Submission in Response to the Green Paper on Disability Reform: A Public Consultation to Reform Disability Payments in Ireland

October 2023

Key Messages

- I am especially concerned about poverty and cost of disability among the M.E. community. We need to move beyond crisis management and into rights-based planning to support disabled people in their everyday lives. The Disability Capacity Review Implementation plan needs to be published now.

- The Government must publish the Cost of Disability Action Plan. Disabled people experience lasting poverty at over 5 times the national average (19.2% vs 4%) as highlighted by Inclusion Ireland and Rehab Group.

- Ireland should increase expenditure on social protection for people with disability as it is below the EU average.

- I reject the proposed 'tiering' of disabled people and the proposed method for allocation of welfare payments which is diametrically opposite to the UNCRDP and a potential human catastrophe for disabled people. I call on the Government to stop this cruel and discriminatory policy from being implemented.

- The green paper is not an agreed policy. It is a proposal by the Department to create a focussed discussion on how disability payments could be changed in the future. No decision has been made as yet, and the Department did say that through consultation it is possible that no changes would be made. It is imperative that the government listens to various Disability groups, to patient groups and to disabled individuals and involves them in consultation with a view to learning and fighting for a society fit for all. There is need for the reinvigoration of the social model of disability which can function as a guide for action rather than as a subject of endless debate.

- I call on the Government for a significant provision of economic support for people with a disability, given the greater risk of poverty they face, and the extra costs associated with having a disability i.e., to raise Disability Allowance/Invalidity Pension to take over 100,000 disabled citizens out of abject poverty, to make the Disability Allowance a universal, non-means-tested payment and provide disabled people with a supplementary payment to cover additional costs associated with people's respective disabilities.

- I call on the Government to fully ratify all protocols of the UNCRPD as set out in the Programme of Government.

- The government's approach to disability appears to hold the view that the best way out of poverty is through work, and its proposed policies are targeted at supporting more disabled people into employment. The best way out of poverty for people who have chronic illness related disabilities, e.g., people with Myalgic Encephalomyelitis (M.E.) who are unable to work because of disability and symptom severity, is not through work.

- The proposed welfare reform appears futile; the government does not appear to recognise that those who receive disability payments and who can work parttime or fulltime can already seek work and receive reduced welfare.

- In addition to the potential harm caused by the current proposed welfare reform, far-reaching negative impacts will be experienced into the future. This will be a consequence of permanent damage to the physical, and mental, health of a substantial proportion of the population, including people with Myalgic Encephalomyelitis (M.E.) requiring unmet long-term health and community support. Cuts to public and community services as well as the ignoring of DPO and disability advocacy groups suggested pre-budget measures have already negatively impacted on adults and children with disabilities, the damage to their health and life opportunities will have repercussions in terms of inequality, social cohesion, and demand for adequate provision of support services for generations to come. A decade of austerity has already impacted on the lives of the disabled community.

People with Myalgic Encephalomyelitis (M.E.) - associated disabilities live with elevated levels of poverty and exclusion. While low-income earners, people with disabilities, and others are currently amid a cost-of-living crisis, disabled people have been living through a cost-of-disability crisis for years. Our domestic economy is growing, and the Irish economy is doing well, however current social protection supports maintain thousands of disabled people in poverty.

Myalgic Encephalomyelitis (M.E.) and Associated Disabilities

The Disability Act, 2005 defines disability as *"a substantial restriction in the capacity of the person to carry on a profession, business or occupation or to participate in social or cultural life by reason of an enduring physical, sensory, mental health or intellectual impairment"*. This is consistent with the UNCRPD definition of people with disabilities as *'persons who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'*.

People with a diagnosis of Myalgic Encephalomyelitis (M.E.) live with a condition that causes substantial restriction in the capacity to continue a profession, to be active physically or mentally or to participate in social or cultural life by reason of enduring physical impairments associated with M.E.

People with M.E.-associated disabilities live with elevated levels of poverty and exclusion.

Myalgic Encephalomyelitis (M.E.), a neurological illness as defined by WHO, is an illness which leads to disability; the NASS uses the World Health Organisation codes as per ICD 10; Myalgic Encephalomyelitis (M.E.) is coded as G93.3. However, while various parts of the HSE recognise M.E., other parts do not; there are post code lotteries between CHO areas with regards to accessing Home Care and Community Supports, and there are no public doctors and consultants who are ME-knowledgeable.

Myalgic Encephalomyelitis (M.E.) is similar in a number of significant ways to illnesses such as Multiple Sclerosis, Lupus, and Poliomyelitis (polio). M.E. can be extremely severe and disabling and in some cases fatal.

Myalgic Encephalomyelitis (M.E.) which often follows a viral infection, is a complex, chronic, multi-system, physical disease which causes severe disability affecting multiple systems of the body, involving profound dysregulation of the central nervous system and immune system, dysfunction of cellular energy metabolism and ion transport and cardiovascular abnormalities. The underlying pathophysiology produces measurable abnormalities in physical and cognitive function, providing a basis for understanding the symptomatology.

Myalgic Encephalomyelitis (M.E.) which includes mild, moderate & severe forms of M.E., all of which can evidence fluctuating severity of symptoms, can involve profound levels of suffering & extreme symptoms which can be life limiting and in some cases life threatening. The life of someone with M.E. is reduced to basic survival struggling moment by moment, enduring extreme pain & no let up to the high intensity of symptoms. Patients' needs are diverse & complex. The danger is that the extensive list of disabling symptoms they suffer from can unintentionally, underplay the severity and seriousness, the totally disabling nature and the individual intensity of each symptom, which 'together add up to a physical nightmare of indescribable proportion'.

For each M.E. patient there is a separate set of symptoms and within each symptom there are different severities experienced by the patient, even in one day. All M.E. patients suffer from an atypical post exertion response to activity, i.e., Post Exertional Neuroimmune Exhaustion (PENE), the cardinal feature of M.E.

Post Exertional Neuroimmune Exhaustion (PENE), also referred to as Post Exertional Malaise (PEM) by some, is a pathological inability to produce sufficient energy on demand with prominent symptoms primarily in the neuroimmune regions. Any action whether physical, cognitive, emotional, social etc drains available energy and if the ability to replace this energy is impaired this can lead to a worsening of all symptoms which can last for days, weeks or months, even causing permanent, non-recoverable systemic damage. Indeed, many people with M.E. who have pushed far too hard beyond their limits have become bedbound and carer dependent for years.

The M.E. body's ability to generate and produce energy at a cellular level is seriously impaired meaning systems and organs cannot function properly causing progressive systemic deterioration which leads to my disabilities.

There is a lengthy list of atypical disabling symptoms that occur when a person with M.E. suffers from Post Exertional Neuro-Immune Exhaustion – PENE; marked debilitating illness and weakness, cognitive dysfunction, symptom flare-up and paralysis, can follow ANY physical or cognitive exertion requiring energy, no matter how small or insignificant the exertion.

Worsening symptoms in M.E. as a result of Post Exertional Neuroimmune Exhaustion -PENE can include exhaustion, extreme chronic pain, paralysis, brain fog, cognitive dysfunction, unrefreshing sleep, headaches, migraines, muscle pain and muscle fatigability, orthostatic intolerance, neurally mediated hypotension, or POTS, inability to eat, swallow or digest food, and much more. The onset of Post Exertional Neuroimmune Exhaustion - PENE in M.E. can occur immediately, hours later or delayed up to 24-72 hours, and depending on M.E. severity can last days, weeks, or even months.

The Jason et al 2019 study entitled, *'Assessment of Post-Exertional Malaise (PEM) in Patients with Myalgic Encephalomyelitis (ME)'* refers to the list of disabling symptoms in M.E. which are potentially made worse due to physical or cognitive exertion. The full study was based on feedback from 1534 patients who responded to questions about PEM, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6468435/

Invisible Disability

There are numerous debilitating physical and mental conditions that fall under the umbrella of invisible disability including Myalgic Encephalomyelitis (M.E.) diabetes, cancer, pain conditions, endometriosis, and many more. Underlying inequalities are constantly faced by people with M.E. and others with invisible disabilities associated with an illness like Myalgic Encephalomyelitis (M.E.). Patients experience a lack of complete understanding and knowledge of their illness which leads to misunderstandings, false perceptions, and wrong judgments by many including medical professionals, welfare assessors, and community support services.

Addressing Poverty and the Extra Costs of Disability

Economic Impact

According to the Disability Federation of Ireland a total of 1,109,557 people (22% of the population) are reported as having a disability. There are more than 700,000 people living with neurological conditions in Ireland. Of these, in excess of 10,000 people live with M.E., which is one of the largest neurological diagnoses that primarily feature physical and cognitive disabilities.

This group of patients and their families and carers are treated with absolute neglect by the State with lack of HSE clinical guidelines, lack of education, lack of appropriate health and social care; they suffer chronic ill-health, poverty, social isolation, loneliness, and in some cases homelessness.

Understanding the economic impact on patients can help inform decisions relating to the provision of services and supports for those affected. A 2020 study, '*Understanding the Economic Impact of Myalgic Encephalomyelitis/chronic fatigue syndrome in Ireland: a Qualitative Study'* concluded that the economic burden of M.E. on patients in Ireland is considerable.

People with Myalgic Encephalomyelitis (M.E.) - associated disabilities live with elevated levels of poverty and exclusion. At present, hundreds of thousands of disabled Irish citizens struggle to get medical appointments, or essential medical interventions and struggle in poverty and crisis conditions.

The Government's own Cost of Disability in Ireland Research Report published in 2021 has indicated that the cost of disability increases depending on the severity of the disability. Their estimations indicate that the cost of a severe disability ranges from €9,600 to €12,300 extra per year, and between €8,700 and €10,000 extra per year for those with limited disabilities. These figures were calculated based on data from 2020 and earlier years, so predate the current cost of living crisis.

This is before a disabled citizen pays rent or tries to feed themselves or heat their homes. These are hugely significant financial burdens faced daily by people with disabilities.

The cost of disability is the extra spending needs that people with a disability like me face in their day-to-day lives that others in society do not face.

These extra costs are a direct result of the person's disability and would not arise otherwise.

Research conducted in Ireland and internationally over many years has shown that there can be significant costs of disability. In order to get a better understanding of the extent and composition of these costs, and the way they affect people differently, the Department of Social Protection commissioned Indecon International Research Economists to conduct research into the cost of disability in Ireland. The result of this analysis gives a range of costs of disability in Ireland. Additional costs of disability go across a number of areas of expenditure including:

- Additional living expenses;
- Mobility, transport, and communications;
- Care and assistance services,
- Equipment, specialised aids, and appliances,
- Medicines.
- Healthcare costs,
- Costs of assistance with daily activities,
- Transportation costs

- Fuel and light, transport,
- Therapeutic equipment,
- Domestic services,
- Daily living costs & Utility Bills,
- Housing adaption costs,
- Assistive technology

There are many items that are used by everyone but which people with disabilities often use more, such as extra taxi journeys due to a shortage of accessible public transport or extra energy costs because of a greater need to stay warm when not mobile. It can also be the case that some products cost more for an individual with a disability. Individuals with M.E. associated disability may also have significant unmet needs due to poverty, it is important to consider in estimating the additional costs of disability, those costs which an individual may incur but which they are unable to afford to meet.

Current Rates of Social Welfare Payments

The current annual means assessed income provided by Disability Allowance, ahead of implementation of Budget 2024 proposals, is €11,440 a year which barely meets this additional cost of disability. Disability Allowance should be a universal, non-means-tested payment.

One of the most prevalent issues amongst people with disabilities including those with M.E. is the struggle to access and live on current rates of social welfare. This is especially so when the person is living independently or wants to live independently.

A sizeable percentage of adults with a disability live in consistent poverty because of financial difficulties due to:

- job loss,
- expensive rent payments,
- the expense of medical appointments,
- expense of tests and treatments,
- the lack of access to loans and mortgages – this is linked to social exclusion and housing issues,
- being unable to pay for items such as annual car insurance and being penalised when paying quarterly,
- unfair private insurance ceasing income protection payments.

Feedback I see from the M.E. patient community evidence patients being unable to survive independently without financial support from family in the cases of those with family, being dependent on food banks to meet food bills or being unable to cope with exceptionally high energy costs. Some report that they are seeking assistance from community supports such as Saint Vincent De Paul to ensure that they can heat their homes and use their cookers. Some patients can't survive independently on what they get in their Disability Allowance and Invalidity Pension, payments that come nowhere near previous work earnings. Others can't always afford to buy enough food to keep them going. Others are struggling to power equipment like a powered wheelchair and don't have funds to replace batteries on mobility scooters.

People living independently are three times more likely to struggle with basic bills. The struggle to meet one-off unexpected bills is evident too. While it is useful for policymakers to consider the average cost of disability, there is a need for recognition that the actual cost to some individuals who have specific needs may be significantly higher than the average. In a recent survey by Inclusion Ireland, 'nearly half (48%) of the respondents declared that they had difficulty paying their bills and managing living expenses all the time, or most of the time. Another 32% said that they had difficulty some of the time. 94% of people said they had experienced some level of difficulty in paying bills.'

The cost of living is going up all the time, but welfare payments are not being increased to match that despite various DPOs highlighting the issue repeatedly. The cost of living is more than some have in income. Disabled people experience lasting poverty at over 5 times the national average. (19.2% vs 4%).

People with disabilities also face additional costs such as specialist disability aids, home adaptations, higher energy costs and an increased need for taxis due to inadequate public transport. These costs are estimated between €207- €276 per week as per the Survey on Income and Living Conditions (SILC) 2021.

There is a clear lacking in the State's response to people with disabilities. On average EU countries spend 2% of their GDP on social protection expenditure for disability. Ireland's expenditure is just 0.8%, the second lowest in the EU. Ireland has the highest percentage of people with disabilities at risk of poverty in Western Europe (37.8%) (EU SILC).

While the measures taken in the recent budget are welcome (disability allowance and invalidity pension increase, fuel allowance increase, one off payments), decision makers are clearly underestimating the requirements of people, and measures in place do not even alleviate the pressures caused by inflation. A 12-euro increase in core social welfare despite several calls for it to be more than double that amount will bring little relief to people with disabilities. Many asked the government to match the disability allowance to the poverty threshold. The 12-euro increase falls drastically short and is a disturbing blow to human rights. Rehab, for example, had advocated for a minimum 30-euro increase.

Our government need to move beyond crisis management and into rights-based planning to support disabled people in their everyday lives. The state needs to increase expenditure on social protection for people with disability, as per the EU average, given the greater risk of poverty

disabled people face, they just cannot keep up with the cost of living. More targeted action is needed to give my community the same chance at living as able-bodied citizens.

It is devastating to experience the sidelining of disabled people and the tokenistic attitudes to disabled people. The government know what needs to happen to properly resolve the crisis that disabled people exist in, and the solution is not to oppress them further.

I vehemently oppose the Green Paper proposal by the Irish Government to categorize disabled people for the purposes of allocating social welfare payments for the following reasons:

- Against the above outlined context, which has been repeatedly highlighted by disabled persons organisations, advocacy groups, patients, carers and families, Ms Humphreys has published proposals which, in my view, will further harm disabled Irish citizens including those with M.E.;

- The proposal breaches the UN convention on human rights for those with M.E. and other disabled people by using a medical model approach not a social model as enshrined in the UNCRDP - it constitutes degrading and humiliating treatment under the UNCRDP;

- The proposal sets out a categorisation of those 'deserving' of full benefits rights and those not, it is a value judgement;

- It is a proposed punitive system, a direct copy of a British austerity measure introduced by the Tories in 2008 called the ‘Work Capability Assessment’ for disabled British citizens, a punitive system which has been brought into complete disrepute in the UK. This year, the Work and Pensions Committee of the UK parliament found there was a "pervasive lack of trust" associated with this system of assessment, with no regard for whether people with disabilities, many of whom have already been assessed as being unfit for work, are actually capable of work;

- It will blame disabled people for seeking welfare benefits and will set up public resentment towards those disabled people who claim welfare benefits;

- The proposal gives a message to the general public that people with M.E., and other disabled people, are falsifying the nature and extent of their impairment or illness;

- It will set disabled people against each other;

- It will result in thousands of disabled people without monetary resources for daily living and cause hardship, despair, and suicide, it is the antithesis of a human rights approach to disability;

- Whilst there is an increase in payment in Tier one and Tier two, neither come close to the cost of disability in the Department's report.

The Green Paper raises the issue of cost of disability, but it is approaching solutions in completely the wrong way, severity of disability is not an accurate indicator of cost; it is a crude measure that will see very many people suffer extreme poverty. Targeted additional supports should be made available to people who most need them. This should take the form of an additional regular payment, rather than the creation of a cruel and discriminatory hierarchy. Employment supports for disabled people need to be enhanced, but they must remain entirely optional, anything else will simply place further barriers in our way.

I call on the Government to:

- reject this 'tiering' of people with M.E. and other disabled people, and this proposed method for allocation of welfare payments which is diametrically opposite to the UNCRDP;

- be fully aware of your proposed implementations and policies and do not push on regardless; stop this cruel and discriminatory policy from being implemented. The appalling vista contained within the minister's proposals should be resisted and opposed, it is completely inconsistent with the Government's current and expensive PR campaign entitled 'Disability Rights are Human Rights;

- immediately drop this harmful proposal to medically assess people with M.E., and hundreds of thousands of disabled citizens who will be forced into work which those with M.E. and other disabled citizens cannot do; people with disability should not have to live in fear of being wrongly deemed 'fit to work' or be forced to attend meetings with employment services whose sole function is to intimidate them into taking up work they are unable to do;

- immediately drop the harmful proposal to have a hierarchy of disabilities which would only serve to minimise and trivialise the lived experiences of those with M.E., and that of the majority of disabled people. The government's proposal would mean that those with M.E. and most disabled people will be reclassified as a subsection of jobseekers, with devastating consequences for the life and wellbeing of those with M.E., and the lives of others;

- acknowledge that in the medical report that is submitted as part of the Disability Allowance and Invalidity Pension applications, doctors are already required to state how severe an individual's disability is and how long it is expected to continue – in current cases doctors have already made that determination and patients have already been through stressful lengthy assessments, appeals processes, and delays to payments;

- not to make engagement with employment services a condition of Disability Allowance and Invalidity Pension – people with M.E. and others with a disability, want to live in a decent society where the most vulnerable are respected and protected, we cannot allow an already flawed system to be made infinitely worse. The Government's published Pathways to Work Strategy, which includes as one of its key actions the extension of targeted employment supports to groups facing additional challenges accessing work such as people with disabilities, is a welcome development for some people in certain disability groups, i.e., those who can work whether part-time or full-time. The ability of people with disability varies significantly by type and severity of disability;

- acknowledge that an M.E. diagnosis is regarded as a dynamic disability because it is a complex, chronic, fluctuating, multi-system, physical disease which causes unusually severe disability affecting multiple systems of the body. M.E. sees fluctuations in symptoms, severities, and associated disabilities in those of all ranges of the severity spectrum.

In M.E., any activity (physical, cognitive, emotional, or social) drains available energy, and the ability to replace this energy is impaired leading to a worsening of all symptoms which, can last for days, weeks or months, even causing permanent, non-recoverable systemic damage. Myalgic Encephalomyelitis is an illness in which energy at cellular level is not created normally and the acts of daily living deplete the body far beyond what people understand as 'fatigue,' this energy depletion affects every system and organ in the body. Exceeding energy availability will result in a 'crash.' At worst, patients will be weak and disorientated as the brain 'shuts off' nonessential physical and cognitive function in order that the remaining limited energy is available to organs and systems essential for life.

Overload phenomena is part of the complex pathophysiology of M.E. as the body reacts to sensory inputs which it does not have the energy to manage. Simply put the post exertion response in M.E. means that exceeding available energy, ('available energy' depends on how well a patient is on a certain day/part of a day), results in an exacerbation of symptoms.

The post exertion response can be caused by any 'activity' (physical or mental) i.e., activities of daily living, speaking with someone, moving around the house, conducting essential business like paying a bill over the phone or shopping online. There is a long list of disabling symptoms that people with M.E. suffer from, and more horrendously debilitating symptoms which occur when a patient suffers from the post exertion response, i.e., Post Exertional Neuro-Immune Exhaustion – PENE; marked debilitating illness and weakness, cognitive dysfunction, symptom flare-up and possible paralysis, can follow ANY physical or cognitive exertion requiring energy, no matter how small or insignificant the exertion;

- base measures to address the additional costs of disability on a multifaceted approach involving increased cash payments, enhanced access to service provision and specific targeted grant programmes;

- make the Disability Allowance a universal, non-means-tested payment and provide people with a supplementary payment to cover additional costs associated with people's respective disabilities. Raise Disability Allowance to take over 100,000 disabled citizens, including other citizens with M.E. out of abject poverty. Supports for people with M.E. and other individuals with a disability should be focused on the alleviation of poverty, reducing inequality, and improving social inclusion and the quality of life of individuals living with disabilities in Ireland;

- provide economic support for people with M.E. and other people with a disability, given the greater risk of poverty they face, and the extra costs associated with having a disability. Additional income, grant or direct service provision should be based on a needs assessment, not another means test;

- address poverty among disabled citizens and the extra costs of disability - implement the recommendations of the Cost of Disability Report as a matter of urgency and put the following measures in place:

- Establish a cost of disability payment of €50 per week for every disabled person;

- Increase the disability allowance by at least €20 per week for those who receive it;

- Invest at least 10 million euro in a special fund to support grants to cover expenses of people with higher support needs;

- reintroduce the Combat Poverty Agency to provide research and advice to government, State agencies and local authorities to help eliminate poverty and social exclusion while promoting a just and inclusive society. The Combat Poverty Agency previously helped to shape national policy through local experience. It made necessary connections at many distinct levels of administration in order to co-ordinate change;

- stop hounding people with M.E. and other disabled people off benefits - award claimants permanently and do not introduce constant reassessment for conditions like M.E. that do not improve over time, or are progressive;

- step back from mandatory work activity requirements for people with M.E. and other people already assessed as being unfit to work; it is likely that large numbers of disabled people who currently receive disability payments will be incorrectly turned down future payments on reassessment. Please consider the fact that people with M.E. and other individuals currently receiving payments have already undergone lengthy assessment and means testing and in many cases have been put through appeals processes, and that any further means testing could be onerous on individuals with disabilities. There will be high rates of mental distress among disabled citizens, and the potential for even greater adverse impacts than are already experienced in welfare administrations;

- step back from mandatory work activity requirements for people starting welfare applications or currently in the process of a welfare application, who are assessed by general practitioners and consultants as being unfit to work;

- start acknowledging supporting documentation in application and appeal processes by individuals assessed by general practitioners and consultants as being unfit to work;

- recognise the impact on families of individuals with a disability and in particular, the loss of earnings and sacrifices made by families in caring for those most in need, the same families would be affected by this 'tiering' of disabled people, and this proposed method for allocation of welfare payments;

- scrap the savings target attached to proposed welfare reform and instead target the richest in society; the aim of these proposals is clearly an intention to make savings in the welfare budget through pushing disabled people who are not fit to work into work;

- not to include disabled people reassessment as part of the government’s welfare to work system; many disabled people want to work and to be fully engaged in the community and society but have no choice;

- not to introduce a compulsory ‘ill-health and work conversation’ as part of a disabled person’s application process for essential financial support; do not introduce the idea of bringing welfare support into the scope of further conditionality where receipt of benefits is dependent on engaging in set mandatory activities where the disabled person is not fit to be active, and especially where, in an illness like Myalgic Encephalomyelitis (M.E.) any activity, physical or mental, causes worsening of illness and illness severity;

- not to implement the ideological goal of reducing numbers of disability benefit claimants to avoid a climate of future tragedies and fatal impacts on individuals wrongly found fit for work;

- not to use public money to fund the accumulation of profit in return for pushing the most disadvantaged members of society off social security and into destitution;

- not to ignore the thousands who are overwhelmingly against the proposals and the warning of the dangers of pushing an already disadvantaged group deeper into poverty;

- fully ratify all protocols of the UNCRPD as set out in the Programme of Government;

- stop sowing the seeds for future cuts that will take disabled people’s inclusion in society back decades.

Name: ________________________________

Email: ________________________________

Date: ________________________________