

THE HIDDEN COST OF DISABILITY

Social Mobility Student Research Hub

Scarlett Timlett

PROJECT INTRODUCTION

“Disability involves a lot of hidden labour that is not helped by the perception of disabled people as lazy that is spread by the media” - Interview Participant

This project aimed to explore the lesser discussed **costs and barriers** for disabled students in higher education.

In this research, the **hidden labour** for disabled students has been analysed including the time cost, mental health effects and extra energy involved in their university experience. It was crucial that disabled students' **lived experience** and recommendations were made central to the report.

Over the course of four semi-structured interviews and a survey, this study investigated the experiences of disabled people under the three broad areas of time and organisation, mental health, and financial costs.

1

Methodology

2

Literature Review

3

Findings

4

Conclusion and Recommendations

METHODOLOGY

AIMS OF THE PROJECT: This project used interviews and a survey and aimed to centre disabled students' experience at university including their recommendations going forward. It also aimed to non financial costs of disability, increase awareness of the hidden labour disabled students do and address hostile aspects of support services and university life.

ABOUT THE METHODS: Survey

Participants:

- 16 participants: criteria was self-defining disabled students at University of Warwick.
- This survey was shared in society channels among disabled communities at university.

Analysis:

- Participants were given a series of statements under the broad categories of **mental health, time and financial cost**.
- A **likert scale** was used with options ranging from strongly disagree to strongly agree.
- Underneath all questions was a separate box where participants could expand on their answers and talk about their experiences.

Interview:

Participants

- 4 interviews were conducted with self-defining disabled students at Warwick
- Participants had a range of disabilities with three participants having **physical disabilities**, two participants being **neurodivergent** and one participant having a **specific learning disability**.
- The study also attempted to have a range of **diagnostic experience** among participants with some being diagnosed since they were young and others still in the process.
- Participants were across **a range of years** with one first year student, two third year students and one fourth year.
- A limitation of the study was the fact all participants were **UK home students**.

Analysis:

- Questions were semi-structured and split into three main sections: mental health, time and financial.
- They were subsequently thematically analysed

LITERATURE REVIEW: BACKGROUND

WHAT DOES DISABILITY MEAN?

“You’re disabled under the Equality Act 2010 if you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.”¹

WHY DOES IT MATTER?

Disability is often treated like a characteristic that is categorised by bureaucratic systems deciding if you are impacted “enough” to deserve support. This is bound up with a conception of diagnosis that ignores intersectional issues of how gender, race and class all shape medical treatment and the difficulties of finding a diagnosis.

RELEVANCE TO PROJECT

This project recruited participants who were “self-defining” disabled students to ensure inclusion and reflect the issues of diagnostic criteria that are often exclusionary.

WHAT DO WE CURRENTLY KNOW?

According to research done by Scope, university is more expensive for disabled students.²

Kendall’s report found that disabled students struggle to find individual specific support at university and lack autonomy in finding reasonable adjustments.³

Furthermore, numerous studies by people such as Chipchase found that disabled students struggle to participate in extra-curricular activities such as career development, sports and other social events.⁴

¹ GOV.UK. (2010). Equality Act 2010. Legislation.gov.uk; Gov.uk. <https://www.legislation.gov.uk/ukpga/2010/15/contents>

² Sowden, C. (2022). University shouldn’t cost more if you’re disabled - but it did for me. | Disability charity Scope UK. Scope. <https://www.scope.org.uk/news-and-stories/disability-and-university-costs>

³ Kendall, L. (2016). Higher education and disability: Exploring student experiences. Cogent Education, 3(1). <https://doi.org/10.1080/2331186x.2016.1256142>

⁴ Chipchase, S., Seddon, A., Tyers, H., & Thomas, S. (2023). Experience of university life by disabled undergraduate students: the need to consider extra-curricular opportunities. Disability & Society, 1–18. <https://doi.org/10.1080/09687599.2023.2233687>

LITERATURE REVIEW: SUPPORT

WHAT SUPPORT IS OFFERED CURRENTLY?

Reasonable Adjustments: These are defined as “modifications or accommodations” ensuring “equal access” to education and can range from recording of lectures, flexibility on deadlines or extra time in exams. They are organised by the university’s Disability Services. To access these, students would need medical documentation but the requirements are less strict than Disabled Students Allowance and Personal Independence Payment.

Disabled Students Allowance (DSA): This is support provided by the government to cover “study-related costs” at university. This can include support related to specialist equipment like adapted computers or non-medical helpers like note-takers for lectures. DSA is harder to apply for than reasonable adjustments and requires eligibility evidence and a diagnosis. DSA only covers this equipment and is paid directly to the supplier.⁶

Personal Independence Payment (PIP): This is monetary support towards extra living costs for disabled people under two broad categories of: daily living and mobility. Many disabled people have talked about difficult and dehumanising applying for PIP. Being in receipt of benefits is heavily stigmatised and demonised by all sides of political spectrum.⁷

Many of these benefits aren’t available to disabled students, especially Personal Independence Payment.

Furthermore, not all disabilities are perceived as being “deserving” of support with research done by Geiger demonstrating “a hierarchy of impairments.” When evaluating the costs of disability, this study attempted to draw from a wide variety of disabled students to reflect this.⁸

93% OF PARTICIPANTS AGREED WITH THE STATEMENT “APPLYING FOR SUPPORT IS DRAINING”

Disabled students have to spend time energy ensuring they receive support and access needs from the university, medical professionals and people around them.

⁵ Wellbeing Support. (2023). Reasonable Adjustments | University of Warwick. Warwick.ac.uk. <https://warwick.ac.uk/services/wss/students/disability/how-can-we-help/reasonable-adjustments/>

⁶ GOV.UK. (2021). Disabled Students Allowance. GOV.UK. <https://www.gov.uk/disabled-students-allowance-dsa>

⁷ GOV.UK. (2012, October 15). Personal Independence Payment (PIP). GOV.UK; gov.uk. <https://www.gov.uk/pip>

⁸ Geiger, B. B. (2021). Disabled but not deserving? The perceived deservingness of disability welfare benefit claimants. Journal of European Social Policy, 31(3), 095892872199665. <https://doi.org/10.1177/0958928721996652>

OVERVIEW OF FINDINGS

1

Lack of support and inaccessibility

- Inaccessible environments.
- Extra paperwork, bureaucratic processes and system of applying for support.
- Barriers to support via diagnostic requirements and demands of proof on disabled students.
- Unhealthy cultures of work and attitudes towards rest.

2

Everyday extra work and organisation

- Participants described how everyday activities take more time due to their disability which went unnoticed by people around them.
- Disabled students have to spend more time organising their days than their non-disabled peers.
- Another cost of disability explored is the need to advocate for yourself as a disabled person.

3

Mental health impacts and social isolation

- Many disabled students felt isolated and excluded from university life, specifically the social aspects due to inaccessibility and social isolation.
- Disabled students face lack of understanding from other students and even their friends regarding their limits and accessibility needs.
- All participants agreed that their experience as a disabled person impacts their mental health.

INACCESSIBLE ENVIRONMENTS

ENSURING PLACES ARE ACCESSIBLE

Checking places are accessible takes up time and energy as disabled students have to check:

- How and if they are able to enter a room.
- Whether this room will be sensory friendly
- Where the nearest disabled toilet is

This is worse in unfamiliar environments, affecting new disabled university students. Furthermore, the inaccessibility of many houses, clubs and social environments has serious mental health effects for many disabled students.

One interview participant described all the ways just one building on campus was inaccessible to disabled students and staff:

- Closed wellbeing room.
- Lack of signage and clarity over where rooms are.
- Overstimulating environment due to noise
- Heavy doors

One of the interview participants who uses a wheelchair described their experience getting to a classroom.



“Leave the building to visit the concourse. Go downstairs. Go outside.”

Round the chemistry building to the wheelchair access for L3 and L4



Then go through in front of a lecturer. Then get round to the sides to L5.”



PAPERWORK

“I have to regularly prove that I’m disabled”

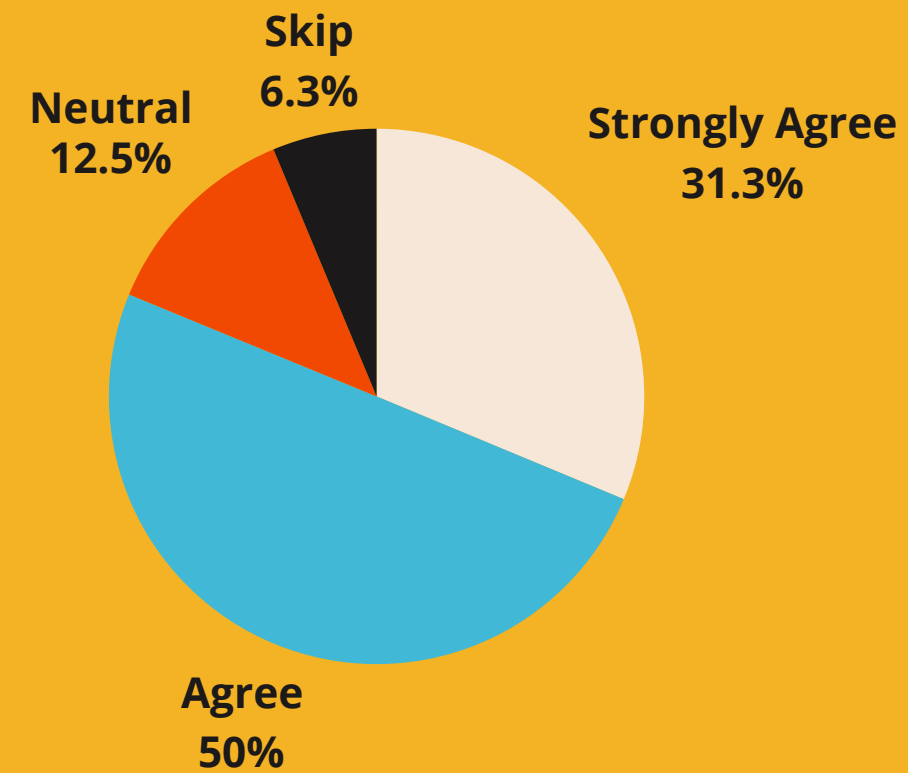
Paperwork and doing forms to ensure they are supported takes up a considerable amount of many disabled students time.

This ranges from forms for DSA, PIP or for students trying to pursue a medical diagnosis.

“I jumped through all the hoops and spent 3 hours talking to people and they came back and said no you’re actually not eligible”

The hostile government policy and culture towards anyone claiming benefits has led to invasive and exhausting policies for disabled students claiming support. Disabled people are put in positions where they have to prove their disability and the extent of their needs rather than being listened to.

Multiple interview participants commented **on how tiring it was to do paperwork for Disabled Students Allowance** that can extend throughout the year if students have one-to-one mentors for support.



80% of participants agreed with the statement that coordinating with wellbeing and disability services is tiring

UNIVERSITY SPECIFIC SUPPORT

Another participant noted how they had restricted access to Disability Services due to a lack of a diagnosis for which there was over a two year waitlist to receive. Spending time fighting for a diagnosis is exhausting and the social factors like class, race and gender in receiving a diagnosis are often ignored. This is exacerbated by media stories that focus on a diagnosis “culture” where disabled people are getting diagnosed easily.

Some participants noted the helpfulness of Disability Services but it must be acknowledged how any adequate support still relies on the disabled student to manage. This takes up time and energy to coordinate and can be a struggle to maintain alongside academic work and seeking a diagnosis.

REST AND SELF-CARE

COORDINATION AND WELLBEING

Disabled students often have to spend more time resting and managing their health than their non-disabled peers.

All four interview participants explained how they needed to take **more regular breaks** and spend more time resting than their non-disabled peers.

An interview participant described the **exhausting cycle** of having to take a break, then becoming overwhelmed with work, so requiring another break for emotional regulation.

One interview participant described needing to break due to overstimulation and emotional regulation with multiple others describing experiencing fatigue and needing to rest after nights out.

Additional demands on disabled students' time include coordinating with GPs, the hospital or therapists for check ins and appointments or having to take more regular breaks to avoid burnout and overexertion. Just like coordinating with Disability Services can be tiring, an interview participant described how organising care services is time consuming.

"I often miss teaching or spend a lot of my time ill due to over exertion."

This quote above is from a survey participant that was not eligible for PIP so did not have access to a wheelchair.

The effort of taking care of yourself and ensuring your needs are met is invisible and is often exacerbated by lack of support.

Another described the tiring impact of constantly having to talk about their disability, their accessibility needs and what they can and cannot do.

DAY TO DAY WORK

TIME EFFORT OF ORGANISING THE EVERYDAY

EVERYDAY ACTIVITIES TAKE LONGER

“People have no idea at all of the extra work and time that goes into being disabled.”

For disabled students, lots of day to day activities take longer whether this be due to their disabilities or due to extra organisation that they have to undertake.

Tasks that came up during interviews were

- **Changing a lightbulb:** One participant had dyspraxia and therefore problems with fine motor coordination which meant that tasks such as changing a lightbulb can be difficult.
- **Garden upkeep:** A participant who uses a wheelchair cannot use an electric mower as this would be unsafe.

Although this is not directly related to university as academic work is, it still highlights how the university experience differs for disabled students.

Multiple interview participants also highlighted how getting up in the morning takes longer because of their disability due to needing to be hoisted, chronic pain or fatigue.

“Everything feels like it takes up more time.”

All survey participants either strongly agreed or agreed with the statement:

“I have less time in the day than my non-disabled friends.”

ORGANISING THE EVERYDAY: DRIVING

1 Check you're allowed to drive

Some disabled people are not able to learn to drive due to their disability.

2 Get a provisional license

3 Driving lessons and practice

Finding a driving instructor with an adaptable car is difficult and expensive for many disabled students.

4 Buying your own car

Buying accessible cars can be expensive or time consuming with constant back and forth with companies and numerous forms.

All of these barriers to transport were discussed in interviews and provide a succinct example of how lack of accessibility measures and thought towards disabled people make organising day to day life harder.

DAY TO DAY WORK

PLANNING THE EVERYDAY

ORGANISATION

Due to the inaccessibility of various places and transport options, many disabled people need to arrive to events early or research places in advance to ensure accessibility. This takes **time** and **effort** even if it's just to ring a restaurant to check if they are step free.

An interview participant spoke about transport being widely inaccessible to him since getting a larger wheelchair which impacts his travel and organising his day.

Other participants spoke about having to organise their time to avoid burnout or fatigue. This often means they, and other disabled students, have to spend time monitoring their energy levels and being careful about how much they take on.

ADVOCACY

Another cost of disability is the energy spent advocating for your needs. Part of organising the day to day is assessing who is going to be accommodating and who is not: a question that disabled students should not have to weigh up daily.

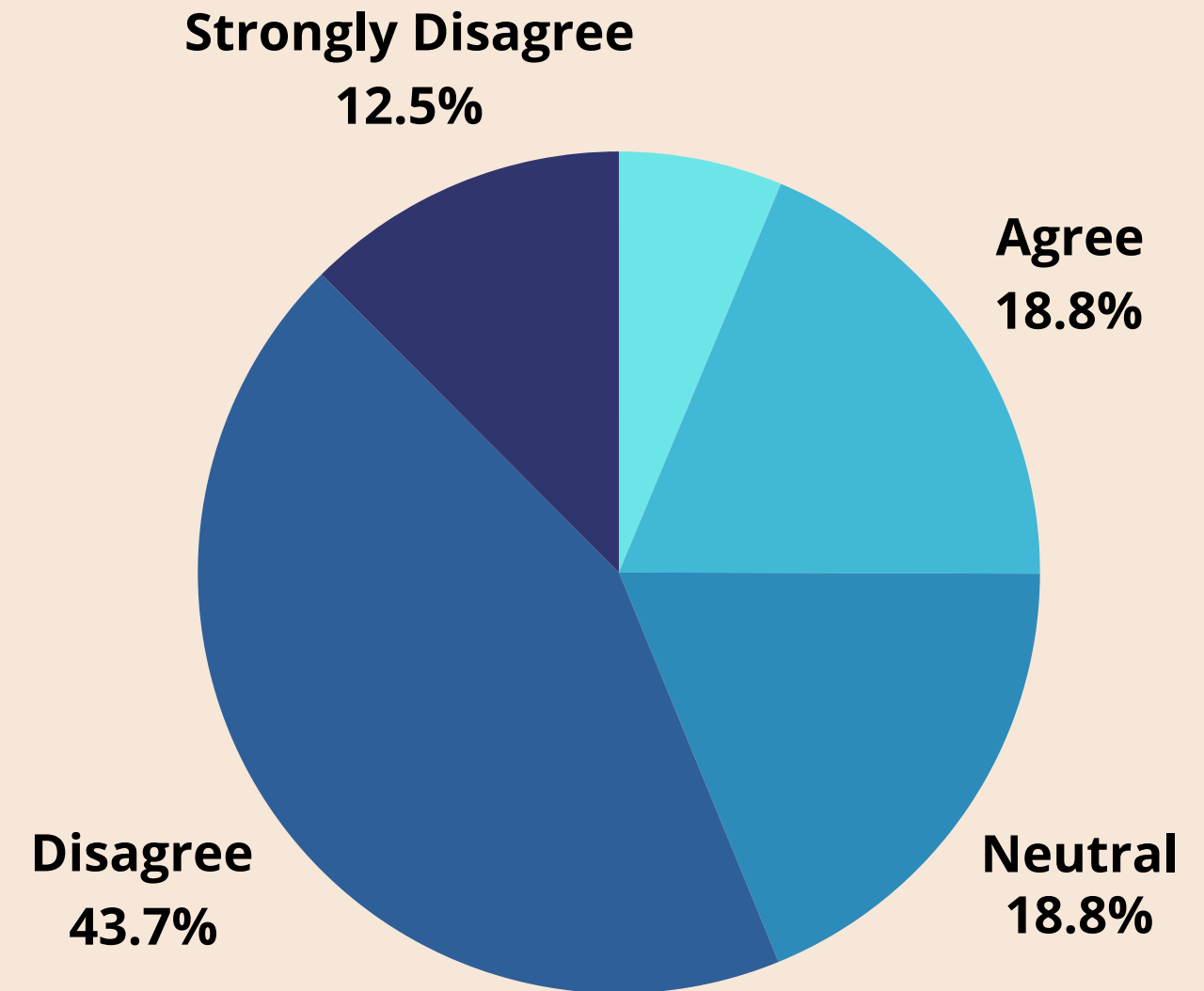
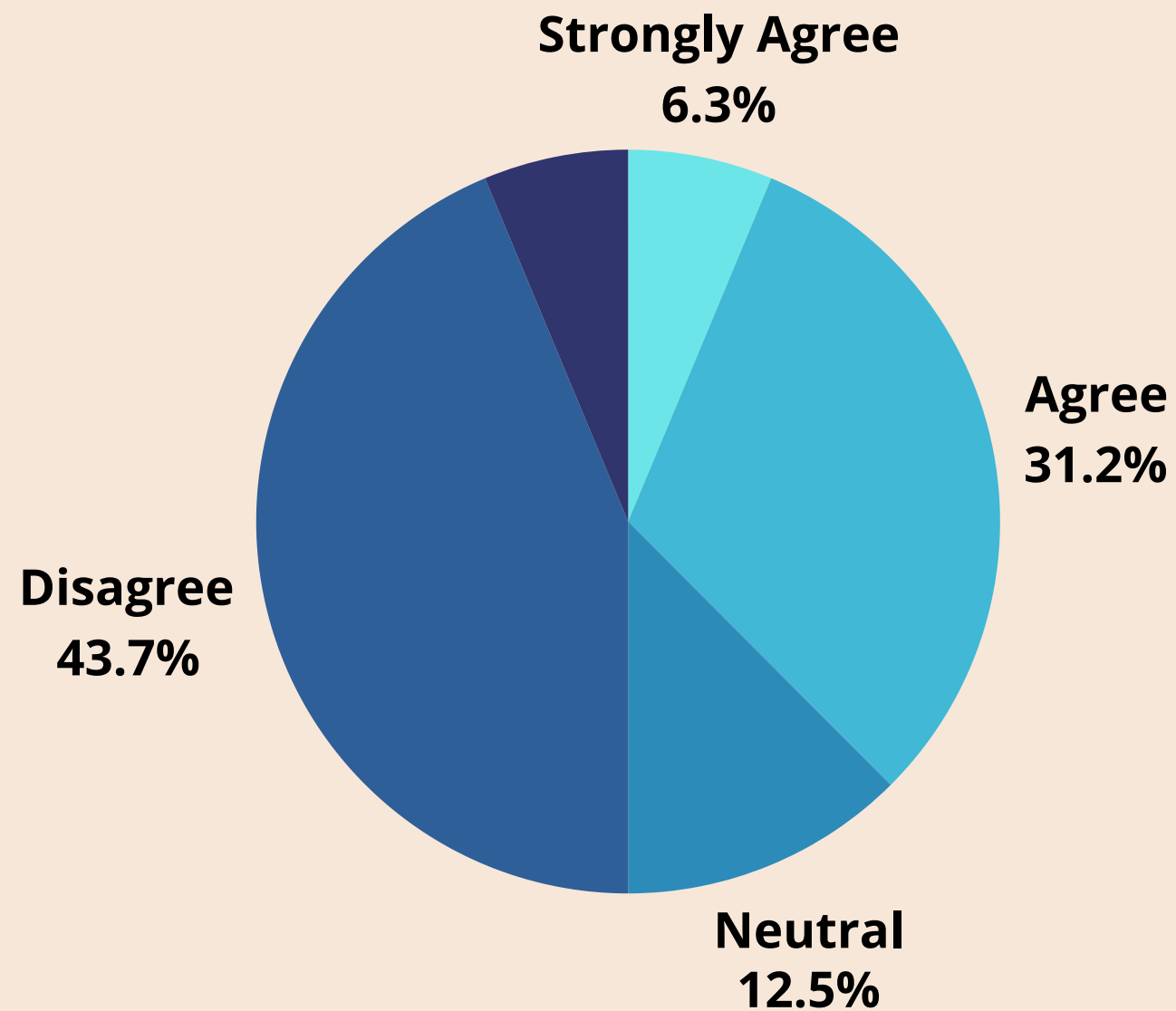
One interview participant spoke passionately about the cost of constantly advocating for themselves, for the disabled people around them and figuring out who would be a "suitably decent human being."

"It is itself a cost to advocate for ourselves."

An interview participant spoke about having to spend a lot of time researching and speaking to people about staff's "reputation" on accessibility and disability.

LACK OF UNDERSTANDING

“The impact of my disability is recognised by my lecturers and seminar tutors”



“The time my disability takes up is recognised and understood by people around me.”

DAY TO DAY WORK

ACADEMIC WORK

Academic work takes longer for many disabled students.

One interview participant talked about how their work takes longer due to difficulties with typing that means making notes take longer. **This was exacerbated due to a lack of university support regarding a note taker** during seminars that meant even more time was spent on academic work.

Other participants described how academic work takes longer because of their disability due to **concentration issues or fatigue**. Research can take longer due to having to re-read it and transcribing lecture notes is more effort.

Writing essays also often takes disabled students longer. One interview participant explained how they have to spend extra time proof reading and attending their DSA provided study skills appointment.

SOCIAL EXCLUSION

Many of the hidden costs of time and energy explored previously have a significant impact on disabled students' mental health.

- Applying for assistance can be draining and dehumanising,
- Prioritising health can often mean to missing out on socialising
- Lack of support and accessibility is isolating.

Inaccessibility and Exclusion

Inaccessibility of social events often means disabled students are excluded. One interview participant spoke about the lack of university society policy around accessibility with **lots of societies holding events in inaccessible places.**

Multiple participants talked about struggling with drinking culture at university and the inaccessibility of drinking games.

“University life is hostile to disabled students in a lot of ways.”

Due to having less time in the day than non-disabled students and often less energy, many disabled students struggle with finding capacity for social events.

One participant talked about how difficult it was to accept that they **could not do the same amount** as their non-disabled peers which was particularly tough at the start of the year during freshers week. For another participant, they need more sleep due to fatigue so cannot stay out as late or as often.

Understanding

During an interview, one participant said how people struggle to understand that their ability to go out is changeable due to their fluctuating disability.

“I don't look traditionally disabled so most of my friends/peers tend to forget until it visibly affects me”

Another commented on how tiring it is to explain to people and how they often have to be the one to organise social events to ensure accessibility.

MENTAL HEALTH

100% of survey participants strongly agreed with the statement:

“My disability has an impact on my mental health”

The mental health impacts of disability are often overlooked when discussing how disability affects everyday life. As explored, facing the lack of support, inaccessibility and ableism has a serious impact on disabled students' mental health.

“I view my mental health as part of my experience as a disabled person”

- This interview participant talked about one part of their disability is getting overstimulated.
- This means they often have to take time out to emotionally regulate which is tied up with their mental health.

Furthermore, another person commented that Wellbeing Support lacked understanding and insight into disability whilst providing them mental health support.

Importance of Community

All participants talked about **how finding a community on campus** helped them handle inaccessibility and isolation existing in a lot of university spaces.

One interview participant commented that:

“the only reason the inclusion of disabled people is achieved is through the creation of community between disabled and non-disabled people.”

Another explained how many of their friends have the capacity to be supportive after time and another participant commenting how they found understanding through people who have been through similar **“bureaucratic nightmares”** particularly other disabled students.

A survey participant commented how **“Autism at Warwick and Warwick Enable are fabulous communities”** and an interview participant commented how they had had good experiences with societies they had plenty of involvement with.

This suggests that finding inclusive and actively accessible communities is crucial for disabled students at university.

CONCLUSION

Lack of support and inaccessibility

- Inaccessible environments present a tangible barrier to education and inclusion for many disabled students.
- The extra paperwork and bureaucratic processes many disabled people have to go through to ensure support are often hostile, dehumanising and tiring.
- Disabled students face barriers to accessing support due to difficulty of gaining diagnosis and constantly needing to prove “how” disabled they are.
- Unhealthy cultures of work and attitudes towards rest impact disabled students disproportionately. Disabled students often have to take more breaks and focus more on their health than their peers which takes time and energy that is often misunderstood or unrecognised.

Everyday extra work and organisation

- Multiple participants spoke about how everyday activities took more time due to their disability that went unnoticed by people around them.
- Disabled students have to spend more time organising their days than their non-disabled peers for a variety of reasons. This can be because of inaccessibility of transport, to avoid burnout or emotionally regulate.
- Another cost of disability participants spoke about is the need to advocate for yourself as a disabled person.

Mental health impacts and social isolation

- Inaccessibility and negative attitudes towards disabled people mean many disabled students feel isolated and excluded from a lot of university life, specifically the social aspects.
- Disabled students spoke about the lack of understanding they face from other students and even their friends regarding their limits and accessibility needs
- All participants agreed that their experience as a disabled person impacts their mental health.

RECOMMENDATIONS

RECOMMENDATIONS: PAPERWORK

Simplifying paperwork and making bureaucracy less hostile to disabled people. This can be done by ending dehumanising and intrusive questions and removing the burden of proving “how disabled you are” whilst trying to claim benefits.

For university settings:

- This could include **removing requirements for proof of disability or diagnosis** when providing support.
- Ensuring Disability Services will advocate for disabled students even if it clashes with university policy.

National change:

- A reworking of DSA so that it properly covers costs of living for disabled students and **does not exclude** many disabled students.

Challenging harmful rhetoric about disabled people and laziness when confronted with it.

RECOMMENDATIONS: INACCESSIBLE ENVIRONMENTS

An interview participant spoke about a positive experience they had where staff were **proactive** about an inaccessible path and worked quickly to make sure it was fixed.

Another participant commented on how **consulting disabled students** whilst planning new buildings can mean inaccessible areas are identified early and sorted.

Moreover, a recommendation from a participant is **understanding** around lateness as it can take disabled students longer to get around campus due to inaccessibility or their disabilities.

RECOMMENDATIONS

RECOMMENDATION: REST AND CARE

Listening to disabled people when they talk about their limits and understanding fluctuating energy levels.

- Flexibility around deadlines and attendance is key to this.
- Many interview participants spoke about the value of offering **hybrid or online meetings**.

Valuing rest in workplaces and re-imagining unhealthy cultures of work.

- Currently the energy of taking care of yourself through physiotherapy or emotional regulation is unrecognised or not valued as valid and hard work.
- Ensuring university timetables have lectures that are spread out to allow for regular breaks.

RECOMMENDATION: ORGANISATION

Ensure events, classrooms are accessible and that any accommodations are available or in place.

- Understanding that disabled students have less time in the day than their peers.

Advocate for disabled students when they speak about inaccessibility and their barriers to education or inclusion.

Consider events like welcome week can be made more inclusive and focused on **community building** for marginalised groups.

- Investment in societies and spaces for disabled students.

RECOMMENDATION: MENTAL HEALTH

Invest in **mental health support** that focuses specifically on disabled people and their experiences.

Ensure university society policy takes accessibility seriously and holds society to account in **holding accessible events**.

Build and support **community spaces** for disabled people on campus to combat social isolation.

REFERENCES

Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

Chipchase, S., Seddon, A., Tyers, H., & Thomas, S. (2023). Experience of university life by disabled undergraduate students: the need to consider extra-curricular opportunities. *Disability & Society*, 1–18. <https://doi.org/10.1080/09687599.2023.2233687>

Geiger, B. B. (2021). Disabled but not deserving? The perceived deservingness of disability welfare benefit claimants. *Journal of European Social Policy*, 31(3), 095892872199665. <https://doi.org/10.1177/0958928721996652>

GOV.UK. (2010). Equality Act 2010. [Legislation.gov.uk; Gov.uk. https://www.legislation.gov.uk/ukpga/2010/15/contents](https://www.legislation.gov.uk/ukpga/2010/15/contents)

GOV.UK. (2012, October 15). Personal Independence Payment (PIP). [GOV.UK; gov.uk. https://www.gov.uk/pip](https://www.gov.uk/pip)

GOV.UK. (2021). Disabled Students Allowance. [GOV.UK. https://www.gov.uk/disabled-students-allowance-dsa](https://www.gov.uk/disabled-students-allowance-dsa)

Hughes, F. (2022, November 9). Universities “illegally hitting disabled students with extra housing costs.” *Open Democracy*. <https://www.opendemocracy.net/en/disabled-students-equality-act-adapations-accessible-rooms/>

Kendall, L. (2016). Higher education and disability: Exploring student experiences. *Cogent Education*, 3(1). <https://doi.org/10.1080/2331186x.2016.1256142>

Office For Students. (2019, October 17). Beyond the bare minimum: Are universities and colleges doing enough for disabled students? - Office for Students. [Www.officeforstudents.org.uk. https://www.officeforstudents.org.uk/publications/beyond-the-bare-minimum-are-universities-and-colleges-doing-enough-for-disabled-students/](https://www.officeforstudents.org.uk/publications/beyond-the-bare-minimum-are-universities-and-colleges-doing-enough-for-disabled-students/)

Sowden, C. (2022). University shouldn't cost more if you're disabled - but it did for me. | Disability charity Scope UK. [Scope. https://www.scope.org.uk/news-and-stories/disability-and-university-costs](https://www.scope.org.uk/news-and-stories/disability-and-university-costs)

Wellbeing Support. (2023). Reasonable Adjustments | University of Warwick. [Warwick.ac.uk. https://warwick.ac.uk/services/wss/students/disability/how-can-we-help/reasonable-adjustments/](https://warwick.ac.uk/services/wss/students/disability/how-can-we-help/reasonable-adjustments/)