

# Nothing About Us, Without Us: TCDSU Submission to the Department of Social Protection on the Green Paper on Disability Reform

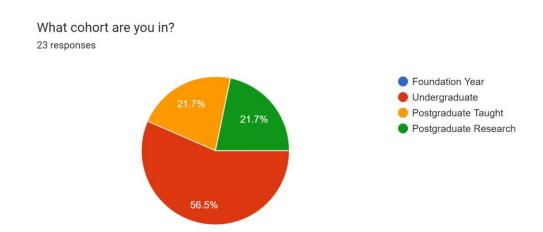
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#### Introduction

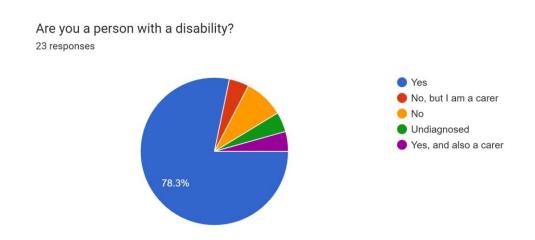
The Trinity College Dublin Students' Union (TCDSU) is run by students, for students. We collectively represent, defend and fight for students' rights, alongside standing in solidarity with the workers' movement. We represent 20,000 students, 4,500 masters students, and 1,500 researchers. We provide access to services, support and we engage in political activism.

This is our submission to the Department of Social Protection to respond to their Green Paper on reforming disability payments. We undertook to survey students and make this report to capture the reality and genuine fear, anger and questions that this proposal is raising. Our College has around 2,000 students with disabilities, many more undisclosed, and it is crucial that their voices be heard in this process.

# **Demographics**



The TCDSU survey aimed to gather opinions from students on the Green Paper on Disability Reform, focusing on those who self-identify as persons with disabilities. There were 23 responses. Participants were drawn from various cohorts, including Undergraduate (56.52%), Postgraduate Taught (21.74%), and Postgraduate Research (21.74%).



The survey responses were made up of 86% people with disabilities, 8% carers, and 4% people without disabilities.

# **Disability Allowance and Payments**

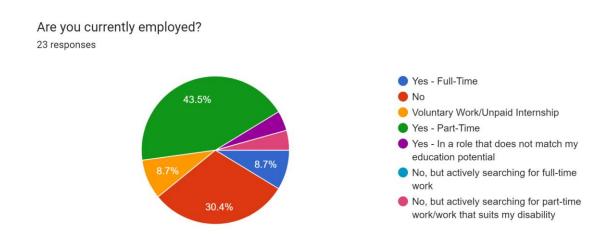
Do you currently receive Disability Allowance or any other disability payment such as "Blind Pension" or "Invalidity Pension"?

23 responses



A significant portion of respondents (65.22%) reported not receiving Disability Allowance or other disability payments. A small percentage (17.39%) confirmed receiving such benefits, with some noting challenges such as denials or the need for breaks/reductions in employment (13.04% combined for related issues).

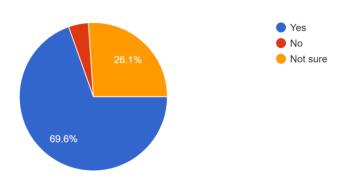
# **Employment Status Among Respondents**



The majority of employed respondents are engaged in part-time work (43.48%), while 30.43% are not employed. Other employment statuses include voluntary work/unpaid internships (8.70%), full-time employment (8.70%), and roles not matching their education potential (4.35%).

# Opinions on the Green Paper on Disability Reform

Do you believe the Green Paper on Disability Reform should be scrapped? 23 responses



A clear majority (69.57%) believe the Green Paper on Disability Reform should be scrapped. A significant portion remains unsure (26.09%), with a minimal percentage (4.35%) opposing this view.

# **Qualitative Insights on the Green Paper on Disability Reform**

#### Reasons for Support to Scrap the Green Paper

View of People with Disabilities in Economic Terms: A lot of respondents
expressed the view that this policy treats people with disabilities as economic
categories. This is a neoliberal way of perceiving and responding to issues.
This Green Paper is a copy of the Tory-policy that was implemented during
austerity in the United Kingdom and which saw people being forced into the
workforce and suicide rates amongst people with disabilities skyrocket.

"I think this is an unreasonable approach to disability and to human beings in general. We should not be placed on a scale in this way when it is already so debilitating to have to constantly prove our illnesses/disabilities. Even reading the word Mandatory beside Intreo is giving me anxiety. This was the bane of my existence as I was trying to apply for disability. I think this does not serve as a means of supporting disabled individuals, but rather it seems to be a response to a subversive feeling of disbelief levelled at disabled people. It reflects a worry about people who are scamming and taking advantage of the system that is already in place. The disabled people of Ireland are not the central concern of this proposed measure, but finances are. We are having a monetary value applied to us in a disquieting way. When we as a society are already conditioned to measure our value as people based upon our jobs and how much money we can earn, this measure of pushing people into a workforce that cannot accommodate them appropriately is indicative of late stages capitalism at its most barbaric."

"As a postgraduate student navigating my academic journey with a disability, the Green Paper proposal on introducing a tiered system for disability payments has personally stirred a mix of apprehension and concern within me. The thought of navigating an even more complex disability benefits system is daunting. It's challenging enough to manage my studies and disability without the added stress of bureaucratic hurdles that could delay essential support. The fear of getting entangled even further in red tape rather than focusing on my research and personal development is disheartening. The subjectivity involved in assessing disabilities and assigning tiers is also deeply troubling. The idea that someone can quantify my daily challenges and place them within a neatly labelled box feels reductive and potentially unfair. There's a lingering fear that these assessments could lead to arbitrary decisions, affecting my access to the support I rely on. Moreover, there's an underlying worry that this tiered system might be a strategy to cut costs. ultimately reducing the benefits for many of us who depend on them to live dignified lives. The mental toll of undergoing assessments, facing potential benefit reductions, and living with constant uncertainty can't be overstated. It adds a layer of anxiety to the already challenging experience of pursuing higher education with a disability."

Administrative Burden on Healthcare System and Biased Processes:
 Due to the requirements of screening in a medical setting for work capability as a result of the tiering system, concerns were raised by respondents that the healthcare system would not be able to cope with the pressure and that resources are being funneled into unnecessary processes. There are also issues around the tiers and the biases that could occur, putting into question the entire idea of categorizing approach.

"The administrative burden and costs associated with implementing such a system raise questions about resource allocation. It seems counter-intuitive to spend more on managing the system rather than directly supporting individuals with disabilities.".

"An individual's "ability to work" cant be accurately assessed and sorted into one of three categories without controversy. Fluctuating disabilities such as chronic pain or neurological disorders would be unfairly assessed, and pressure would be put on these people to overwork themselves and sacrifice their health for the sake of keeping up with these expectations to work, or take courses in order to find work, motivated by fear of losing the little support and livelihood they can be provided with. Also it would be entirely unmanageable to attempt to assess or reassess every individual, as what they are proposing would need to be a thorough and lengthy process for each person, conducted by specially trained medical professionals. The demand would far exceed the capability to provide appropriate assessments, and the system would become rushed and corrupt, with many individuals with invisible disabilities being neglected, overlooked, and outright ignored."

"it will just add more bureaucratic challenges for people that face enough challenges in daily life to do the same as anyone else without a disability"

 Lack of Inclusivity and Representation: Following on from the earlier points, many respondents who advocate for scrapping the Green Paper express concerns over the perceived lack of inclusivity and adequate representation of the diverse needs of individuals with disabilities. They suggest that the reform does not properly address or understand the challenges faced by people with disabilities, both in the educational system and beyond. They suggest that the reforms will be actively harmful to people with disabilities.

"It does not respect the dignity of the person and their disability. A disability is not optional and it is wrong for someone to grade another disability."

• Insufficient Consultation Breaching UNCRPD: A recurring theme is the perceived insufficiency in the consultation process with stakeholders, particularly with people who have disabilities. Respondents feel that their voices and experiences have not been adequately considered in the formulation of the Green Paper, leading to policies that may not effectively address their needs. The process should be a bottom-up approach involving people with disabilities and the organizations that they lead. This would be in line with the UNCRPD, which it is currently not. The Green Paper breaches UNCRPD, particularly Article 33.3, as it lacked the involvement of disabled individuals or organizations in its drafting and by using a medical model approach not a social model as enshrined in the UNCRPD Article 1 and Article 2.

"I hope you will listen to the many disabled voices who are raising concerns with these proposals."

"The paper should be developed with the impacted groups in direct collaboration."

• Gaps in Policy Proposals: Respondents critical of the Green Paper highlight specific gaps in the proposed policies, especially concerning employment, education, and accessibility. They call for more concrete, actionable strategies that go beyond the current scope of the document. The focus seems to be on the people with disabilities themselves, rather than addressing systemic barriers within the workforce, and this is a flawed approach. Once again, this approach was taken because of the lack of consultation with people with disabilities and their grassroots representative organisations.

"I also believe that this reform is not focusing on the correct things here at all. The focus of disability reform should not be forcing disabled people to try look for a job, instead it should be making workplaces more accessible and making the working world far more accommodating to those with different abilities. We know that most disabled people want to work but companies are usually inflexible and will not accommodate the needs of disabled people leading to a lack of disabled people in the workforce. The answer to this is not to force disabled people into jobs that will refuse to accommodate their needs, instead it is to ensure that the working world is accessible to disabled people and to

provide supports for people who want to work. Also, some people can't work at all because of their disability and they should not be forced to compromise their health and medical care to try and work."

The small percentage of respondents who oppose scrapping the Green Paper generally see its potential for positive change. They argue that, despite its flaws, the document lays a foundation for reform that, with proper adjustments and more inclusive consultation, could lead to significant improvements in the lives of people with disabilities. Those who are unsure of the Green Paper due to a lack of information or understanding also indicated that they want to see reform, but it has to be done via proper consultation with people with disabilities. In essence, support for the Green Paper is minimal, but the desire for change is great.

#### **TCDSU Position**

Our Union, based on the results of the survey and analysis of the policy, is that the Green Paper should be scrapped, and in its place a new proposal drawn up, in a grassroots manner that involves meaningful participation from people with disabilities and the organisations that they lead. The current Green Paper is actively harmful to people with disabilities and should be scrapped. A student aptly sums it up as follows.

"As a postgraduate student navigating my academic journey with a disability, the Green Paper proposal on introducing a tiered system for disability payments has personally stirred a mix of apprehension and concern within me. The thought of navigating an even more complex disability benefits system is daunting. It's challenging enough to manage my studies and disability without the added stress of bureaucratic hurdles that could delay essential support. The fear of getting entangled even further in red tape rather than focusing on my research and personal development is disheartening. The subjectivity involved in assessing disabilities and assigning tiers is also deeply troubling. The idea that someone can quantify my daily challenges and place them within a neatly labelled box feels reductive and potentially unfair. There's a lingering fear that these assessments could lead to arbitrary decisions, affecting my access to the support I rely on. Moreover, there's an underlying worry that this tiered system might be a strategy to cut costs, ultimately reducing the benefits for many of us who depend on them to live dignified lives. The mental toll of undergoing assessments, facing potential benefit reductions, and living with constant uncertainty can't be overstated. It adds a layer of anxiety to the already challenging experience of pursuing higher education with a disability. There's also a peculiar irony in the possibility that striving for improvement or engaging more actively in rehabilitation could inadvertently decrease support should my condition be deemed less severe upon reassessment. It's a discouraging thought that improvement could be penalised rather than encouraged. The administrative burden and costs associated with implementing such a system raise questions about resource allocation. It seems counter-intuitive to spend more on managing the system rather than directly supporting individuals with disabilities."

It is also to note that the aims of the Green Paper, specifically the one to reduce poverty, is a broader socio-economic issue. The government needs to take action on the housing and the cost-of-living crisis. Forcing people into the workforce is not the solution. Respondents mentioned a living wage for postgraduate researchers, rent controls, more funding to healthcare services and abolition of tuition fees as well as a variety of other measures. Specifically for disabilities, having individualized support, being able to earn more without it affecting one's disability allowance as well as specific measures for education were listed.

"Addressing poverty among disabled individuals, including postgraduate students like myself, requires a multifaceted approach that acknowledges the unique challenges we face due to our disabilities. Here are some actions I believe the government could take to improve the financial situation for disabled students and reduce their reliance on social welfare overall: 1. Guaranteed Minimum Income for PhD Students: Implementing employee rights and minimum wage for PhD students, regardless of their disability status, would provide a stable financial foundation supporting researchers and encourage more diversity within academia. 2. Disability Supplement: In addition to a minimum income, a SUSI disability supplement should be provided to disabled PhD students to cover the extra costs associated with their disabilities. This could include medical expenses, assistive technology, transportation, and personal care assistance, ensuring these costs do not detract from their ability to focus on their studies. 3. Flexible Funding Schemes: Recognising that disabilities can affect the pace at which students complete their studies, government funding schemes should be flexible. allowing for extensions without financial penalty. This flexibility would accommodate the need for medical leave or part-time study due to disabilityrelated issues. By taking these actions, the government can significantly improve the financial situation and overall well-being of disabled postgraduate students, moving closer to the goal of reducing poverty among disabled people by allowing them to access further education opportunities. These measures provide immediate financial relief and foster a more inclusive and supportive environment that enables disabled individuals to thrive academically and professionally."

### Conclusion

The qualitative analysis reveals a complex landscape of opinions on the Green Paper on Disability Reform, driven by concerns over inclusivity, consultation, and the effectiveness of policy proposals. The majority call for scrapping the document reflects deep-seated frustrations with the current approach to disability reform. The presence of uncertainty and a minority opposition to scrapping the Green Paper suggests a path forward that involves revising the document through a more inclusive, consultative process. However, we interpret this, as the TCDSU, that the best path forward is to scrap the Green Paper, and begin anew, with a bottom-up approach of involving disability organisations. Nothing about us, without us, should be the mantra.

#### **Towards a New Green Paper**

If nothing about us, without us, should be the mantra, then there are key principles which the government must follow.

- Grassroots Consultation: Initiate a more comprehensive consultation
  process that is bottom-up and includes a wide range of voices from the
  disability community to ensure their needs and concerns are directly reflected
  in the reform proposals.
- 2. **Adopt UNCRPD Principles**: Set down a holistic and social, rather than an economic, model for disability supports, then communicate with clarity on how it intends to improve the lives of people with disabilities.
- 3. Focus on Inclusivity and Practical Solutions: Revise the Green Paper with a focus on inclusivity, practical solutions, and actionable strategies that address the specific challenges identified by the disability community in education, employment, and accessibility. The proposal should not be focused on tiering, or categorizing of people with disabilities for economic efficiency, but to breaking down barriers in the workforce, universities and institutions.

#### **Career Goals and Preparedness**

Our survey also included other questions. These questions relate to the main theme of the Green Paper, which is employability of people with disabilities. The analysis of responses related to career goals revealed several key themes:

• Aspiration for Education and Academia: Some respondents expressed a desire to pursue further education or careers in academia, highlighting the importance of continuous learning and teaching as career paths. At the same time, concerns were expressed with regards to the ability of people with disabilities to participate in this. This was especially the case for those wanting to engage in academia and are early-track academics, who exist in a sort of 'liminal' space with very little support. Postgraduate researchers, in line with the Postgraduate Workers Organisation (PWO) need to be given workers' rights, in line with other EU countries, which the TCDSU fully endorses. The need for distance learning, flexible scheduling and part-time study options was also specifically highlighted.

"Clear guidelines and support should exist for reasonable accommodations in academic and non-academic workplaces. This includes adjusting the work environment, flexible working hours, and access to assistive technologies, ensuring disabled PhD students can participate fully and equally in work opportunities. The ability to work remotely is crucial for people like me who are severely immunocompromised, suffer from chronic fatigue and often have mobility issues".

<sup>&</sup>quot;In postgraduate study, which occupies a liminal space between education and job, there are very limited supports in place for sick leave, bereavement leave."

"Educational programs that do not offer flexible scheduling, part-time study options, or distance learning opportunities can be particularly challenging for disabled individuals who may need to manage their health or cannot commit to a traditional, full-time program due to their disability."

- Challenges and Support Needs: Following on from the previous point, respondents noted a range of challenges, from the need for more accessible learning environments to specific skill development. There was a call for more targeted support services to help bridge gaps between their current capabilities and their career aspirations. For careers that have additional costs associated with them, such as being an early-track researcher, it was mentioned that people with disabilities may have a harder time taking on extra part-time work to cover these costs, therefore missing out on career opportunities. Additional financial support for this would be a good measure.
- **Skills and Employability**: A common thread was the concern over employability skills, with many seeking additional training in areas that would enhance their job prospects, such as technology competencies, communication skills, and specialized professional training.

#### **Government's Role in Facilitating Employment**

Responses concerning the government's role in supporting employment for disabled individuals brought to light several critical areas for action:

Enhanced Support Services: There was a strong call for the government to
provide more robust support services, including job placement programs
tailored for individuals with disabilities, mentorship opportunities, and financial
incentives for employers to hire disabled individuals. The state thus needs to
take a more active role in the workforce to enforce inclusive employment for
all.

"I think the government should focus more on incentivizing employers. There are plenty of disabled people who wish to work, or who already do. If employers were to be held to greater standards of inclusivity by the government, I believe that the workplace environment would become more accessible."

Policy and Legislation: Respondents highlighted the need for more inclusive
policies and legislation that actively promote the employment of people with
disabilities. Suggestions included reforms in disability allowances, enhanced
accessibility standards such as flexible working hours and work environments,
more breaks for people with disabilities, access to assistive technologies and
legal mandates for workplace accommodations and stronger antidiscrimination laws. Accessible spaces and furniture and the general
environment in the workplace was a massive priority.

"Have more clear anti-discrimination laws in place. There is not enough support for people who have part-time employment, and they are often treated quite poorly. Improve requirements for employers to provide healthcare and pension to part-time employees. And perhaps if it is the case that a disabled person has a job which they must stop (health is not static), allow us to sign on to our disability payment again, with less difficulty than the current system. There is terrible toxicity in the workplace surrounding sick-leave, which seems to set a hard limit to how often a person can be sick and still hold down a job. These limits increase the stress and deplete the overall health of those with chronic illness and/or disability."

"I was not working due to headaches I had and difficult to complete shifts, I do think government can introduce extra breaks for those with disabilities"

"The government should ensure disabled PhD students have access to employment opportunities within and outside academia. This includes enforcing and enhancing employment rights, promoting inclusive hiring practices, and providing support for transitions into the workforce. Treating PhD students as staff with full worker's rights would give them more protection from discrimination in the workplace overall. Clear guidelines and support should exist for reasonable accommodations in academic and non-academic workplaces. This includes adjusting the work environment, flexible working hours, and access to assistive technologies, ensuring disabled PhD students can participate fully and equally in work opportunities. The ability to work remotely is crucial for people like me who are severely immunocompromised, suffer from chronic fatigue and often have mobility issues."

• Awareness and Education: A significant number of responses pointed to the need for greater awareness and education among employers about the capabilities of individuals with disabilities and the benefits of a diverse workforce. Programs that facilitate direct engagement between employers and disabled job seekers were suggested as potential solutions. Within the workplace, employers should be made aware of what it is to live with a disability, with understanding being the key word. For employees with disabilities, the importance of knowing about legal routes to challenge discrimination was also mentioned.

"Strengthen advocacy and legal support services for disabled PhD students [and people in general], ensuring they have the resources to navigate employment rights issues. This includes providing information on rights under the law, assistance with making reasonable accommodation requests, and support in cases of discrimination."

"understanding from manager that I do not have even levels of energy (like most people) they tend to peak and troph more often than normal this impacts my concentration and attention. Also a flexible schedule to allow for necessary medical appointments."