showed that gatekeepers remain to play a significant role. Whilst the Mental Capacity Act (2005) promotes the active participation of disabled people and requires others to provide support and reasonable adjustments, if it is used at all, it is often applied to prevent and isolate rather than encourage and empower disabled people's participation. In conclusion, the three researchers' experiences question the quality of available evidence, our knowledge base and how well our policies and directions reflect disabled people's voices rather than the key gatekeepers' and their connected representatives' voices, ideals and positions. The researchers argue that unless we improve our recruitment practices and widen the access to potential participants, we must exercise caution in using 'evidence' in our practices and making large-scale and long-term decisions and policies about the life of people living with a hidden disability: intellectual disability, autism and mental health conditions.

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