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Volume 18

Issue 7 *Collaboration in higher education:  
Partnering with students, colleagues and  
external stakeholders*

Article 03

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2021

## Inclusive, multi-partner co-creation for the teaching of special educational needs and disabilities in higher education

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### Recommended Citation

Wright, E., Smith, R., Vernon, M., Wall, R., & White, L. (2021). Inclusive, multi-partner co-creation for the teaching of special educational needs and disabilities in higher education. *Journal of University Teaching & Learning Practice*, 18(7), 25-40. <https://doi.org/10.53761/1.18.7.3>

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# Inclusive, multi-partner co-creation for the teaching of special educational needs and disabilities in higher education

## Abstract

Co-creation of curriculum content is a growing priority across Higher Education and, while many projects stress the market benefits to institutions and students, this research instead focussed on promoting inclusion, social justice and anti-oppressive practice, with theoretical underpinnings in the social model of disability. This joint research project between staff and students at De Montfort University (DMU), Leicester, led to the co-creation of a Level 6 SEND module on the BA Education Studies programme. The co-designed research explores how the experiences of neurodivergent people, those with SEND, their families and practitioners, can inform teaching practices and module specifications at undergraduate level in Education Studies. Qualitative data, collected via questionnaires, focus groups and interviews with students, parents, practitioners and academics, revealed rich, diverse perspectives on the knowledge and understanding that future educators need, as well as the most inclusive methods for teaching and assessing that knowledge. The practice-based implications of the research included co-creation of a Level 6 SEND module which recognises value in 'non-professional' voices and embeds anti-oppressive practice in its design, delivery and assessment.

## Practitioner Notes

1. Educators need to know more about neurodiversity and developing inclusive environments for disabled and neurodivergent learners - but this does not necessarily mean needing to know more about individual SEND.
2. Stigma, especially around mental health, can mean appropriate support is not put in place for learners and the language used to talk to, and about, learners with SEND is often negative.
3. Collaborative research projects where students and staff can be candid and honest around their learning and communication styles, in order to meet each other's accessibility needs while co-producing, can improve the educational experience for both future educators and learners.
4. Inclusive (research) projects are essential to create inclusive curricula.
5. Widening the parameters, and departing from the traditional university submission formats for assessments, enables students to present their work in a way that showcases their strengths, while still being held to high standards for criticality and creativity.

## Keywords

Co-creation, social model of disability, neoliberalism, special educational needs and disabilities, higher education

## Introduction

Co-creation of curriculum content is a growing priority across Higher Education (HE) (Healy, Flint and Harrington, 2014; Willis and Gregory, 2016; Bell and Pahl, 2018), and this project employed co-creation to research and re-design the Special Educational Needs and Disabilities (SEND) module on the final year of an undergraduate Education Studies degree programme at a UK Higher Education Institution (HEI). After completing their degree, which covers historical, political and sociological aspects of education in the UK and internationally, many Education Studies graduates go on to teacher training, and the new module aims to address the growing concern amongst future educators and in-service teachers that they feel ill-equipped to teach disabled, autistic and neurodivergent children and children with SEND (Mintz, 2019; Robinson, 2017; Warnes, Done and Knowler, 2021).

While many projects stress co-creation's market benefits to institutions and students (Higher Education Academy, 2014; Willis and Gregory, 2016), this research focussed instead on promoting inclusion, social justice and anti-oppressive practice, with theoretical underpinnings in the social model of disability. To achieve this, a research team consisting of two lecturers on the Education Studies programme and three students – two from the Education Studies programme and another from a SALT (Speech and Language Therapy) course – was created. All members of the team had lived experience of disability, autism, neurodivergence and/or SEND. This disabled and neurodivergent team then designed qualitative research that drew specifically on the voices of those too often marginalised in research and made the objects, rather than the subjects, of educational knowledge and practice. Thus, we aimed to gather data through questionnaires and focus groups from a wide range of participants, including disabled students, their parents and the practitioners who work with them, as well as drawing on interviews with recognised specialists and on feedback from current students on the Education Studies programme. Our methodology, together with the horizontal structure of the research team itself, reflected the value we as a team placed on lived experience, viewing this as a form of expertise alongside that of traditional 'experts.' From this wealth of data, this paper focuses specifically on the findings from student, parent and practitioner questionnaires, supported by some preliminary findings from the focus groups, and includes some reflections on working collaboratively and the issues we encountered in terms of data collection and co-creation.

## Context

This research interprets the social model of disability as a movement towards social justice and proposes that there is a need to destabilise traditional power relations within academic research to further the emancipation of disabled and neurodivergent people and those with SEND (Liddiard et al., 2019). To attempt this destabilisation and promote a more inclusive approach, this co-designed research recognises not only the importance of collaboration between student researchers and their lecturers but also extends this notion of collaboration beyond the academy to explore the experiences of neurodivergent people, those with SEND, their families and practitioners. This meant that the research could explore forms of knowledge “often overlooked or undervalued by more traditional forms of academic research, including embodied, emotional and tacit ways of knowing and representing the world” (Bell and Pahl, 2018, p. 106) to ensure a socially just approach to supporting disabled, autistic and neurodivergent pupils in the education system.

This extended notion of collaboration between groups is underpinned by the social model of disability. Introduced to mainstream practitioners in the early 1980s (Oliver, 1983), the model

explains that people are not disabled by their impairments but by disabling barriers within society. Despite its history within academic and professional circles, the social model of disability has not led to policies which have adequately addressed these disabling barriers (Oliver, 2013; Barnes, 2019). As academics and students within HE, it is imperative to explore why, and to assess what barriers remain for disabled, neurodivergent or SEND children and young people in order to ensure that future educators become equipped with the knowledge and understanding to “contribute to the ongoing struggle for change” (Barnes, 2019, p. 26) and to the development of more inclusive learning and teaching approaches, through research by, with and for disabled people.

Our project aimed to operate as a site for an alternative form of knowledge production, drawing on expertise from within and without the academy and remaking ways in which research affects everyday life (Bell and Pahl, 2018), with the specific remit of understanding how the lived experience of neurodivergent people, those with SEND and their families, can inform teaching practices and module specifications at undergraduate level in Education Studies. The project proceeded with caution. When working with marginalised communities, Liddiard et al. (2019) note that to avoid a tokenistic approach to co-production, researchers must commit to believing that co-producers and participants “can and will shape your research, construct and challenge your ideas and bring their own ideas and agendas to the table” (p. 155). The co-creators also operated with a cautious awareness of neoliberalism’s ability to appropriate our practices so that the knowledge we have co-produced could become “diluted, repressed, or turned against those who produce them” (Bell and Pahl, 2018, p. 108).

Currently, HE in the UK is market-driven, encompassing a neo-liberal approach within its policies and marketisation, aiming to draw in new and increasing numbers of students. This move sets up a financial model of HE designed to increase the institution’s profit margin in order to participate in a cycle of attraction, ‘improvement’ and marketing, which is made possible through promoting metrics-driven quality assurance, often synonymised with ‘excellence’ (Maisuria and Cole, 2017). Neoliberalism, defined as deregulation and privatisation from the state in order to promote entrepreneurial values, has enabled HE to move from a public good to a commodity that trades. This, via a process of commercialisation – and thus cost allocation – has forced a divide between what is researched and what is practiced within HE (Coate, Barnett and Williams, 2001; Harvey, 2007; Maisuria and Cole, 2017). Therefore, rejecting a market-driven approach to co-creation allows for issues to be addressed which are of direct importance to people’s lives, instead of researching and collecting data to just form research ‘outputs’ (Morrish, 2017). Furthermore, by not choosing a market-driven approach, it allows for research to be conducted that is often overlooked and undervalued in more traditional forms of data collection (Bell and Pahl, 2018).

Co-creation has become very popular over the recent years in HEIs and is seen by students as a way to improve the student experience from ‘within’ and by HEIs as a way to engage with their students and also to earn more funding from the government via subsidiaries (Dollinger et al., 2014). When done in a meaningful way, co-creation can improve students’ experiences and improve interaction between students and their university (Dollinger et al., 2014). Co-creation can take many forms: for example, co-researching a university-wide study whereby students act as agents of change (Bovill, 2019). In this study, the role of the student as co-creator is similar to that of a co-researcher, in that all students involved have constructed the research methodology (including data collection tools), interviewed participants and led focus groups – as well as being paid the equivalent of their lecturers’ hourly rate to undertake this work. This is different from a usual co-production or collaboration project between students and lecturers, as students being equally compensated monetarily promotes equality between student researchers and lecturer researchers, a decision made possible through funding via an Advance HE Good Practice Grant. Even when roles and payment are equivalent, a

sense of parity can be difficult to achieve because students may go into these co-production projects with the preconceived notion that the lecturers automatically know what they want to do and how to do it (Symonds, 2021). However, equivalent payment, along with being actively encouraged to voice their ideas and, importantly, seeing their suggestions taken seriously and implemented, can give them the reassurance and confidence to become ‘full’ members of the group. Non-academic and non-professional participants on the project were also recompensed for their time, in the form of vouchers, to recognise the value of lived experience as a form of expertise.

Often, during co-creation projects where students are recruited as active participants, there can be a tendency to select the students who are always actively engaged and are high attaining (Bovill, 2019), which may mean disengaged or marginalised students still have their voices unheard. In this project, to avoid selecting student co-creators based on staff pre-conceptions, applicants were invited to submit statements (written or in another medium), which were marked against clear selection criteria by a selection panel consisting not only of the lecturers on the project but also of the Chair of the university’s society for neurodivergent students and a sabbatical officer from the Students’ Union. These statements were anonymised and the lecturer who had the applicants’ details did not have a say in grading their statements.

## Methodology

With the co-creation team in place, we met to discuss our ideas and priorities for the project. It was then that we collectively decided to re-design the existing ‘flawed’ SEND module, keeping those elements identified as good practice from our own and previous students’ evaluation of the module, as well as identifying areas that were missing or needed adaptation. It was here that we acknowledged the need for further input from marginalised voices beyond the team and designed a research project that enabled us to base our co-created module not only on our own combined expertise, but also on a qualitative empirical research study. This paper reports some initial findings from this research phase of the project, with the module design process that built on that research to be reported elsewhere as chapter in an upcoming Education Studies book.

Having identified the key groups whose voices needed to be included and a simple focus for the research – what they thought future educators needed to know and understand about SEND – we split into two groups, each with one lecturer and two students, to design and carry out the initial stages of the research, checking in regularly with the wider team and gaining institutional ethics approval as a single application in accordance with British Education Research Association (BERA) guidelines, with all participants giving informed consent. An overview of the research tools used across the project is included below (Table 1).

Table 1: An overview of research tools used

Research tool(s)	Groups	Participant numbers	Notes
Questionnaires	Neurodivergent/disabled students (current/previous)	16	The sixteen student respondents had all studied in further or higher education but reflected on their experiences across all levels of learning.
	Parents of neurodivergent/disabled students	4	The four parents who completed questionnaires had autistic and/or neurodivergent children and/or children with mental health conditions at various stages of formal diagnosis, across primary and secondary schools.
	Current teachers and teaching assistants	10	The ten current educational practitioners who completed questionnaires came from the primary, secondary and further education sectors; mainstream and specialist SEND schools were represented, and respondents' roles included Special Educational Needs Coordinator (SENCo), teaching assistant, specialist support lecturer and class teacher.
Focus groups	Neurodivergent/disabled students (current/ previous)	5	The focus groups were drawn from questionnaire respondents who were keen to discuss their responses further. Each of the three focus groups included participants from more than one of the groups studied.
	Parents of neurodivergent/disabled students	2	
	Current teachers and teaching assistants	2	
	Members of the research team (pilots)	5	
Individual interviews	Specialists in particular aspects of SEND	13	Interviewees included academics teaching on inclusive MA provision and on the National SENCo Award, expert support practitioners, specialist teachers and advisors on specific aspects of disability from early years to HE, social services practitioners, advocacy organisations, disability artists and the head of a specialist SEND school.
Reflective writing	Students studying the existing SEND module	10	All participants in the research team were involved in reflective writing in the post-research phase of the project.
	Members of the research team	5	

It is worth noting at this juncture that the research was conducted during the Covid-19 pandemic and a series of national and local lockdowns, which meant that all of our meetings, as well as our interviews and focus groups, took place using video conferencing software. Despite our fears that this could affect the quality of communication and, as a consequence, of the data obtained, we found working online to be a positive advantage in most cases. Online working allowed for the involvement of participants where anxiety, mobility or caring responsibilities would have made it difficult for them to attend in-person sessions. It also facilitated tools for inclusion, such as subtitling, time-outs, written question prompts and the use of written comments where social communication and turn-taking was challenging. In our own planning and discussions, it meant that we naturally made more use of interactive tools, such as shared documents, Padlets and Mentis, which we were all becoming adept in a way through the process of online teaching and learning. These tools helped us to work more collaboratively and less hierarchically, sharing ownership of processes and outcomes that might otherwise have been dominated by the person recording the discussions. On the other hand, we believe that the immediate stresses and challenges posed by the pandemic, which research suggests has disproportionately affected disabled people (Scope, 2020), may have been instrumental in the initial slow response to our callout for participants.

### ***Strand one: Principal data collection***

This portion of the research sought the expertise of disabled and neurodivergent students and alumni, their families and practitioners currently active in the field.

#### ***Questionnaires***

Questionnaires were drafted for each of the three groups employing free-text written responses. The option to respond in an alternative format (e.g., audio or video) was made available but no respondents took up that option. To ensure the inclusion of participants using accessibility software, questionnaires were initially distributed as editable Word documents and widely distributed through university societies. After a low response rate, however, we switched to an online form with the option to request a Word.docx copy, which yielded better results. The questions themselves focussed on recommendations for content, strategies and issues that future educators should learn about, and the individual's positive and negative experiences of educational inclusion. In line with our contention that these participants are 'experts by experience', the recommendations questions were presented first, encouraging participants to share their reflections and accumulated knowledge, rather than simply present their experiences for 'expert' analysis.

Questionnaire responses were thematically coded by the team, and it is principally these findings that are reported below, although some reference is made to later focus groups. As we coded, we also noted emerging themes that our questionnaire prompts had not given space to develop fully. These themes were then used to form the basis of our focus groups.

#### ***Focus groups***

Questionnaire respondents who had indicated their willingness to participate in further research were invited to participate in a one-hour online focus group. Those able to attend were organised into groups of two to four people based on related themes emerging from their questionnaire data, and questions were designed (while not breaching the confidentiality of their initial responses) to elicit further discussion of these themes. Consequently, the focus groups included participants from across the three groups originally surveyed. This was beneficial, because it avoided an echo-

chamber and allowed for alternative perspectives on the same issues to be heard, but also inevitable – we quickly discovered that many respondents belonged to more than one group.

The focus groups were led by our student co-creators and, in order to test our questions and build their confidence in running the sessions, we ran two pilot focus groups using the other co-creation team members as participants. This was valuable in ensuring the actual focus groups ran smoothly but also hugely beneficial in sharing our experiences as equals and reflecting on our shared knowledge. While the data is not used in our reported outcomes, it inevitably contributed to our framing of the eventual module.

### ***Strand two: Specialist interviews***

We quickly recognised that our co-creation group did not cover the range of SEND or the range of intersectional identities needed to ensure that the eventual module had a broad and inclusive base, and that voluntary participation in questionnaires would not necessarily plug these gaps. For example, our lived experience was heavily centred on specific learning difficulties, neurodiversity and mental health, with far less expertise in, for example, physical disability or visual and hearing impairment. We also wanted to benefit from the experiences of those who had already crafted inclusive HE provision. To this end we conducted a series of individual interviews with professionals selected because of their specific expertise. Personal and professional contacts and snowballing were used to identify these participants. These were semi-structured interviews; questions varied according to the interviewee's area of expertise but centred on the same key theme of what future educators need to know about SEND. These findings, referred to only briefly here, are to be reported in full elsewhere. This group also included a number of individuals who were themselves disabled, neurodivergent or had SEND, and it is important to recognise that many individuals are simultaneously experts by experience, by qualification and by profession. The decision to conduct separate interviews, rather than simply involving this group in the focus groups, was made in order to prevent the risk of other participants deferring to their views or lacking the confidence to express themselves freely.

### ***Strand three: Reflective writing***

As the project progressed, two additional data sources were introduced. The first gave students on the current iteration of the module, that we had now identified as 'flawed', the chance to share their thoughts about their changing perceptions of SEND, what they valued about the module and what they would have liked to have learned more about. All students participated in this reflective writing and were given the option to contribute their reflections to the research project. After the success of our pilot focus groups, it became clear that it was also important to record and consider our own experiences as co-creators. Consequently, as we entered the post-research, decision-making phase of the project, we each recorded and shared regular written and/or audio reflections. Mentioned briefly in our discussion here, these reflections are integral to our upcoming book chapter on our module-planning process.

## **Findings**

On analysing the data collected from the questionnaires, four emerging themes were identified: understandings of SEND, including misconceptions; language and communication; policies versus practices; and accessibility. This article will mainly present the findings from the questionnaires,



arranged thematically, with some preliminary findings from the focus group interviews also included.

### ***Understandings of SEND***

The single theme that cuts most clearly across all practitioner responses is the need to know each student well and to respond to them as a unique individual; in the words of one teaching assistant, staff must “find out what lights the spark ... there is a person behind the need.” This ethos led several respondents to point out that inclusion is not synonymous with integration into mainstream but is, rather, focussed on the best educational experience for that student. Several participants warned against making assumptions about students based on their diagnoses or initial presentation. When discussing effective teaching and support strategies, this approach translated into a process of observation, action and reflection that correlates closely with the “assess, plan, do, review” cycle advocated in the SEND Code of Practice (Department for Education and Department of Health, 2015). It was repeatedly highlighted that new educators should understand that this person-centred approach should be collaborative, drawing on the expertise of students’ families and external specialist practitioners, and appreciating the importance of implementing recommendations based on this expertise. In the case of further education, there was greater recognition of the student as an expert on their own needs and on the strategies that are effective for them. Students in the research project similarly felt that knowing and understanding students as individuals was key. When asked to identify what examples of good practice they felt would be beneficial for new educators to know about, students’ suggestions included: adapting resources, finding alternative ways of communicating, getting to know students and their special interests, recognising individual needs and directly asking students for input, and increased autonomy for learners.

Despite this clear focus on the individual, most respondents also felt it was vital for new educators to learn the characteristics of the different SEND that they are likely to encounter. Alongside knowledge of different SEND, most practitioners argued that there was a need to learn a range of specific support strategies, which they stated had been very limited in their Initial Teacher Training (ITT). Educators valued Continuing Professional Development (CPD), where available, to address these knowledge gaps and had found such training far more useful when student and parent voices were incorporated. The feeling of not having received sufficient training on SEND was, however, common, with the notable exception of the two further education lecturers, each of whom had undertaken specialist qualifications for their roles as support lecturers. The very existence of this specialist teacher role in further education was in clear contrast to the experiences of educators in mainstream schools, who noted a concerning distinction between teaching, on the one hand, and support on the other, which led to teachers focussing on students without a diagnosed SEND, while support staff were made responsible for those who arguably needed the most skilled provision. They argued that new educators should be taught that ‘every teacher is a SEND teacher.’

Students and parents also felt it was important that neurodiversity should be taught and discussed in educational environments. Student respondents believed that if more neurotypical students and educators were educated in the field of SEND and neurodiversity, school experiences and educational environments would become more positive and inclusive. Having well-educated teachers in the field of neurodiversity can help in producing an inclusive environment for all learners. Participants felt the urge to tell educators to “please try to be understanding, please don’t get angry” and that “a little bit of patience goes a long way.” As well as educating teachers about neurodiversity, the student participants also mentioned that neurotypical students learning about neurodiversity would also be of benefit as that can reduce friction or misunderstandings between students about learning differences. This need to educate other pupils was also echoed by the parent

participants. Parents felt that understanding the individual child was important to developing an appreciation that, as one parent put it, “one rule is not for all”, but echoed practitioners’ feelings that alongside this individual understanding, there did need to be a more general understanding of SEND and neurodiversity.

Whilst not the focus of this paper, it is important to note that whilst practitioners, parents and students identified a need for educators to know about specific SEND, this contrasts with the consensus among the specialists interviewed. Most of the specialists argued that, since this information is readily available and changes frequently, it is more important to learn transferable principles and approaches. Their responses indicate a number of different ways of structuring this content; for some, this would be by specific diagnosis, while others felt that the four areas of need set out in the SEND Code of Practice (Department for Education and Department of Health, 2015) would be a more effective framework. Several respondents also mentioned language and communication as a key area of knowledge underpinning all effective SEND practice. The research team felt these differences in responses between specialist practitioners, and students and parents may be because the specialists are aware of the constraints placed on educators by policy and practice and were thus concerned with the most efficient use of educators’ time.

### ***Policies versus practice***

When discussing the challenges they faced in their roles, teachers made clear that these principally arose from insufficient funding, data-focussed education policy and unsustainable workloads, which were seen as working against the student-centred approach they all advocated. This raises interesting questions for the newly revised Education Studies module in terms of how to balance teaching excellence in inclusive practice with preparing new educators for supporting the needs of students in the real contexts they are shortly to encounter. Despite the challenges they experienced, all educators were able to cite examples of excellent practice. These included: curricular adaptation; inclusion of students with SEND in extra-curricular activities, which should also include roles of responsibility; joint projects between SEND and mainstream schools; incorporation of arts, cultural and sporting organisations; holistic transition programmes; work experience; active learning outside of the classroom; and collaborative work between curriculum teams, specialist support (internal and external), families and students.

These examples of good practice did not appear to reflect the experiences of the students and parents in our research. The inflexibility of school systems and policies – particularly regarding behaviour and attendance – was a clear theme that emerged across the majority of parent responses. Parents felt that flexibility around routines, to allow for practices important to the child, would reduce distress. In addition, routines that allowed for flexible timings to the school day and flexible attendance policies were felt to be important in supporting children to attend either from home or to attend later in the day following a challenging night or morning. Inflexible behaviour and uniform policies were also noted as causing a challenge to children and their parents, with little regard given to seating arrangements and sensory issues with the materials of school uniforms. Our preliminary findings from the focus groups suggest that even where policies did follow elements of good practice, such as creating learning plans with the SENCo, parent and child, these were not then put into practice in the classroom. In light of the challenges parents felt that they had faced in ensuring a positive educational experience for their children, they were also asked to identify what they felt would be a good practice response which would be important for future educators to know, in order that they might integrate this into their practice. The suggestions from parents included: ‘hidden’ disability workshops; positive reinforcement; staff spending time building relationships with children so they know them well and their successes can be recognised and celebrated; relaxation

of clothing, uniform and footwear policies; changes to the school day timings; having an online alternative for days when attending school in person is too overwhelming; reducing stimulation in the school environment including consideration of lighting; flexibility to move seats; and staff being aware that an autistic child may not always use the ‘correct’ language or terminology to communicate distress so teachers should be trained to detect the body language of distress before a crisis point is reached. Practical strategies of this kind are important to share with future educators who will have to face the ‘mismatch’ between policy and practice in their new roles. Practitioners were particularly keen that students on the Education Studies course should understand the challenges faced by teachers and support workers who attempt inclusive practice in normative environments, developing a realistic outlook that allows them to push for and create change while hopefully avoiding complete disillusionment and ‘burnout.’

These issues with policies and practices were echoed by student participants, with the majority of questionnaire respondents citing inflexible teaching practice into which they were expected to fit or be subjected to behaviour management interventions. One student reported that their teacher’s practice was so inflexible that they “expected all students to act the same, and any deviation from that was insubordination resulting in detention.” Preliminary findings from our focus groups with students seem to suggest that stigma and a lack of understanding can mean that policy is not put into practice. Students particularly highlighted a disconnect between mental health support policies and what was practiced in HEIs, stating that “they like to say that they do it, but it’s not there in reality.” As a research team, we found it distressing to hear of some of the student participants’ experiences throughout their time in education, though they often mirrored our own learning experiences.

### ***Accessibility***

Themes of mental health awareness, particularly in relation to struggles with accessing support services, were a recurring topic of concern in the student questionnaires. Participants had told us that outdated notions of mental health were still weaponised against them to discredit any requests for support they needed – and are entitled to under the SEND Code of Practice (Department for Education and Department of Health, 2015). One of the parents in the focus group echoed this stigma around mental health in education settings stating, “that’s the biggest thing that needs to change.” Student respondents also felt it was important for educators to have better awareness about what support is available and that education settings should have a variety of support available. Parents echoed concerns around access to support, although this was more focussed around delays in diagnosis and the support offered to their children during this period of waiting – sometimes for considerable lengths of times – for diagnosis and then, treatment. Parents felt that whilst waiting for these diagnoses, it was important for practitioners to liaise with families to draw on their expertise in light of what families already know about their child’s triggers and the techniques that do or do not work with their child – including supportive routines, and medical information.

### ***Language and communication***

Communication was another common theme that emerged from the research, most markedly from the student questionnaires. Students felt that the way in which sensitive information was transferred from professionals to classroom teachers was not effective in helping them with their educational needs. Another concern from students about communication was that often students would be “singled out” in public which caused them embarrassment. Students told us that some educators would make their educational differences known in public and some found that experience distressing. The ways in which educators and neurodivergent learners communicate about their educational differences, and the language used when discussing difficulties, was raised as generally

negative. Parents echoed this discontent with language use and all parents who completed questionnaires raised issues with the language used to identify their children and/or their children's traits, with the majority stating that language used to describe their children's traits was negative. One parent noted, "I don't recall positive feedback that doesn't have 'But' at the end of it" and another parent noted that tone was important, both in terms of the tone of voice teachers used with pupils and also that teachers needed to recognise that the tone of voice a child might be using can convey information about how they are feeling, which should be understood rather than punished. Interestingly, reflective feedback from students on the current 'flawed' module stated that they understood the importance of using inclusive language far more fully when it was presented with a clear rationale, rather than simply as a rule to follow. Incorporating young people's emotional responses to different language around SEND may be very effective in this regard.

## **Responses to the data**

The findings included here offer a snapshot of a rich and extensive dataset. For the student co-creators in particular, working on our first larger research project, facing such a mass of data felt overwhelming. For all of us, as insider researchers, the first response to that data was emotional, rather than analytical, because it is a topic that concerns us also on a personal level.

The consensus established from the questionnaires of students who are disabled, neurodivergent or have SEND – people like us – is that education has been difficult. They described feelings of being left out and patronised, while simultaneously being held to normative, default standards. The students on the project expressed that their SEND needs have often been falsely correlated with their intelligence and that they have been recommended to complete foundation level papers, spoken to loudly and slowly, or in fact labelled as 'slow.' They describe support determined or recommended by others to be, in some instances, detrimental to their learning and mental health.

It is empowering to be able to respond to this emotional onslaught by taking action, however small, to change these experiences for the future. Bringing together this lived experience through the collaborative research highlighted key shared demands that can be incorporated in practical ways into the new revised module: the need for awareness for SEND that truly represents differences but that does not teach segregation or alienation; the right to be listened to by educators so that they may understand their true needs and what their differences entail; and that these educators should have valid knowledge around how to provide support that meets those needs.

All of these basic demands coalesce around a core ethos of understanding difference, and welcoming it with collaborative, personalised practice. When interviewing professionals and surveying parents, we found a similar pattern. There was a lot of emphasis around person-centred practice and explanations of how practices cannot always be transferable. Inclusive practitioners discussed working *with* those with lived experiences of SEND, changing themselves as practitioners to best fit their students' needs, and about using multiple formats for communication and delivery. This Universal Design approach (Capp, 2017) does not only support learners with SEND. In their reflective writing, students on the existing 'flawed' module, many of whom are neurotypical, non-disabled and do not have an identified SEND, nevertheless valued an open, flexible approach where, for example, they could complete their assessed and in-class work using a variety of media (written, visual, verbal, etc.).

While it is impossible to detail here all of the ways in which the research data has been used in the construction of the revised new module, an instructive example is the new assessment structure. The proposed assessments (detailed below in Table 2) are mapped against pertinent research findings and emerged from discussions of how we could assess the students' understanding of the content in a way that would be accessible to all. By widening the parameters and departing from the traditional university submission formats, we hope that all students will be able to empathise with how liberating it feels to be able to present their work in a way that showcases their strengths, while still being held to high standards for criticality and creativity. This not only reflects the idea of person-centred learning within the module but also creates a praxis that allows students to understand and experience the nature of inclusion on a deeper, more intuitive level.

*Table 2: Proposed assessments*

Assessment	Lessons from the research data
Creating an 'easy read' document to outline a key concept in disability studies.	<p>Specialists highlighted the importance of understanding underlying themes, such as anti-oppressive practice and the social model of disability.</p> <p>Practitioners advised that it was useful for new educators to be familiar with differentiated materials and alternative formats.</p> <p>Students complained that their differences had been assumed to limit their ability to learn complex ideas. The challenge of this format is to present nuanced and sophisticated ideas in an accessible form.</p>
Creating an inclusive resource for a specific audience on any aspect of SEND and offering a written or verbal rationale.	<p>All participant groups stressed the importance of students being able to submit in a range of formats in order to make sure that it is underlying understanding that is being tested.</p> <p>Neurodivergent students discussed the value of being able to select an area of specific interest to ensure focus, but stated that this needed to happen within a clear framework.</p>
Making evidence-based recommendations to support a student based on a case study.	<p>Addresses the core consensus that every learner is different and that understanding the individual is key to offering effective and respectful support.</p> <p>Practitioners and parents both wanted future educators to understand the complexities and contradictions of accessing support. The task will require students to consider what should be done to support the student but also to use the local offer to identify how that support can be accessed.</p> <p>The case studies will be written by co-creators with lived experience of those SEND, recognising them as experts.</p>

## The weight of collaboration

Throughout the research and co-creation process, our own challenges as disabled and neurodivergent women with 'spiky' profiles and a range of responsibilities beyond the project did not disappear. In our reflections, staff and student co-creators talked about becoming overwhelmed when discussions lacked clarity, feeling anxious or under-prepared due to external pressures, and

struggling with turn-taking and with confidence. Of course, as we would do as educators, we minimised these issues where possible. We were flexible about the media we preferred to communicate in (typing or talking), the amount of work we could opt to take on and how that would be presented back (written, spoken or dyslexia friendly documents), taking on the leading of meetings and presentations according to who was feeling most confident that day and who needed support. The real difference from working on other projects, though, was that our reflections show that each of us saw the group as a space where we could be vulnerable, where we could be our ‘true’ selves.

We displayed notable candidness and honesty around our learning and communication styles and that allowed us, as a team, to meet each other’s accessibility needs while co-producing. Each member of the team has expressed what they feel to be their weaker areas and has been honest about their struggles and anxieties throughout the project, and each has been met with adjustments, support and understanding. This meant that we felt able to be honest about what we could accomplish, that we did not feel compelled to mask our stims (self-stimulating behaviours, which can be used to help regulate) or to present as ‘slick’ and confident at all times, as a consequence of which we produced better quality work. This has undoubtedly reinforced our commitment to the social model of disability because we have demonstrated to ourselves that it really is the barriers of normative practices and expectations that disadvantage us.

## **Conclusion**

The research and module design phase took place over eighteen months and led to a redesigned module for forthcoming delivery to Education Studies undergraduate students. The redesigned module is based on the four overarching themes identified from the research findings as well as the realities of delivery within a market-driven system, which required us to confront systemic realities in relation to our utopian vision for SEND practice. This means the newly designed module considers assessment and delivery as well as content and continues our commitment to valuing lived experience as a form of expertise by including a range of guest speakers in the delivering of meaningful and sometimes ‘disruptive’ content. Speakers come from a range of backgrounds including those considered more traditional ‘expert’ practitioners such as SALT, as well as practitioners from disability arts backgrounds. We envisage further publications on the redesign of the module itself but our conclusion here reflects on the unique nature of our collaboration within the HE context.

Our focus was SEND and our aim was to include marginalised voices and experiences not usually included in HE research. When reflecting on this, we considered the impact of time. We had to build substantially more time into this project than originally planned for, to enable us to work in a new way within the institution which recognised neurodivergent and disabled participants’ capacities and caring responsibilities at each stage of the process. The project took twice as long as envisaged due to this – and we felt that it was right that it did – however, we feel that the reality of time taken is something which needs to be built into collaborative projects in HE to enable the inclusion of those most at the margins of academic research. Here again, we came to reflect upon the impact of the reality of lived experience of collaborative research with marginalised participants within the market-driven, bureaucratic HE system.

Completing the module design does not mean the end of this project. Our team discussions have also turned to the sustainability of the project and how we can ensure that the module will continue

to reflect good practice and how we can share our practice within our own institution and beyond. We are keen to share our experiences and findings not just via publications but also with other HEIs offering similar programmes, and to sustain and build on the relationships we have established with local organisations while conducting the research. As the module is implemented, we also intend to collect ongoing, reflective feedback from students to hone and improve the provision, using the reflections of the cohort on the existing module as a benchmark. Seeking funding to ensure that those with lived experience can continue to be meaningfully involved in evaluating and updating the module in future years is also vital. Moving beyond the module, we would like to consider how we can use our research to challenge existing assessment policies and practices in HE. We feel our research highlights the value of collaborative research projects, where students and staff work closely together to improve the educational experience for both future educators and learners.

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