Project 8: Diagnosis, screening and self-advocacy

1. Background information		
Strand	Black British students	
	Disability/Mental Health student	√
Topic
The broad educational point that impacts student performance/ attainment gaps	Assessment & Feedback	
	Teaching & Learning	
	Learning development/skills support	
	University/College systems and processes	√
Specific research question	How can disabled students with mental health conditions who have co-occurring neurodiverse conditions be identified and supported?	
Student co-researchers	Chay Graham, undergraduate, Natural Sciences	

2. Executive summary
Students with mental health conditions may have support needs arising from neurodiverse conditions such as ADHD, autism, dyslexia and dyspraxia. Identification of neurodiverse conditions in students can be challenging if mental health conditions are emphasised when students come forward for support. Simultaneously, a lack of support for neurodiversity can lead to poor wellbeing and attainment. The aim of this project is to explore how students with co-occurring neurodiverse and mental health conditions can be identified and supported in an effective manner. To achieve this, analysis of Disability Resource Centre student records was conducted to estimate how many students are impacted by co-occurring conditions, and this estimation was further contextualised by synthesising sector-wide and medical literature. Qualitative interviews of student co-researchers with mental health conditions who had attempted to access support for neurodiversity were collected to examine trends in diagnosis and support. Based on DRC record analysis, approximately 1 in 6 Cambridge undergraduate students with mental health conditions also have a neurodiverse condition, although this is likely to be an underestimate. Thematic analysis of interviews and literature synthesis was used to create a summary model of the hardship experienced by neurodiverse students, and determine key intervention points. Five factors were found to be integral to an effective process: (1) an accessible screening, both financially and accounting for disability access; (2) relevant competencies of the evaluator, and wider staff training in neurodiversity support; (3) supporting students with disclosure; (4) empowering students to self-advocacy; (5) signposting students to specialised services and communities.

3. Rationale
Students with mental health conditions potentially have unidentified neurodiverse conditions that are not reported. The Office for Students has recognised that there is more complexity behind HESA data because their categories are inefficient at distinguishing multiple conditions, especially with mental health and neurodiversity[1]. Neurodiversity can be defined as natural variations in brains and nervous systems amongst humans. When referring to neurodiverse health conditions, a distinction can be made from

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[1] https://www.officeforstudents.org.uk/publications/mental-health-are-all-students-being-properly-supported

mental health conditions. There are many ways to make this distinction; in Cambridge services the distinction is mainly made whereby neurodevelopmental health conditions such as ADHD, autism, dyslexia, dyspraxia, Tourette's syndrome and specific learning difficulties are considered neurodiverse, whereas conditions such as depression and anxiety which are not developmental in nature are considered mental health conditions. Whilst this distinction is possible for particular services to make, it is not always understood in this way by individuals, and can mean that students with neurodiverse conditions are erroneously reported as having mental health conditions, particularly for ADHD which is conceptualised as a learning difficulty, neurodiversity and mental health condition all at once. Further, students are arriving at Cambridge, identifying with, developing and/or being diagnosed with multiple conditions which may affect learning and well-being. In order to investigate the attainment gap in disabled students with mental health conditions, it is therefore relevant to consider the extent to which this reflects students with unsupported neurodiversity.

Attainment and welfare Students report that lack of support or ill-fitting support due to missed diagnoses, context-specific manifestations of characteristics and undiagnosed neurodiverse conditions have a significant impact on student lives and academic progress. It is well documented that when support needs are not met there is a significant effect on academic attainment of well-being of the individual[2]. Misdiagnosis, missed diagnoses and other evaluation issues are common in early adulthood[3,4,5,6], and co-occurrence of mental health conditions and neurodiverse conditions is known to be high[7,8]. However, there has been no exploration of missed or co-occurring diagnoses in Cambridge Students, nor has there been exploration of how the students could be supported so that barriers do not compound and have significant effect on the student's progress. An estimate as to the number of Cambridge students with co-occurring conditions could provide insight into how prevalent this issue is.

The Disabled Students' Campaign provide a network of support, self-advocacy and listening services for disabled students at Cambridge. Co-researchers working within the Disabled Students' Campaign have cited continuous concern amongst disabled students with struggles to obtain documentation or diagnoses that accurately reflected their individual experiences, needs and strengths. This in turn acts as a barrier to accessing meaningful support, appropriate to the individual in the context of Cambridge. They also explained that there was little evidence to illustrate the complexity, financial expense and emotional demands of navigating diagnostic and screening processes. This was discussed in the first forum and was perceived as a barrier to the attainment, wellbeing, academic engagement and progress of disabled students with mental health conditions. Qualitative data can be collected to develop an understanding of the barriers faced by disabled students, and how to mitigate or navigate these barriers.

Anxiety amongst students has been heightened due to the removal of screening services from the Disability Resource Centre. There is typically demand for over 250 screening sessions each year. Whilst a diagnostic process aims to identify conditions from a medical perspective in order to determine treatment routes, screening allows educational institutes to identify students at higher risk for a condition, instead emphasising their specific needs and strengths, in order to begin support. A screening within a university

[2] Williams, V., & Heslop, P. (2005). Mental health support needs of people with a learning difficulty: A medical or a social model?. Disability & society, 20(3), 231-245.

[3] Berenson, C. K. (1998). Frequently missed diagnoses in adolescent psychiatry. Psychiatric Clinics of North America, 21(4), 917-926.

[4] Grasso, D., Boonsiri, J., Lipschitz, D., Guyer, A., Houshyar, S., Douglas-Palumberi, H.& Kaufman, J. (2009). Posttraumatic stress disorder: The missed diagnosis. Child Welfare, 88(4), 157.

[5] Aggarwal, S., & Angus, B. (2015). Misdiagnosis versus missed diagnosis: diagnosing autism spectrum disorder in adolescents. Australasian Psychiatry, 23(2), 120-123.

[6] Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. Good Autism Practice (GAP), 12(1), 34-41

[7] Nelson, J. M., & Gregg, N. (2012). Depression and anxiety among transitioning adolescents and college students with ADHD, dyslexia, or comorbid ADHD/dyslexia. Journal of attention disorders, 16(3), 244-254.

[8] Koulopoulou, A. (2010). P01-221-Anxiety and depression symptoms in children-commorbidity with learning disabilities. European Psychiatry, 25, 432.

setting can function more generally as a welfare measure, whereby disabled students are socially empowered in an otherwise highly medicalised diagnostic process. Without screening, there are several considerations that can be examined: how unaffordable is the cost to the individual of seeking private services; in what time-scale might the individual be able to access public services, and is this keeping with the expectations of degree length in Cambridge; what further challenges might students need support with in accessing diagnosis, and how can screening remediate these challenges.

The removal of screening from DRC services is due to a lack of funding and resourcing. This is despite diagnostic services for neurodiversity being expensive and time consuming to the individual. The cost of a private educational diagnosis for SpLD is £400, and full private assessment of ADHD and autism can cost approximately £1300 or above. There is poor opportunity for SpLD support through the National Health Service (NHS), which does not offer any diagnosis or support for dyslexic adults and provides no formal services for dyspraxia diagnosis. Furthermore, many general practitioners are unaware of the diverse manifestations of ADHD characteristics[9], and there is a 1-3 year long waiting list for ADHD support services, which are frequently thought to be fast-moving by university staff. A similar time-scale is required for autism evaluation. As neither the NHS or University takes steps to support neurodiverse students, they frequently fall through the cracks. Exploring how this impacts student experience with qualitative data can identify an intervention.

As mentioned above, screening provides an opportunity to give disabled students information about their strengths and challenges, as well as a safe contact in the form of a DRC mentor to advise on disability. Requests for reliable information on neurodiversity are frequently submitted by disabled students to DSC online forums, due to the frequency at which misinformation is presented in mainstream media channels. Experiences of discrimination, low accessibility and long wait times for ADHD diagnosis via the NHS has prompted the publishing of a guide for University of Cambridge students by the DSC with a similar planned effort to address diagnosis of Autism Spectrum Disorder (ASD). Qualitative data can be used to determine the kind of signposting and specialist support students will need when they come forward for evaluation.

4. Existing evidence

There are reasons to believe that undergraduates at Cambridge with mental health conditions are particularly likely to have co-occurring conditions as well as difficulty accessing a diagnosis that accurately reflects their experience, strengths and needs in the unique context of Cambridge. The literature reports:

1) So-called '2e' students ('twice exceptional'), defined as being simultaneously gifted and having specific learning difficulties (SpLD), are thought to be one of the most underdiagnosed groups, which likely affects Cambridge students in particular[10];

2) There are conceptual problems distinguishing and identifying characteristics that relate to

[9] Baverstock, A. C. & Finlay, F. (2003) Who manages the care of students with Attention Deficit Hyperactivity Disorder (ADHD) in higher education? Child. Care. Health Dev. 29, 163–166.
[10] Beckmann E, Minnaert A. Non-cognitive Characteristics of Gifted Students With Learning Disabilities: An In-depth Systematic Review. Front Psychol. 2018;9:504. Published 2018 Apr 20. doi:10.3389/fpsyg.2018.00504

neurodiversity and mental health conditions, as symptoms and impairments can overlap[11,12], and the problems caused by unsupported neurodiverse conditions can create poor mental health[13,14];

3) Neurodiversity and mental health conditions frequently co-occur[15], yet mental health conditions tend to be diagnosed first and solely, with the average ADHD diagnosis only being made after 1-3 co-occuring mental health conditions have been (mis)diagnosed[16].

5. Generation of evidence

The leading student co-researcher of this project, Chay Graham, collaborated with Dr Ruth Walker (CCTL), Helen Duncan (DRC) and Dr Juliet Scott-Barrett (CCTL) to develop questions to help understand the complexity of these issues and to develop an understanding of what may help students and staff in the future. The document containing these questions is appended to this report.

Although originally designed as an interview, it was decided that due to the highly personal nature of the questions (disclosing diagnoses and discussing barriers), this interview would best be conducted over email, with a document that respondents could save and fill in in their own time, and on a medium that best suited their accessibility needs, as many students work with particular software or screen overlays that can easily be added to word documents.

Responses were emailed directly to Juliet who anonymised the data, stored it securely and passed on the anonymised data for co-analysis with Ruth and Chay using a thematic analysis. Thematic analysis offers a strategic way of organising, analysing and interpreting one's data according to the 'patterns' (themes) that both respond to the research questions and accurately reflect what is in the data (Braun & Clarke, 2006[17]). Thematic analysis is a process that can enable researchers to critically examine the dialectal relationship between their research questions and what the data present (Srivastava & Hopwood, 2009)[18]. We chose thematic analysis because the flexibility of the analysis strategy can offer opportunities to highlight similarities across data, as well as differences, which may help researchers deal with diversity in their data sets, and to see unexpected insights (Braun & Clarke, 2006).

An analysis of anonymised Disability Resource Centre Data, shared by Helen Duncan, was conducted to explore if there was evidence of co-occurring mental Health Conditions and Neurodiversity in the Cambridge Student population.

Based on qualitative data, chronology of student diagnostic pathways were also documented and measured for the following features: the number of times students would come attempt to access

[11] Asherson, P., Buitelaar, J., Faraone, S. V & Rohde, L. A. (2016) Adult attention-deficit hyperactivity disorder: key conceptual issues. The Lancet Psychiatry 3, 568–578.

[12] Berenson, C. K. (1998). Frequently missed diagnoses in adolescent psychiatry. Psychiatric Clinics of North America, 21(4), 917-926.

[13] Findling, R. L., Arnold, L. E., Greenhill, L. L., Kratochvil, C. J., & McGough, J. J. (2008). Diagnosing and managing complicated ADHD. Primary care companion to the Journal of clinical psychiatry, 10(3), 229.

[14] Choi, K. R., Ford, J. D., Briggs, E. C., Munro-Kramer, M. L., Graham-Bermann, S. A., & Seng, J. S. (2019). Relationships between maltreatment, posttraumatic symptomatology, and the dissociative subtype of PTSD among adolescents. Journal of Trauma & Dissociation, 20(2), 212-227.

[15] Berenson, C. K. (1998). Frequently missed diagnoses in adolescent psychiatry. Psychiatric Clinics of North America, 21(4), 917-926

[16] Hodgkins, P. et al. (2013) Management of ADHD in children across Europe: patient demographics, physician characteristics and treatment patterns. Eur. J. Pediatr. 172, 895–906.

[17] Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77-101.

[18] Srivastava, P., & Hopwood, N. (2009). A practical iterative framework for qualitative data analysis. International journal of qualitative methods, 8(1), 76-84.

support before getting neurodiversity-specific support; the number of times students would access services where an opportunity for identification of neurodiversity was missed; the number of times students would have a missed identification of neurodiversity whilst a mental health diagnosis was identified; the number of times students would experience misdiagnosis of their neurodiversity as something they did not feel relevant to their needs.

Results were synthesised with literature findings presented above to develop a model of student hardship and identify intervention sites.

6. Small project research findings

In order to reflect the findings of this research, the experiences of the interviewees, and contextualise these with higher education experiences reported in research literature[19][20], the lead researcher (Chay Graham) designed 'the Neurodiversity Cycle' (Figure 1).
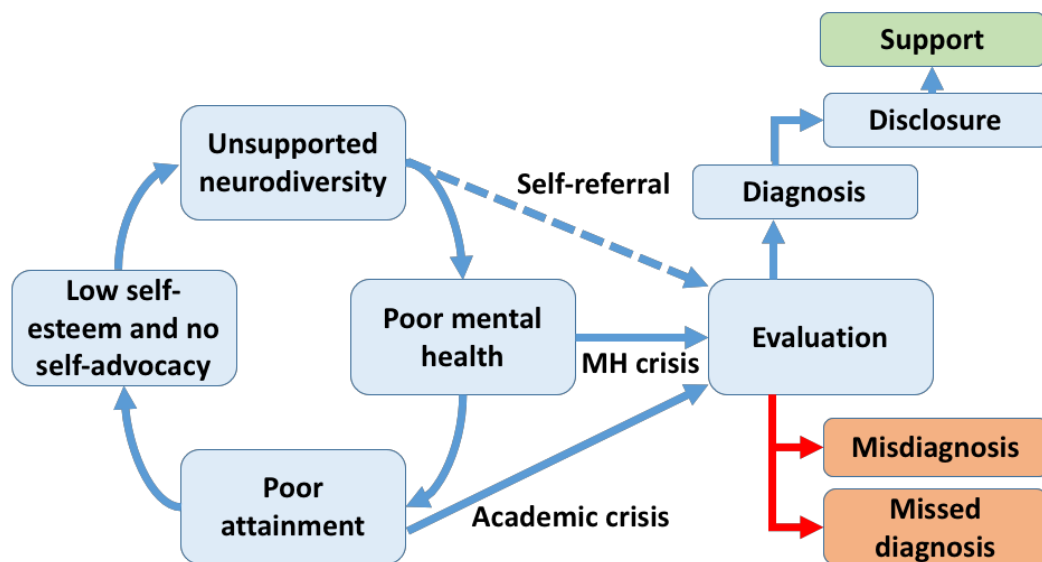
Figure 1. The Neurodiversity Cycle.

Cambridge students with unsupported neurodiversity reported that they experience poor mental health as a result, which they perceive as related to poor attainment, low self-esteem and a lack of self-advocacy. This exacerbates barriers relating to unsupported neurodiversity (such as autistic burnout), and the cycle repeats. Intervention often only occurs due to a mental health crisis (often resulting in hospitalisation), or academic crisis (which may result in intermission, however, this does not break the cycle if neurodiversity and mental wellbeing is not supported during, and on return from, intermission). Self-referral can occur, but is notably rarer (represented by a dashed line). In a good scenario, the student at evaluation is correctly diagnosed, supported to disclose and receives support implementation. More common however is a bad-case scenario, where there is misdiagnosis of the neurodiversity as a mental health condition, or a missed diagnosis of neurodiversity whilst mental health problems are identified. Both mis-and missed diagnoses can be particularly dangerous especially if medication is

[19] Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. Journal of Autism and Developmental Disorders, 46(1), 31-41

[20] Emmers, E., Jansen, D., Petry, K., van der Oord, S., & Baeyens, D. (2017). Functioning and participation of students with ADHD in higher education according to the ICF-framework. Journal of Further and Higher Education, 41(4), 435–447. https://doi.org/10.1080/0309877X.2015.1117600

involved. As students arrive for medical evaluation in a crisis, the emphasis tends to fall on immediate mental health-related symptoms rather than exploring longer term characteristics of neurodiversity (which may have led to the crisis).

Based on results and the literature, a model of student hardship was developed (Figure 1). Students have a cyclical hardship when struggling with unidentified neurodiversity, and frequently do not obtain support until a crisis. Due to arriving for evaluation in a crisis, as well as factors outlined in qualitative themes below, diagnosis is often wrong or unhelpful. Furthermore the co-occurrence of neurodiversity and mental health conditions at Cambridge was also explored using anonymised data from the Disability Resource Centre (Figure 2).
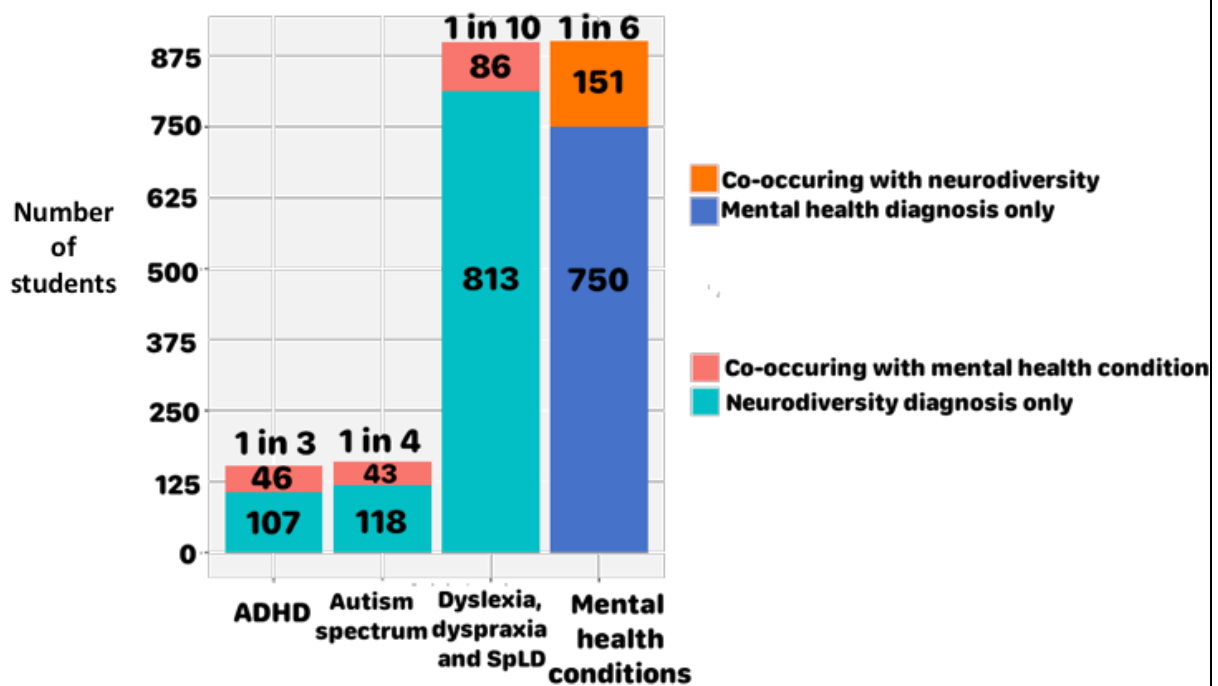
Figure 2. Number of Cambridge undergraduate students, registered with the Disability Resource Centre as of February 2020, with either mental health or neurodiverse conditions compared to students with both types of condition.

Each stacked bar reflects students with the condition printed below on the x-axis. Numbers in bars reflect number of students. Proportions above bars show the approximate proportion of students with co-occurring conditions by category.

Analysis of disability resource centre records, shared with co-researchers by Helen Duncan, shows that a high proportion (1 in 6) of students with mental health conditions have co-occurring neurodiverse conditions also. Several records could be found whereby mental health is first disclosed to the university, then within a few years, neurodiversity is also identified. The number of single-diagnosis students is likely to be an underestimate, as students will have issues accessing a diagnosis, and may have issues disclosing multiple conditions, especially if they are identified at different times. For example, childhood neurodiversity diagnoses may be overlooked by students, or may be disclosed to HESA but not the DRC.

The co-researcher interview uncovered key themes, presented below:

Key themes:

- **Access to Screenings/Diagnostic Assessment**
- **Staff Training**
- **Disclosure**
- **Self-advocacy**
- **Signposting**

The data suggest that: access to screening, staff-training, disclosure, self-advocacy, and sign-posting, play a crucial role in accessing support. For each of these themes some factors acted as barriers resulting in negative, stressful and harmful experiences; however, multiple factors acted as facilitators resulting in positive, productive and validating experiences.

Access to Screening

The data not only evidences that students need to have access to screening (Student 1), but also that the screening needs to be conducted by someone with sufficient training as otherwise this can be 'stressful and traumatic' (Student 2), rather than validating (Student 3) or helpful (Student 4).

Participant 3 explained: "The DRC no longer has the capacity to do screenings, which is something I think I really could have benefitted from before going and spending £400 on a SpLD assessment".

Participant 4 found the experience of screening "stressful and traumatic" and explained that "There were no aids (e.g. diagnostic tests to jump off from) to thematically move through relevant issues, instead I was simply asked "why do you think you're autistic?", and told after stumbling to the first immediate relevant answer that came to mind (which was recent and situational) that I "have the traits but don't fit the diagnostic profile".

Participant 1 explained "The assessment itself was a very nerve-wracking 3 hour appointment (I was scared because I identified strongly as autistic and did not know how I'd feel if I did not receive the diagnosis). However, my assessor was absolutely wonderful, did not have any doubts in the diagnosis and it was one of the most validating appointments ever!"

Participant 2 explained "Earlier screening goes a really really long way in terms of making plans that can help negotiate with/navigate persistent barriers to wellbeing and academic progress".

Recommendations as to how screenings could be improved related to staff training (see theme below) and related to the structuring of the screening.

"A screening that would help me would be based around a thematically organised, point by point, written-down checklist/questionnaire or list of questions for discussion. This would be provided in advance so that the pressure of thinking of every relevant thing from your entire life isn't put on you face to face (already a difficult enough situation for autistics!!) in a limited time".

Staff Training

Multiple recommendations were made as to how staff training could be improved, in particular there was emphasis on the need for coproduction of staff training (Student 1), understanding around intersectionality and the overlap of multiple co-occurring conditions (Students 2 and 3), and also that the staff member should have sufficient time and resource built into their role to conduct work meaningfully (Student 4).

Participant 4 recommended: "Compulsory training developed collaboratively between staff and neurodiverse students".

Participant 2 recommended: "Training - someone who understands that neurodiversity is diverse. sounds obvious but it really really isn't. Intersectional awareness is very very important. Commitment to accepting barriers as barriers; no shaming for needing something changing…Intersectional training and awareness; there is no one size fits all and certainly not a 'look'. Not every ND kid is naughty or square and lacking in empathy; they're not all rich; they're not all white; they're not all male. It presents itself in different ways, and will need an approach towards it that fits".

Participant 1 recommended: "Training into how different groups (women, non-binary people, people of colour, etc) might display less typical autism symptoms and be undiagnosed for a long time. Training into how autism affects the development and manifestation of other mental illnesses and how treatment of autistic people may be affected".

Participant 3 explained: "I don't feel that my college disability officer (staff member) has the time, resources or background knowledge necessary to support me in this, because they have this role in addition to many other roles which take up more time, e.g. lecturer, supervisor, tutor etc. I therefore feel obliged to seek help from fellow disabled students, who are neither paid nor have the time to support me, especially as they have to manage their own disabilities too".

Disclosure

There were a range of experiences with disclosure, with one participant largely comfortable with disclosing (Participant 1) although most participants reported large ranges of staff they would not feel comfortable disclosing to (Participants 2, 3 and 4). It was noteworthy that different students have unique relationships with different yet analogous staff; for example, Participant 2 felt comfortable disclosing to their Tutor but not their Director of Studies, and Participant 3 felt comfortable disclosing to Departmental administrative staff but not Departmental teaching staff. A Neurodiversity Advocate with counselling training was identified unanimously as a safe and comfortable person to disclose to, as were DRC advisors and UCS staff. Students cited various competencies that a good evaluator would have (Student 1 and 2) as well as pitfalls to avoid (Student 3 and 4), suggesting that co-developing a competency list with students would be fruitful.

Participant 2 listed: "Openness/Flexibility to accept … Willingness to do research (coming from the right places. i.e. from ND people, not ones created by NT people who view neurodiversity as a problem to fix/eradicate) …Training - someone who understands that neurodiversity is diverse.… Intersectional awareness is very very important.… Commitment to accepting barriers as barriers; no shaming [students] for needing something changing."

Participant 3 listed: "Professional, trained, discrete, calm, knowledgeable, experienced, organised, reliable, capable"

Participant 1 requested: "Someone without stereotyped ideas of what autism is like, who listens and believes my own experiences".

Participant 4 requested: "Someone who understands the issues with gender bias and neurodivergence diagnosis …Someone who at the very least is able and willing to fully and logically explain the reasons for their opinions … in a way that I understand, rather than making me feel stupid for asking questions"

Self-advocacy

Analysing the chronology of each participants' experience with accessing support, it is seen that there is a significant need to empower students towards self-advocacy. Not only must students be well enough physically and mentally to access support, but they must be informed enough and empowered for repeated engagement with services. The average number of times a student had to try to access support before their neurodiversity was helpfully identified was 6. Further, there were an average of 3 missed opportunities for identification of neurodiversity, and an average of 2 missed diagnoses due to a diagnosis of mental health taking precedence at evaluation. There was an average of 1 misdiagnosis, with students reporting their neurodiversity being misidentified as Borderline Personality Disorder, the impact of bullying, and the effects of stress, all of which are echoed as common misdiagnoses in the literature.

All respondents noted that misdiagnosis seemed gendered, with one student commenting: "it was suggested that I was "statistically more likely" to have a PD than autism because of the gender difference in diagnoses". Respondents also suggested that factors such as race or transgender identity could impact evaluation and support. Self-advocacy may therefore be more important for students marginalised by other factors such as sexism, racism and transphobia, and may need to be delivered in a way that is sensitive to these issues.

Signposting

Specific beneficial services were unique for each student respondent, due to their unique conditions and needs. Several suggestions for signposting were made including: in-person support groups; online support groups; online blogs; neurodiversity-friendly therapeutic services; reliable information on medication options; disabled communities; medical assessment options. This suggests that signposting should be as broad as possible, with as many relevant resources, services and service reviews collated as possible.

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7. Outcomes of research/implications for Cambridge practices and processes.

1. Funding and a role for a full-time Neurodiversity Advocate to supplement and support current provision in the Disability Resource Centre (DRC). They should have a background in screening of disabled students with neurodiversity, and counselling training. They will be expected to handle approximately 250 cases referred for screening annually.

2. Suggest that the Neurodiversity Advocate offers students a one-hour session for screening, integrated with a welfare toolkit for understanding a social model of disability and diagnosis. Suggest that the Neurodiversity Advocate then offers students up to two follow-up disability counselling sessions with the following focuses:
   (1) navigating disclosure to friends and family, staff and peers, future employers and medical services;
   (2) self-advocacy, signposting and next steps.

3. There will be formally regularised contact between the Neurodiversity Advocate and networks that can identify struggling students with undiagnosed neurodiversity, including:
   (1) Tutor/Director of Studies networks;
   (2) Cambridge Students' Union's Sabbatical Officers;

(3) College nurses, counsellors and welfare teams;
(4) University Counselling Service staff.
These networks can also provide feedback and enable accountability of the Neurodiversity Advocate.

4. The advisor will train staff in working with neurodiverse students, advise Departments on inclusive practice and co-develop training with disabled students. The Neurodiversity Advocate will be recommended to Departments and staff who are themselves seeking screening, diagnosis or advice on neurodiversity in the workplace.

5. The Neurodiversity Advocate should coordinate an annual meeting and mailing list for (1) dyslexic and/or dyspraxic staff; (2) staff with ADHD; (3) autistic staff; (4) all neurodiverse staff. The Neurodiversity Advocate should further coordinate a current and alumni neurodiverse staff network list, and flag staff with expertise in neurodiversity. When appropriate, the Neurodiversity Advocate should facilitate opportunities for networking between neurodiverse staff and students.

7. RECOMMENDED ACTION

1. That the University provides funding for a specific role in the DRC that integrates both screening and support (a Neurodiversity Advocate)

2. That the University provides funds to support the co-development of staff training resources and modules.