

Rehab Research Report:

The Challenges facing People with Disabilities in Ireland in 2021 – the voice of people who use Rehab services



Introduction

This research paper sets out the main feedback from extensive engagement with people attending Rehab services in May 2021.

During May, we sought substantial and detailed feedback from people in RehabCare and students in National Learning Network (the training section of Rehab Group). We asked about the main challenges that people in Rehab services faced but also what they would like to see tackled in the next Budget. Over 200 participants took part in 33 focus groups across 21 counties. A full outline of our methodology is set out at the end of this report.

This report seeks to give voice to some of the main issues that were raised by participants and offers some key insights into the matters most affecting people with disabilities or mental health challenges in Ireland.

Summary Findings

Overall, five key issues were most prominent in the feedback we received from people in our services:

- 1. The most prevalent issue raised was the struggle to live on current rates of social welfare. And this is especially so if the person was living independently or wanted to live independently.**
- 2. Challenges in finding employment**
- 3. The cost and availability of suitable Housing**
- 4. The lack of appropriate Transport and the high costs this imposes**
- 5. Hidden healthcare costs**

We expand on each of these areas below.

The Struggle to Make Ends Meet

“My mum buys my clothes for me because I can’t afford to and I’m 25!”

The clear feedback from our focus groups was that many people struggled to live on the income they received through social welfare. This was particularly pronounced among people living independently or who wished to live independently. This is the single most prevalent piece of feedback we received during this engagement and echoes the survey research we completed last year. In that research, people living independently were three times more likely to tell us that they struggled with basic bills than people who lived at home. There is a clear lacking in the State’s response to this group.

Respondents also had concerns about the high costs imposed by inadequate transport in rural areas and how social welfare fails to compensate for this. The struggle to meet one-off unexpected bills was also highlighted in many groups, as was the reliance on family to meet their basic costs. And many pointed to the fact that basic social welfare rates had not increased since 2019. Finally, many pointed to difficulties with the lack of top-up payments if they are attending training courses.

Some of the typical comments we received through our focus groups included:

Disability Allowance is too low:

“[I’m] Left with very little to live on... [I] can’t have savings. [I] Have had to spend more on phone and internet bills due to the lockdown to keep in touch with friends and with staff. [The] Cost of living is going up all the time but the DA is not. It really is a struggle.”

“The fuel allowance helps but it isn’t enough and I sometimes have to choose between buying fuel and general living costs, for example topping up [my] phone. Electricity and gas are constantly increasing.”

“Rent keeps going up but DA stays the same...DA should be increased. It’s not easy to live on just DA...it is hard to afford things like phones, laptops, all my bills too...A deposit for rent is very hard to save for.

It is an enormous struggle to live independently:

“DA is not enough to live on, especially not if you are to live alone.”

“DA has to be increased, it is difficult to make ends meet, especially when living alone.”

“Increase DA, the cost of living is more than I have in income”

Many people in rural areas highlighted the high cost of transport:

"I find it hard to keep a car on Disability Allowance – costs like insurance, NCT, Motor Tax, then getting it serviced. It's worth it as I'd be lost without it."

"I have to limit how often I come in [to my day centre], because of the cost of taxis."

"I'm really struggling. Some months are better than others. I need my car as I commute 150km round trip for my course. It can be really difficult to keep things going."

The adequacy of social welfare is often disguised by the extent to which families are relied upon:

"Sometimes it's difficult to pay bills, I have to ask family for help now and again."

"My parents give me a helping hand. They shouldn't have to. They're pensioners and I'm nearly thirty. It's not right".

"My mum buys my clothes for me because I can't afford to and I'm 25!"

Many people highlight that the rate of Disability Allowance has not increased in two years (last increased in March 2019):

"DA rate hasn't gone up since 2019...I was disappointed in the budget last year that it didn't go up, and I do feel that it's leaving people with disabilities behind."

"Everything is getting more expensive, so why is DA staying the same?...you have to watch every penny going out".

"Inflation means that we need a bit extra, rents went up so much, why not DA too?"

Many struggle to afford one-off bills:

"Bills can be a worry, if they change or increase it can be stressful."

"If you get an unexpected bill it can be very difficult to pay- can cause stress. [It's] Impossible to save money, it is just enough to exist."

"I have a car and if it breaks down I can't afford to fix it".

Training Allowances are inadequate

A growing issue for people who use Rehab's services is the loss of the Rehabilitative Training Allowance (RTA). RTA was a training support to help students meet the costs of participating in further education. In 2019, the then Government decided to no longer pay that allowance to anyone starting a new course. Participants raised this as an issue for them in our focus groups:

"Training allowance is a lifesaver. There should be training allowance for people with disabilities on more courses, not just some."

The withdrawal of that allowance, worth €31.80 per week, means that many students struggle with participation costs. Some courses partially cover travel costs and some do not, and participants felt strongly that there should be a much more uniform system and that supports should be improved:

"There's no extra allowance for being here, we may as well be at home."

In many cases, the cost of participating largely uses up any income support participants receive, leaving participants dependent on family for other expenses or unable to participate at all.

The Challenge of Finding Employment

“Employers don't want to know once they see you have a disability.”

Barriers to Employment

There was a consensus among participants in our focus groups that the main barrier they face to gaining employment are employers themselves. Many participants expressed that employers “do not understand disability” and that employers should receive more training on diversity and inclusion of people with disabilities in the workplace.

Participants feel that it is **very difficult for a person with a disability to get a job because of employer attitudes** towards them:

“Employers don't really show an interest in taking on people with disabilities.”

“Employers don't want to know once they see you have a disability.”

“Companies sometimes look down on people with disabilities.”

“It is really difficult to get work. Having a disability holds us back. Employers are nervous about taking us on.”

People using Rehab services said that **employers should engage with diversity and inclusion training**:

“Sometimes the changes that companies have to make are very small, I wish they realised that.”

“...if they understood more there would be more people with a disability working”.

“I would like employers to focus on my ability, not my disability.”

Some participants highlighted that people are less likely to disclose their disability to employers for **fear of discrimination or being treated differently in the workplace**:

“a lot of people have to go in and not say what their disabilities are, and I think that's unfair.”

One participant explained that they had to leave their job because they were **treated differently in the workplace**:

“I used to have a job...I ended up leaving for personal reasons because some...people were watching me like a hawk...”

Participants also felt that the Government could do more to support employers by providing **incentives to hire people with disabilities and funding for training**, while also involving people with disabilities in the process:

“We feel the government should invest in supporting businesses to educate themselves around disability. They should give more incentives to businesses to employ people with disabilities.”

“Government don’t tell employers about the grants that are available to help them take on people with disabilities”.

“The government should involve people with disabilities in planning incentives and education for the employment sector.”

Fear of losing Disability Allowance

Participants were fearful that they would **lose their Disability Allowance if they were to take up part-time or full-time employment**. The prospect of losing Disability Allowance, and the challenges to receive the payment again if they can no longer work, appears to be a significant deterrent. Participants would like to be able to work more hours and earn a higher wage without the threat of losing the Disability Allowance:

“...why would you work if you are going to end up losing your Disability Allowance money?”

Participants also shared their **dissatisfaction with the Community Employment (CE) Scheme**. Participants were critical of the scheme as once it ends some people find it difficult to get back onto their Disability Allowance payment. They felt that CE Schemes do not provide job security and are not a long-term solution to help people with disabilities into the workforce.

Covid-19

Covid-19 and the corresponding restrictions have undoubtedly had a major impact on people with disabilities. Some focus group participants are employed - however they have been unable to work during the pandemic due to underlying health conditions or closures.

One participant, who works in a school, could not go back to work despite schools re-opening because of his disability:

“Even though the workplace is open I still can’t go in because of my disabilities. I’m wondering will I be able to back to work.”

He hopes that he can return to work in September.

Another participant became visibly upset because she has not been able to return to work since the beginning of the pandemic:

“I need my job, I’m out of work a long time now.”

Other participants expressed how difficult it has been for them to gain employment or attend work placements due to the restrictions. Many felt that the restrictions were a barrier to gaining vital work experience.

Housing

“People should have access to appropriate housing for their needs. People should not end up in nursing homes because there are no proper services or the HSE doesn’t want to pay for supports”.

The housing crisis affects anyone in Irish society looking for a home. A lot of the people we spoke with continue to live in their family homes. However, many participants expressed that they want to live independently. They said they plan to have their own homes in the future but are aware of the barriers that may prevent them from moving out of their family home into their own housing or accommodation.

Participants said they would like to see more housing built, especially social housing, and to have more accessible housing in general. There was also agreement that the Government should help to support people to live independently through schemes to make homes accessible and affordable.

Participants felt that housing should be a particular priority for the government in 2022.

Accessible Social Housing

Participants cited the lack of supply of social housing as a significant barrier to housing. The lack of supply means that many are waiting years on Council waiting lists.

Participants made it clear that they want the government to build accessible social housing near to services and amenities so that they can live independently:

“There should be more social housing, especially small apartments for people who want to live alone. The available houses are often not suitable, too far out of the city...”

“There should be more social housing for people with disabilities to help them move out of home.”

“The government should be building more houses and apartments for people with [a] disability, they are not putting enough effort into it”

One person said they waited for five years to get their home.

Social housing is already limited around the country, with many people on waiting lists for a house. For people with disabilities, this can mean longer waiting times as they require a house to suit their needs. Participants said the lack of accessible social and private housing in their locality is a serious issue. One participant said, *“We are left with very little options”*. Some also said that they feel people with disabilities are at risk of being homeless because of the lack of accessible social housing.

Participants would like to see new builds made accessible and reserved for people with disabilities so they can live independently.

Affordable housing and accommodation

The cost of housing and rented accommodation was mentioned in our focus groups by a range of participants – some living independently and struggling to pay the rent, and others who would like to move out but are unable to because of the cost.

Those who live independently struggle with the money they have left after paying for rent. One participant who lives in private rented accommodation said rent is high and so they have very little of their Disability Allowance left after paying for groceries and other necessities. Others in shared accommodation also struggle financially:

“I live in shared accommodation and sometimes find it hard to pay my rent - sometimes my sister helps me out with food or stuff”

Those that live in the family home but would like to live independently said the cost of rent was a barrier to move out because of the amount received on Disability Allowance payments:

“Rent keeps going up but DA stays the same...a deposit for rent is very hard to save for”.

“With rent, bills, and shopping it’s just impossible to move out of home”.

There is a need for local authorities to increase accessible housing supplies to ensure the rights of persons with disabilities to live independently, and affordably, in their communities.

Nursing homes/congregated settings

Thankfully, Ireland is moving away from placing people with disabilities in congregated settings. However, following the recent Ombudsman’s report, people in our focus groups expressed fear that they would have to move into nursing homes should they be unable to get supported accommodation or afford to live independently with supports:

“We are frightened that if we apply for something else and it isn’t available that the only option left open to us is a nursing home.”

“People should have access to appropriate housing for their needs. People should not end up in nursing homes because there are no proper services or the HSE doesn’t want to pay for supports”.

“I don’t want to end up in a nursing home”.

People also said they were concerned for their futures, especially those living in family homes with the support of an elderly parent or family member:

“Housing is such a scary thing to think about for the future”.

“My dad worries all the time about the future, it makes him stressed. I am afraid too but don’t want to make it worse for him as he is not well.”

“We don’t really talk about it, my sister will take care of me when I get old”.

People with disabilities need security in their housing options, whether they wish to live independently or with family for as long as they choose or is possible.

Transport

“Only for my Dad I would have no social life... he insists he’ll drive me anywhere I want to go. The only thing is he’s 82. It’s unreasonable for me to be getting my Dad to drop me everywhere in the car at 82 years of age.”

According to the National Disability Authority, Ireland has fallen behind comparable countries in making its transport system more accessible for everybody, which has hampered the mobility of people with disabilities.¹

The main issue with public transport that arose in our focus groups was the poor service in rural areas and the inaccessibility of buses and trains.

The majority of focus group participants said that public transport was an important service for them. Those who use Rehab services use public transport to access services, attend training colleges and universities, socialise, and get to work:

“I need it every day I couldn’t live without it.”

“I rely completely on public transport, I live at home but my family don’t have a car.”

Those who use public transport rely on their travel pass to afford it. Many said the travel pass was crucial for them to be able to attend their centre and training courses:

“The travel pass is very important...I would be lost without it.”

“The bus pass is a lifesaver.”

Participants living in rural areas that aren’t serviced by public transport felt penalised by the cost of private transport. Some felt that the reinstatement of a mobility or travel allowance for people who rely on a lift or taxi is required.

The National Disability Inclusion Strategy 2017-2021 aimed to “improve accessibility and availability of public transport”. However, the lived experience of people with disabilities who use Rehab services has shown that there remains limited access to public transport in rural areas, poor infrastructure and there has been little reduction in the notice period that wheelchair users are required to give bus and rail companies.

¹ <http://nda.ie/disability-overview/key-policy-documents/report-of-the-commission-on-the-status-of-people-with-disabilities/a-strategy-for-equality/a-strategy-for-equality-report-of-the-commission-on-the-status-of-people-with-disabilities/transport-and-mobility/>

Lack of transport services in rural communities

Poor service and infrastructure in rural communities have led many people with disabilities who live there to rely on lifts from family and friends as well as taxis. Not having access to public transport limits people's mobility and restricts them to others' schedules to attend services and appointments. The free travel pass is redundant for them as their localities are not served by buses or trains. The cost of using private transportation can also limit a person's mobility due to the expense.

The cost of petrol and taxis can be upward of €25 per week. Some have had to limit the number of days they are in the centre because of the cost of getting there:

"I only attend one day per week as I can't afford any more days due to having to take taxis."

"I need to use taxis because there isn't a Local Link service in my area, taxis are very expensive and it takes a lot of my allowance each week if I need to go anywhere."

"I have to find some other way of getting to the centre. My dad is having to drive me every morning...he's spending lots of petrol on it, he drives to the centre every day."

Some people rely on elderly family members to bring them to and from their day service. Without them, they feel they would be unable to come to the centre, access their communities, or socialise:

"Only for my Dad I would have no social life... he insists he'll drive me anywhere I want to go. The only thing is he's 82. It's unreasonable for me to be getting my Dad to drop me everywhere in the car at 82 years of age."

Bus routes and services are lacking in rural communities. Participants living in rural areas were particularly critical of the Local Link service that was set up to serve rural communities:

"Local link does not operate a good enough service. It doesn't service rural areas."

"Local link does not reach the most rural parts of the country."

"Local Link is fine but it doesn't operate in the evenings or on Sundays. If you wanted to go to the cinema...you would have to get a taxi home which would cost 20/30 euro. It's a lot. If they operated in the evenings and weekends it would be great."

"Local link doesn't service all areas and those it does service the timetable doesn't suit for getting to and from day service."

Others highlighted the lack of services on their routes, and said there was a need for more frequent bus times to suit their schedules:

"We'd need more buses, we only have like one a day."

"a lot of people rely on it, but it's not good enough."

"I could be waiting hours for a bus...I have to plan the whole day around the buses."

Public Transport is inaccessible

Many participants highlighted the inaccessibility of public transport. Wheelchair users rely on lifts or taxis to get around.

Participants agreed that there is a lack of wheelchair accessible transport in Ireland and they would like to see ramp access for buses and trains:

“If you wanted to go out on a Saturday night, as a wheelchair user, it would be impossible as there are very few wheelchair accessible taxis. It excludes me from having a social life.”

Some participants expressed negative experiences accessing rail services, as they are required to give notice before travelling but can still be left waiting on the platform to board the train.

Other participants suggested that there be a person to support you while taking the bus or train and that seatbelts should be installed on buses as one participant says they don't feel secure in their seat without one. The need for more toilets on public transport was also highlighted.

Private transport

For many living in rural areas, private transport is their only means of getting around. Some participants detailed how costs such as insurance, tax, NCT, and maintenance of a car are high but despite this, they said *“It's worth it...I'd be lost without it.”*

One participant said that learning how to drive isn't accessible for some people with disabilities:

“The cost is a lot. You now need a computer to do the theory test, you cannot do it on phones, this is not fair for people with a disability...Learning to drive is a challenge, there are too many barriers if you have a disability.”

Participants who relied on private transport felt that the government should step in to ensure more affordable options are available to people with disabilities living in areas that aren't serviced by public transport,

“The government should help people that live in rural areas to get affordable transports. My Dad drops me in here four days a week, drops me in the morning, and collects me in the evening.”

The reinstatement of the mobility allowance for new applicants must happen to ensure that people living in rural areas can afford to attend services and engage with their communities.

Hidden Healthcare Costs

“Medical Cards are helpful but everything should be covered, there should be no restrictions on it. I think it’s absolutely ridiculous that free health care isn’t actually free”.

Another major issue covered in our focus groups was medical costs, with many participants pointing to the problem of hidden healthcare costs. The common thread running through this was the need for the Medical Card to cover much more costs than it currently does – and how a range of extra costs faced by Medical Card holders eats into their already low rate of income and affects their ability to afford basic healthcare.

Several participants complained about GPs charging patients with Medical Cards for blood tests:

“GPs should not get away with charging Medical Card patients.”

“Some things aren’t covered by the Medical Card – bloods and dentist. That’s an extra cost.”

“Improve coverage of Medical Card – cover bloods.”

About a quarter of focus groups pointed to hidden dental costs:

“[I] Would like the dentist to be covered by the Medical Card...you could go to a dentist and they could hit you with a bill of €500. A person who’s on an allowance or a social welfare payment wouldn’t have the money for that.”

“Dental health costs worry me as dentists will not take medical scheme customers.”

“I can’t afford to get dental work I want done, it’s not urgent and so I have no affordable options, my choice is gone. I am saving and finding it hard.”

“Paying for blood tests, even with a Medical Card, should be a free service, no hidden charges.”

Another common complaint from participants was the cost of prescription charges:

“Prescription charges should stop, medication is far too expensive, especially for people with several conditions.”

“I spent €25 a month on tablets. They should scrap the payments on tablets.”

“I take tablets that I need for systems. The money for that is too expensive, so I want to cut it down a small bit.”

Finally, many participants pointed to weaknesses in the Medical Card system:

“Medical Cards are helpful but everything should be covered, there should be no restrictions on it. I think it’s absolutely ridiculous that free health care isn’t actually free.”

“Medical Cards should be for life we shouldn't have to renew every few years - we have a disability for life.”

“Delays with Medical Card applications cause problems for people. Having to justify the Medical Card every so often- why? Disability is a lifelong issue for some.”

Conclusion

It is three years since the Irish State ratified the UN Convention on the Rights of Persons with Disabilities. Therefore, the Irish government's policies and annual budgets should reflect its commitment to the Convention. Ireland has a long way to go to ensure the equality and human rights of people with disabilities. Hopefully, Budget 2022 will be a step in the right direction.

The voices of those who participated were central to informing the main themes of the organisation's pre-budget submission. They shed light on some of the main challenges faced by people with disabilities or a mental health challenge in modern Ireland. The commentary from participants was powerful, and we hope that their experiences influence the government's budget for 2022.

We would like to thank all those who took the time to participate in the focus groups and the staff who supported people to do so remotely.

Methodology

In May 2021, the Advocacy Team of the Rehab Group undertook a series of focus groups with people who use RehabCare services and National Learning Network students to inform the organisation's pre-budget submission.

This document is the research that has informed the organisation's submission. We aim to highlight participants' lived experiences and to amplify their voices and their needs. Their feedback is concentrated in this document and spans the topics and issues that dominated the focus groups.

Over 200 people participated in the research. Participants were drawn from 21 of the 26 counties in the Republic of Ireland. There was an average of six participants per focus group with an even gender balance overall. All but one of the focus groups were held remotely.

The profile of the participants were mainly people with an intellectual disability, an acquired brain injury, or a mental health challenge. Their main income was either Disability Allowance or a training allowance (which in most cases matches the value of Disability Allowance).

The focus groups included a mixture of people using RehabCare day services and National Learning Network (NLN) students. Within the groups there was a mixture of people who lived independently and those who did not, with the latter in the majority. A small number of participants had a family of their own to support but most had no children.

Questions/Topics were designed in collaboration with Rehab's three Regional Advocacy Committees. We had very detailed and open-ended conversations with participants, asking them about the various challenges they faced. We asked participants about income, services, and any other challenges or barriers that they felt were of importance. The issues discussed in the focus groups covered a broad range of topics and issues. The issues highlighted in this document represent the themes that were most common and recurring across the focus groups.

Rehab – Who we are and what we do?

The Rehab Group is one of the largest not-for-profit organisations in Ireland, providing specialist services to persons with a disability and people who are at a disadvantage. We provide direct services to over 10,000 people including children and adults. We champion the values of diversity and inclusion for persons with a disability or disadvantage in their communities throughout Ireland.

Our mission is to help change the lives of the people we serve by helping them to become more independent and more included in their communities, by empowering them with the skills and confidence to be active in the workforce, and supporting them to be in charge of their health and wellness. The Rehab Group is comprised of RehabCare, National Learning Network and Rehab Enterprises. We specialise in residential, supported accommodation, respite and day services; home support services, further education and training; and employment for individuals with a disability and people who are disadvantaged.

Funded by the HSE, RehabCare is the care division of the Rehab Group providing 52 residential/supported accommodation services, 70-day services including resource and outreach centres, 10 respite services for adults and children, and home support services to both children and adults across Ireland.

National Learning Network (NLN) is the education and training division of the Rehab Group specialising in individualised, person-centred training and education with a specific focus on persons with a disability. We support 6-7,000 students each year, between the ages of 16 and 65 who have experienced a setback, an accident, a mental health issue, an illness, an injury or have a disability, to progress to further education and training or employment. NLN is funded through the Education and Training Boards (ETBs) and the HSE.

Rehab Enterprises provides sustainable employment for persons with a disability. It operates a unique integrated model of employment, where employees with disabilities work alongside employees without disabilities across a number of sectors.