

75 Years Supporting Independence, Shaping Futures

Rehab Group Submission on the Green Paper on Reform of Disability Payments

30 April 2024

1. Introduction

Rehab Group welcomes the opportunity to input into the Green Paper on Disability Reform.

We also welcome the recent Government decision to shelve these proposals in the wake of considerable opposition from people with Disabilities and the organisations that work with them. We believe that the consultation process was flawed from the outset, as people with disabilities (PWD), Disabled People's Organisations (DPOs) and Disability Service Providers were not consulted during the initial design phase of the Green Paper.

In putting together this submission, the Rehab Group Advocacy Team consulted widely with the people who use our services and our staff to ascertain their views on the Green Paper on the Reform of Disability Payments.

We held 20 focus groups speaking to over 300 service users which aimed to garner the experiences and opinions of our service users on how they believe the Green Paper would impact on People with Disabilities. We also ran an online survey in which 81 Rehab Staff including frontline professional staff across Rehab Care, National Learning Network and Rehab Enterprises who have first-hand experience working with the people who use our services.

We hope that this submission will be taken into account in framing future consultations in relation to the Reform of Disability Payments.

2. Overall Comments

We welcome the debate around the reform of disability payments. From our consultation both service users and staff acknowledge the need for reform of the current system, and particularly referenced the need to address the cost of disability.

Disability policy reform must be rooted in the United Nations Convention on the Rights of People with Disabilities (UNCRPD) which was ratified in 2018. We are alarmed and deeply disappointed that there is not one reference to UNCRPD in the Green Paper. Article 28 of UNCRPD (adequate standard of living,) Article 27 (work and employment) and Article 19 (right to live independently) should have been the basis on which the Green Paper was developed.

There are serious problems with the design of the proposed tiered system. The proposal is rooted in a medical model of disability which ignores the structural barriers, which could be addressed if a more social model of disability had been adopted.

A significant flaw in the Green Paper is that it conflates the issue of the cost of disability with capacity to work. The Cost of Disability Report by Indecon, commissioned by Government and published in December 2021 indicated that being disabled costs a person between €11,579 and €16,284. The cost of disability and the employment of people with disabilities are two different (albeit related) issues and should be treated separately.

The Green paper failed to acknowledge or address the real barriers to employment for people with disabilities.

Implementation of the proposals in the Green Paper could prove administratively burdensome, difficult to implement and result in discriminatory practices against people with disabilities.

3. Design of New Proposals

The inherent flaws in the design of the proposals stem from the inadequate consultation process before the Green Paper was published. The consultation only started only after publication. For a process of reform of the magnitude proposed by the Green Paper, people with disabilities and the organisations that work with them should have been engaged in design process from the outset.

Many service users expressed confusion and uncertainty about the proposals because they felt that they were complicated and difficult to understand. Even with the Easy Read it was difficult to explain some of the proposals and how people would be impacted by the changes.

The proposals in the Green Paper rely on a medical model rather than a social model of disability and fail to take account of the societal issues facing people with disabilities. Such an approach will inevitably lead to people falling between the cracks.

PWD are at greater risk of poverty than people without a disability. CSO figures in 2022 show that one in five people who are unable to work due to health /disability live in consistent poverty. Almost one in two people (44.3%) with a disability live in deprivation compared to national average of 17.7%.

The Green Paper fails to address the recognised cost of disability in any meaningful way while at the same time conflates the cost of disability with the capacity to work. The Indecon Cost of Disability Report reported that the additional costs to manage disability fell between $\leq 11,579$ and $\leq 16,284$ or an additional ≤ 223 to ≤ 313 per week. The additional costs referred to included transport, communications, equipment, disability aids, assistive technology, medical care and personal care.

One of the most serious design flaws of the Green Paper is that it conflates the cost of disability with the capacity to work. The two are separate issues – people with disabilities in employment will still have to contend with the cost of disability. Moreover, the payments proposed in the Green Paper do not adequately address the cost of disability. Both service users and staff believed that the rates proposed were too low. The rate in tier 3 is still the same as it is currently which does not take into account the cost of living with a disability. As DFI pointed out the payment on Tier 1 is below standard poverty line and those recommend by the Minimum Essential Standard of Living (budgeting.ie) and does not factor in cost of disability.

Many of our service users initially welcomed proposals to provide additional financial support to those with higher levels of disability and the additional supports to help people with disabilities find pathways to further education or employment. However, when they started to discuss the implications of the proposals for people with disabilities, they concluded that the tiered system approach was unfair and unworkable. Staff also pointed to anomalies within the design of the proposals that would make implementation difficult to administer fairly.

Similarly, many service users initially said that they felt that the additional educational, training, and employment support for those with a lower level of disability was a welcome aspect of the Green Paper. The service users in favour of the proposals felt that such supports might lead to an easier avenue into employment.

"It's good for people on lower level to get support with education, training and to get a job. I find it really hard to get a job and the help would be good."

"It might make it easier to work, it might make things more comfortable."

However, as service users examined what the new proposals would look like when implemented, they started to express serious reservations.

Our service users felt that the proposals would place a disproportionate responsibility on the person with a disability placed in tiers two and three to get a job but that they failed to take account of the main external factors preventing them from doing so. There seemed to be an inherent assumption in the proposals that people with disabilities in receipt of a welfare payment are capable of working but do not want to.

They also felt that they pitted people against each other forcing them to prove how disabled they are and would likely cause division amongst people with disabilities. There was a worry that assessors will not take people with autism or hidden disabilities and mental illness as seriously as they would somebody with a physical disability and as a result that the system itself would not be inclusive. There were strong concerns as to how the assessments would be administered, particularly the approach to assessing people with mental health issues, autism, ADHD, whose disabilities are not always immediately apparent. Similarly, there was concern that people with disabilities the severity of which may flare or fluctuate, could find themselves being assessed on a good day but such an assessment doesn't take into account the numerous days where it's difficult to just get out of bed!

"No everyone should be treated equal."

"It feels like they're putting people against each other."

"It's like being put in a box."

Staff also disagreed with the proposals on the grounds that the amount of disability payment a person receives should correlate not with their **capacity to work**, but on **the cost of disability and the cost of living**. These respondents emphasised the **severe stress and anxiety** that these changes would cause for many:

I am concerned that vulnerable people with disabilities, especially hidden disabilities, and people who present well but have unique difficulties will not be catered for correctly but end up in a situation where they are overwhelmed, anxious and not getting the support they need.'

I have concerns that the payment will be based on people's ability to work. I believe the payment should be based on the persons basic requirements to live, pay bills, have enough food etc.'

Service users felt there was a possibility that if they were to be cynical this could be seen as a money saving exercise:

"They will put a lot of people in the lower tier bracket to save money."

"The government have no interest in the people'."

"I feel like this is a cost saving exercise. I want to be put into a tier based on my actual support needs at that time, not what money I can save the state!"

There was a strong consensus that the focus should be on removing structural barriers to social inclusion rather than focusing on the capacity to work.

4. Implementation of the Proposals

As our service users and staff discussed how these proposals might be implemented, significant problems with the proposed system were identified.

1. Tiered System

The tiering system and how it would be administered seemed complex with the strong potential to place undue stress and burden on the person with the disability to both our staff and our service users.

Our service users were very concerned as to how they would be assessed and categorised into one of the three tiers, in particular what the approach would be to assessing people with mental health issues, autism, ADHD, whose disabilities are not always immediately apparent. They also believed that this approach failed to take account of the main external factors preventing people with disabilities finding employment. As outlined above, there were strong concerns among our services users about compelling people on tiers two and three to engage with employment services.

A strong cohort of staff respondents disagreed with the implementation of a tiered approach for several reasons.

- There were concerns about how the assessments to determine what tier the person would be placed on or what capacity they had for work could operate in an equitable and fair manner.
- They felt that it may well become a lottery based on the assessors' opinions.
- There are concerns that people will be shoe-horned into Tiers 2 and 3 without being offered real support in seeking employment.
- They advocated for a more individualised approach to ensure that people are receiving exactly what they need to live lives of their choosing.
- They expressed significant doubts about how the classification or labelling of people could be done in a way that was not unfair, demeaning or stressful for the people who use our services.
- Several staff member stated that the proposals were an oversimplification, and that the system of assessment for capacity to work was not clearly outlined.
- They echoed the point made by our service users that people with mental health difficulties who might seem to be able to work, but who in reality may not be mentally able to cope with the strains of work-related pressure and stress.
- Many argued that this would end up penalising people who do not have the capacity to work, it would force people with disabilities into employment without the necessary supports and it would undermine their personal autonomy.
- They expressed concern about whether the resources required to set up such assessments would be funded, especially in consideration of the huge delays already in place to assess children for an initial diagnosis of disability.

Many of our staff respondents felt that the amount of payment an individual receives should be based on their circumstances – the cost of living and the cost of disability – not based on capacity to work:

'I think it should consider the individual's needs more than their work ability. An individual with disabilities may be able to work but their income may not match their expenses in relation to their disability e.g. cost of therapies, supports, etc.'

'I disagree with this - how will an assessment determine capacity to work? Surely capacity to work should be determined by our service users and if they feel they do have capacity they are supported to then find employment.'

'A more individualised approach is necessary to ensure that people are receiving exactly what they need to live lives of their choosing.'

People with less support needs will feel pressurised to work which in turn if not adequately supported could cause them harm and distress. Even questioning their ability to work, undermines their disability and the opinion of medical professionals. Allow these individuals choice and if they can work comfortably, then assess their payments but don't penalise individuals who would find the whole working environment overwhelming, don't lower their income, don't discriminate against them.'

2. Assessment Procedure:

Our service users were particularly concerned about the assessment procedure.

As outlined above they questioned how the assessor could fairly judge a person's disability and their capacity for work and how the cutoff point for each tier could be determined.

A particular concern for both our service users and staff was that the proposals could potentially discriminate against those who have hidden disabilities such as mental health issues, anxiety. Mental health can be a transient condition which in many cases is only maintained by the ongoing support of the community mental health team. People can experience periods of wellness and we fear that this could be misconstrued as being total recovery by a case officer or medical assessor who is not a part of an MDT team. These are the vulnerable people who could find themselves forced into work or placed on the lower scale of payment and pushed into poverty.

Responses from service users are captured in the following comments:

"It's a hard one, how to you award it? Your disability can have a low impact on your life for a little while but then you could have a flare up again and your disability may prevent your capacity to work again."

"You can't guarantee that your disability will not have a flare up again".

"People with mental health issues - their conditions can fluctuate. It could be difficult to prove that you suffer with mental health issues when you maybe presenting as well at the time.

It's hard to judge someone's disability as it affects people in different ways".

"It will be really difficult to assess people's disability and capacity to work especially if they don't see how the person functions in day-to-day life."

"Worry that the assessors will not have a comprehensive idea of individuals disabilities and how it affects their lives."

Staff contended that neither the infrastructure nor the trained personnel existed to make this system work effectively, that people with disabilities would undergo an inordinate amount of anxiety, so much so that it could worsen their condition.

The Green Paper proposes to have a medical assessor in INTREO to carry out assessments. However, a number of questions remain unanswered in relation to the assessment procedure:

- Will mental health specialists be used?
- What would their knowledge or experience of the complexities of different disabilities be?
- Will case officers be used also in the assessment process and if so, are staff in INTREO trained in mental health care needs?

- Are INTREO assessors in a position to appropriately assess whether people should "take up reasonable offers of places in training and employment programmes and take up employment opportunities that are appropriate to their capacity and circumstances".
- How do they decide the cut- off point for people with disabilities to go into different tiers?

There was a real fear that the assessment process would be degrading and that applicants would be asked to go into some of the most personal aspects of their life in order to receive a payment to survive.

"Being asked that question is too personal."

"Concerned that there is a person sitting in an office making important decisions about my life."

"Just because we are disabled shouldn't mean we are made to feel bad about it."

"More awareness and understanding are needed."

Both service users and staff advocated for a consultative approach to categorising people into the tiers. Service users expressed the strong view that the person themselves should play a large role in the decision about what tier they should be placed rather than it being based on the opinion of an assessors that they may have only met once or twice.

"Nothing about me, without me. The person themselves should have input."

"I am the only one that knows what my disability allows me to do, so I should decide what tier to go on."

"Someone in social welfare doesn't know me, so I should be asked what tier I want to go on."

"Someone should spend the day in my shoes and then they can have an opinion on what tier I should go on."

"Discuss it with the person and ask them their opinion. It's their right to think where they should be."

"A personal account should be included; we need to be able to advocate for ourselves."

Service users acknowledged the reality that a report would need to include reports and consultation from medical professionals but argued that it also should include reports from guardians, family members, social workers, or key workers in their day service that know the person well and have dealt with them on a day-to-day basis.

The anxiety of being assessed and then reassessed every 2 years, filling out forms that may be difficult to fill out without significant support worried many of our service users.

"Tiers 2 and 3 are unfair as it causes added stress and anxiety for people having to be assessed and then reassessed every two years."

Staff responded negatively when asked if they agreed with the reapplication procedure, they raised concerns over how and by whom the decisions regarding extension or reapplication would be made:

'I don't agree as it is difficult enough to get DA as it is without looking for extensions or to reapply.'

'No - I think it should be done for as long as possible that the person needs it - putting a timeframe on it can put undue stress on people because they may think they need to be recovered in that set time frame and it can actually affect their recovery.'

'No, I think 24 months is too short a time frame and am concerned about how reviews will be conducted and the time frame of same and will the dept be resourced enough to be able deal with the level of reviews required and the complexities of personal circumstances.'

'No, it should be decided by the persons own GP. and let them engage with the person on the length of time that they need to recover. People suffering with PTSD, they look healthy, but mentally cannot guarantee their moods, manners, or triggers if they were given employment under duress.'

'I do not agree with the time restrictions as the timeline can vary greatly if you consider each person's ability to learn new skills, the support they will have/need and where they live/services they can access etc...it will be an unfair link to make. Many vulnerable people will be stuck in the system trying to re-apply etc...'

There were also practical concerns in relation to the assessment process that it may simply delay access to the payment. There was no information on how the appeals system would work and how long that would take.

3. Pathways to employment

Both service users and staff felt that this proposed scheme did not consider how difficult it can be for people with disabilities to find and stay in employment, especially when they are not properly supported. Both groups expressed concerns that a tiered approach would put undue pressure on people with disabilities to get jobs that may not be suited to them and may cause them sever stress and anxiety. It was contended that before any sort of tiered payment system is introduced, the employment options and supports for people with disabilities needs to be radically improved and expanded. They felt it unfair that the Green Paper focussed on compelling people with disabilities to engage with employment services without any meaningful discussion as to how the employment services will actually engage with them.

Many of our service users felt that the proposals would place a disproportionate responsibility on the person with a disability to get a job but that they failed to take account of the main external factors preventing them from doing so.

Realities such as a lack of accessible transport, employers' attitudes to employing people with disabilities, unwillingness to put additional supports in the place of employment for the person all combined to prevent people with disabilities from competing in the open labour market:

"What stops me from getting a job is that I have no accessible transport where I live. I am in a wheelchair and depend on my parents to drive me everywhere as I have no bus and taxis cost too much. I can't ask them to drive me in and out of work."

"There are no jobs for people with disabilities."

"Employers don't want us."

"Employers have to be on board, it can be difficult to find a workplace that suits people and their needs."

"No, what if they don't recognise my disability? The staff in the office would need disability awareness training."

"There needs to be more initiatives for employers to hire people with disabilities".

While most our service users have not had direct experience with INTREO, the majority of the responses from those who did have experience with INTREO were not supportive of its role in the new system and reported having bad experiences with regards the accessibility of its services.

There was also strong concern that INTREO staff did not have the capacity to deal with people with disabilities. Those service users who already had experience of dealing with INTREO provided the following insightful feedback:

"I am deaf and use ISL to communicate. INTREO said that I was not entitled to an interpreter for interview with them or for job interviews. I now know different!"

"No ISL provided, I did not feel supported."

"It was a horrible experience. Staff need disability training!"

"Depends on the person you get."

"Didn't find it helpful, don't want anything to do with them."

"the person looked back at me blankly."

Staff also reported strong concern about compelling engagement with INTREO:

If there are reductions in payments etc based on your engagement with INTREO/Turas Nua etc. this is another area of issue. There is minimal faith in these services based on the many experiences those on jobseekers etc have already had with them. If you are compelled to engage, what you are compelled to engage with must be effective.'

While some staff felt that the proposed changes might increase the uptake of current schemes incentivising employment, most staff respondents were concerned that these changes would not incentivise, but rather **pressurise and frighten** people with disabilities into seeking employment, and would therefore end up in a job that they could not sustain or be comfortable in.

Staff pointed to real incentives to employment such as more opportunities, better supports to and in employment, financial gain, and the retention of travel and medical cards:

"There needs to be additional supports in place to incentives employers to hire individuals with a disability also. Individuals with disabilities may need additional support in workplaces and that needs to be taken into account.'

From speaking to service users there are concerns about losing medical cards and travel passes.'

Several staff made proposals to help people with disabilities back into employment in a non-threatening and inclusive way.

'I know from experience in my own work how hard it is for people with a disability to become employed. The current model of the WSS is a case in point where it favours the employer and not the person receiving the DA'.

'This should only occur after Service User gets a full time/Part time job and have spent time in the job which allows them to feel comfortable in and allows them to develop in their job and so not need to go back on their original payment.'

'It is ok to incentivise people to being employed, but you need to have jobs for them to go into. Ireland has very little manufacturing, manual labour is now a thing of the past. Creating more spaces on indoor CE schemes would be a kinder way to get people back to work, not the INTREO offices.'

'I think people will be much more likely to consider employment if they know that their payment will remain the same or just slightly reduced for a transition period at least. For example, some people in employment are paid monthly etc.'

4. Recommendations

- The Green Paper met with significant opposition as it failed to address so many of the structural barriers to social inclusion sought by people with disabilities. Any new proposals must take cognisance of this, and the starting point must be the United Nations Convention on the Rights of Persons with Disabilities.
- The Optional Protocol of UNCRPD should be ratified without delay.
- The Department of Social Protection should involve people with disabilities in the initial design phase of any new proposals before publishing them.
- The medical model approach to disability should be rejected in favour of a social model approach to disability which seeks to overcome structural and systemic barriers to disability.
- The cost of disability needs to be addressed separately from the capacity to work. The recommendations of the Indecon Report including a cost of disability payment need to be actioned.
- Rates of payment need to be reviewed and reflect the Minimum Essential Standard of Living.
- Greater clarity is required about defining the capacity to work. For some people, working eight hours per week could mark a significant achievement.
- People with disabilities should be centrally involved in any assessment or decision about their welfare payment.
- There must be greater engagement with employers and disability programmes put in place with employers to incentivise them to employ people with disabilities. Programmes proposed by Rehab such as the Workability Programme and Transitional Workforce Solution should be piloted and funded nationwide.
- The report on the consultation on the Wage Subsidy Scheme should be published without further delay. Reform of the WSS is urgently required. See <u>Rehab Submission</u>
- Specialised staff in INTREO should be assigned to work with people with disabilities and <u>all</u> INTREO staff should receive disability awareness training.
- The panel of assessors should include mental health specialists, psychologists, social workers.
- A Government supported transitional service dedicated to helping people back into employment should be considered.

5. Contact Information:

For further information on this submission please contact:

Emer Costello Head of Advocacy and Campaigns Rehab Group 10D Beckett Way Park West Dublin 12 Email: <u>emer.costello@rehab.ie</u>

Mobile: 0861659011

Website: www.rehab.ie