



Special Committee on COVID-19 Response,
Leinster House,
Dublin 2.

29 June 2020

Dear Special Committee Members,

MS Ireland was delighted to receive your invitation to make a written submission to the Special Committee on COVID-19 Response. It is a welcome opportunity for us to outline some of the issues our community have faced during the pandemic and some of the issues that have affected them in this time.

The COVID-19 pandemic has created challenges for our community and our organisation. Issues relating to delays in accessing neurology services, appointments with Allied Health Professionals and in receiving some treatments have been reported by our community. The issue of homecare support has also been raised. Our community are feeling the stress and strain of this pandemic as it threatens their health, social interactions and finances.

In our submission we discuss some of the issues the community have faced and make a number of recommendations on relation to the response moving forward.

This time has also had a significant impact on MS Ireland. Prior to COVID-19, MS Ireland was trying to address a serious deficit in our budget. We, like many other organisations, provide services to people living with disabilities under Section 39 of the Health Act. This sector is at serious risk if funding deficits are not met. We, as members of the Disability Action Coalition (TDAC) have actively sought support from Government in relation to the crisis our sector faces. THE COVID-19 pandemic has only accelerated the speed at which we find ourselves heading towards a major crisis point. Details of this can also be found in the submission.

If you have any further questions or concerns in relation to the COVID-19 response and the MS community, please do let me know. We would be more than happy to address any concerns you may have or answer any questions that will help to support the work of this committee.

Again, we thank you most sincerely for extending an invitation to our organisation to highlight the impact COVID-19 has had on people living with MS, their families, carers and our organisation.

Kind regards,

Aoife Kirwan

Information, Advocacy and Research Officer.



IMPACT OF COVID-19 ON PEOPLE WITH DISABILITIES AND THE DISABILITY SECTOR

INTRODUCTION

The COVID-19 pandemic has had a significant impact on the lives of people living with multiple sclerosis (MS), their families, carers, those who represent them and the services they engage with. We find ourselves in unprecedented times which have brought numerous challenges for those living with MS and their families. Multiple Sclerosis does not stop during a pandemic. Many of our community members are reporting feelings of isolation and anxiety. For people living with MS, stressful or demanding times may cause symptoms to worsen. Cancelled clinic appointments, delays in accessing treatments and the redeployment of many Allied Health Professionals has added to stress and uncertainty. Redeployment of such staff has resulted in further strain on an already overstretched service. The impact of this pandemic has been far-reaching.

COVID-19 RESPONSE FOR PEOPLE WITH A DISABILITY

The Government led a public information campaign providing information to the general public in relation to COVID-19, how it spreads and how to protect oneself and others from it. The manner in which Public Health information was disseminated presented some challenges for people who did not have access to technology. Early on, a booklet offering advice was distributed via An Post but updates on changes to Government guidelines, COVID-19 related restrictions and information were not distributed in the same manner, presenting challenges to those without access to technology. Many remain reliant on others to keep them informed.

A recent survey from the Neurological Alliance of Ireland¹ (NAI) reported that 73% of people access the majority of general COVID-19 related information from the HSE website. However, 35% of people feel they do not have sufficient condition-specific information. 40% choose to access condition-specific information on COVID-19 risk and implications from voluntary organisations, like MS Ireland.

MS is a condition which is experienced in different ways by different people. The set of symptoms a person can experience and the severity of those symptoms can range from person to person. The treatments available to manage MS have different modes of action, some of which suppress the immune system. COVID-19 risks varied within the MS community. There are subsets of people who were advised to cocoon and others who were advised to adhere to the same public health advice as the general public. The information and advice required by each individual community members depended on their individual case, including any co-morbidities, the medication they are receiving and their level of ability. Our organisation was challenged with selecting relevant information for our community and communicating it to them. With input from the National Clinical Lead of



Neurology and the MS Clinical Advisory group, MS Ireland established a COVID-19

Information Centre on our website, offering relevant tailored information to our community. The MS Ireland website saw an increase of over 25% of visitors to our website in March and April 2020, compared to the same period in 2019.

Increased communication between the HSE, MS Ireland and other organisations is essential as we move forward. With 40% looking to our website for condition-specific information, the HSE must recognise the role MS Ireland and other organisations play in relaying information to relevant individuals.

Recommendations:

- **Greater communication between HSE and organisations representing people living with disabilities.**
- **Circulation of hardcopy information to ensure people are kept up to date and access to technology is not a barrier**

IMPACT OF COVID-19 ON DAILY LIFE AND SERVICES

The implications of the COVID-19 pandemic have had an impact on life for people living with MS as well as their families and carers. People living with MS and their families were subject to the same, if not tighter restrictions as those implemented for the general public. Our network of Community Workers have reported many of their clients are feeling isolated, stressed and anxious.

There has been confusion in relation to cocooning measures, whether or not these people need to continue to cocoon. If so, what cocooning will look like from a practical perspective as the country continues to reopen. Greater clarity is required here to enable people to safely and confidently move forward.

The NAI survey revealed that 26% of respondents had significant challenges accessing neurological care including cancellation of neurology appointments and diagnostic testing, delays with some treatments and issues with securing prescriptions for medications. Neurologists and other healthcare professionals have used telemedicine in an effort to continue providing care to their patients. This has received mixed responses within the community. While this is a suitable alternative for some people, it is not appropriate in all cases.

MS nurse services have been decreased which has had an impact on our community. This is a service which can be used to report new or worsening symptoms and to seek advice. 21% of people do not have sufficient information on the steps they should now take if their condition deteriorates during this time. 21% of individuals have also experienced delays in accessing the services of Allied Health Professionals during this time. Timely access to neurology and other services is essential in providing quality care.



Issues in relation to home support emerged in the early stages of this pandemic. MS Ireland was made aware of instances in which our community members were informed of potential issues with the delivery of homecare support. In some instances, people living with MS decided to temporarily suspend engagement with homecare support, fearing they may contract COVID-19 as a result of a carer carrying the virus into their home. Family Carers Ireland recently published 'Caring Through COVID'² a report that said 14% of homes normally availing of homecare services elected to temporarily suspend homecare supports in order to reduce the risk of infection by homecare workers. In some instances, this meant that individuals went without support and in other cases family members were able to assist with care needs. This put additional strain on families and individuals and has resulted in loss of income for some who had to prioritise taking care of a loved one over their employment. Those who elected to suspend homecare services should not experience delays in resuming the services they were previously availing of.

Some of our community members have extensive care needs requiring care on a daily basis. A number of MS Ireland Community Workers were made aware of instances in which such individuals were advised that they should avail of a nursing home placement and in some situations were placed in nursing homes in which there were residents with COVID-19. Their clients reported feeling anxious, worried and as though they had no choice but to avail of nursing home placement. They had shared concerns in relation to possibly contracting COVID-19 while availing of these placements. In one particular instance, this occurred.

Loss of income has been a significant challenge for many individuals and families within our community. Some people living with MS who have been advised to cocoon were expected to return to work, if they chose to cease employment in an effort to protect themselves from exposure to COVID-19, they were ineligible for the COVID-19 Pandemic Unemployment Payment. Working from home has been a challenge for many. Some are juggling work life, child-minding and self-management of their condition, something many would not have experience with managing all at once.

Throughout the pandemic, MS Ireland has continued to provide services to people living with MS and their families. We have adapted our service delivery models to ensure we are at all times working within the safety measures and restrictions implemented by Government. We have utilised online platforms and teleconferencing to continue providing services to our community. Our Community Workers have conducted casework over the phone and online. In March, MS Ireland developed, piloted and rolled out online physiotherapy programmes nationally. In response to the pandemic, MS Ireland also increased the hours of operation of our Information Line, which now operated Monday – Friday from 10am – 5pm. This confidential service ensures our clients receive reliable, accurate and personalised information and support in a timely fashion with the benefit of a human voice in a world where the digital experience can sometimes prove isolating. This Information line also allows people with MS to be directed to Regional Staff and other appropriate services and/or agencies in accordance with their needs.



Recommendations:

- **Greater clarity on cocooning as the country continues to reopen**
- **Prompt resumption of homecare services**
- **Timely access to neurology services, medications and other health services**
- **Limit the financial impact of COVID-19 in people living with MS by implementing measures to protect their income**

IMPACT OF COVID-19 ON CARERS AND FAMILIES OF THOSE WITH DISABILITY

Family carers and carers provide invaluable support to the people they care for. The COVID-19 pandemic introduced overnight closures to respite and day services that many people relied. In some situations, family members have had to step in to provide essential support and care to a loved one. This puts considerable strain on families, especially those who would not normally have provided care before this pandemic and for those who are also working from home. Multiple demands on carers has been a challenge in an already difficult environment.

Family carers have also had issues with accessing appropriate PPE. Those providing intimate personal care have not had access to public supplies of PPE during this pandemic, creating a greater risk of infection for both the person giving and receiving care. Some Family Carers have purchased PPE to mitigate this risk placing an additional strain on their income.

Family carers face additional concerns in relation to COVID-19 as in addition to protecting themselves from the virus, they are responsible for the care and protection of the person in receipt of their care.

The report 'Caring Through COVID' states that 84% of family carers worry about contracting COVID-19 and not being able to look after the person they care for. 60% are worried about a decline in their own mental health and wellbeing and 47% are unable to access the appropriate PPE required for the care they give.

Families need support in preparation planning should they contract COVID-19, so they know there is a plan in place for their loved one to be cared for if they are unable to provide the care due to illness.

Support for family carers is essential moving forward. Before the COVID-19 pandemic, a report from Family Carers Ireland indicated that 69% of respondents found it hard to make ends meet and 1 in 5 said they can do this with great difficulty. Restrictions on movement have meant that people may have increased spending in the home as they may not be able to shop in supermarkets which offer discounts and promotions. Financial support for carers is essential to ensure the sustainability of people being cared for in the home and with their families. Few instances of COVID-19 have been contracted by those being cared for in the home compared to 20% of



those in residential care. This highlights the need for recognition of the quality care that family carers provide in the home, by implementing appropriate supports to enable them to continue doing so.

Families have had different experiences in relation to remaining in their homes. Some families have embraced this and felt they were safe in their home and were happy to stay there. Others felt that being in constant confinement with others had a negative impact on their mental health. Some families are reluctant to stop cocooning and have expressed disappointment at witnessing low numbers of people in the community adhering to social distancing and other safety measures. Greater explanation of how those who have been cocooning can move forward is required for carers as well as people living with MS.

MS Ireland supports the recommendations set out in 'Caring Through Covid' including:

- **Minimising the financial impact of COVID-19 on family carers**
- **Access to appropriate PPE.**
- **Contingency planning for family carers who contract COVID-19**
- **Supporting the mental health and wellbeing of family carers**

IMPACT ON DISABILITY SECTOR

MS Ireland, like many other organisations were greatly impacted by COVID-19. MS Ireland made the decision to temporarily close the MS Care Centre. This was a difficult decision for MS Ireland but to ensure the safety of our clients and staff it was a necessary measure. The staff from the MS Care Centre have either been redeployed or placed on temporary lay-off until our service can safely resume.

This pandemic has highlighted the inadequate funding our sector receives and the flaws in the decision making process regarding the allocation of that funding. Disability funding cuts were announced in HSE Service Plan in January 2020, equating to a €20 million loss in funding across the sector. This is coupled with the estimation that €20 million in additional funding is required to address deficits and restore sustainability to organisations, a deficit that organisations have been bridging from our own resources. This simply cannot continue. As we struggle through COVID-19 and respond to this global emergency, we cannot be expected to endure further cuts.

As well as having to abruptly adapt our service delivery models and allow for additional work in compiling and sharing relevant COVID-19 information, MS Ireland had to suspend plans for various fundraising activities. This has resulted in a major loss for our organisation. MS Ireland, like many similar organisations, entered this pandemic with a funding deficit. In 2019, fundraising activities provided funds of €2,918,330 to our organisation, helping us to provide services to people living with MS. We predict that this year, as a result of COVID-19, our fundraising will decrease by a minimum of 38% on last year. This greatly threatens the services we provide to



our community members and puts our organisation at risk. Knowing this, we have prudently moved forward and are continuing to provide services, information and support to our communities but this crisis needs to be acknowledged and rectified in order for our organisation to remain sustainable.

The recently established Sustainability Fund which provides grants of between €20,000 to €100,000 is inadequate. It falls short in addressing the funding losses we have experienced as a result of the pandemic.

In 2019, MS Ireland joined the Disability Action Coalition (TDAC). This coalition was formed by organisations in receipt of funding under Section 39 of the Health Act, in order to provide services to people living with disabilities. Our organisations joined forces to highlight the urgent need that exists to rectify a funding crisis which threatens the future of our organisations and the services we provide to the thousands of people across the country who rely on us.

MS Ireland supports the key recommendations for COVID-19 set out by The Disability Action Coalition in their submission:

Recommendations:

- **A special fund to meet COVID-19 fundraised income losses**
Our organisations have lost millions of euros in normal fundraised income. Supports announced to date are very far from adequate to meet our needs.
- **Reverse the 1% funding cut applied in January 2020**
We have had to deal with extra costs associated with COVID-19 but are also expected to bear a € 20 million cut-back in funding for disability contained in the HSE Service Plan announced in January 2020. This comes on top of the substantial deficits that most of our organisations are carrying due to lack of funding of core services.
- **Adopt all of the recommendation of the IRG report*** relating to Section 39 organisations (Chapter 8). This includes overhauling the completely flawed system process for how the HSE currently decides to allocate funding to the sector. The COVID-19 pandemic has exposed how dependant the state is on the section 39 sector and how flawed the funding system is.



References:

1. Neurological Alliance of Ireland COVID-19: The Impact on People with Neurological Conditions and Family Carers - https://www.nai.ie/assets/42/09A425FC-94A6-4F82-8CD3A32F19F95592_document/COVID-19_Survey_Report_2020.pdf
2. Family Carers Ireland: Caring Through COVID - <https://familycarers.ie/wp-content/uploads/2020/05/Family-Carers-Ireland-Caring-Through-COVID.pdf>
3. Independent Review Group examining role of Voluntary Organisations - <https://assets.gov.ie/9386/6d02f4a9fb554e30adbabb3eec5091d9.pdf>