

**ACQUIRED
BRAIN INJURY**
IRELAND

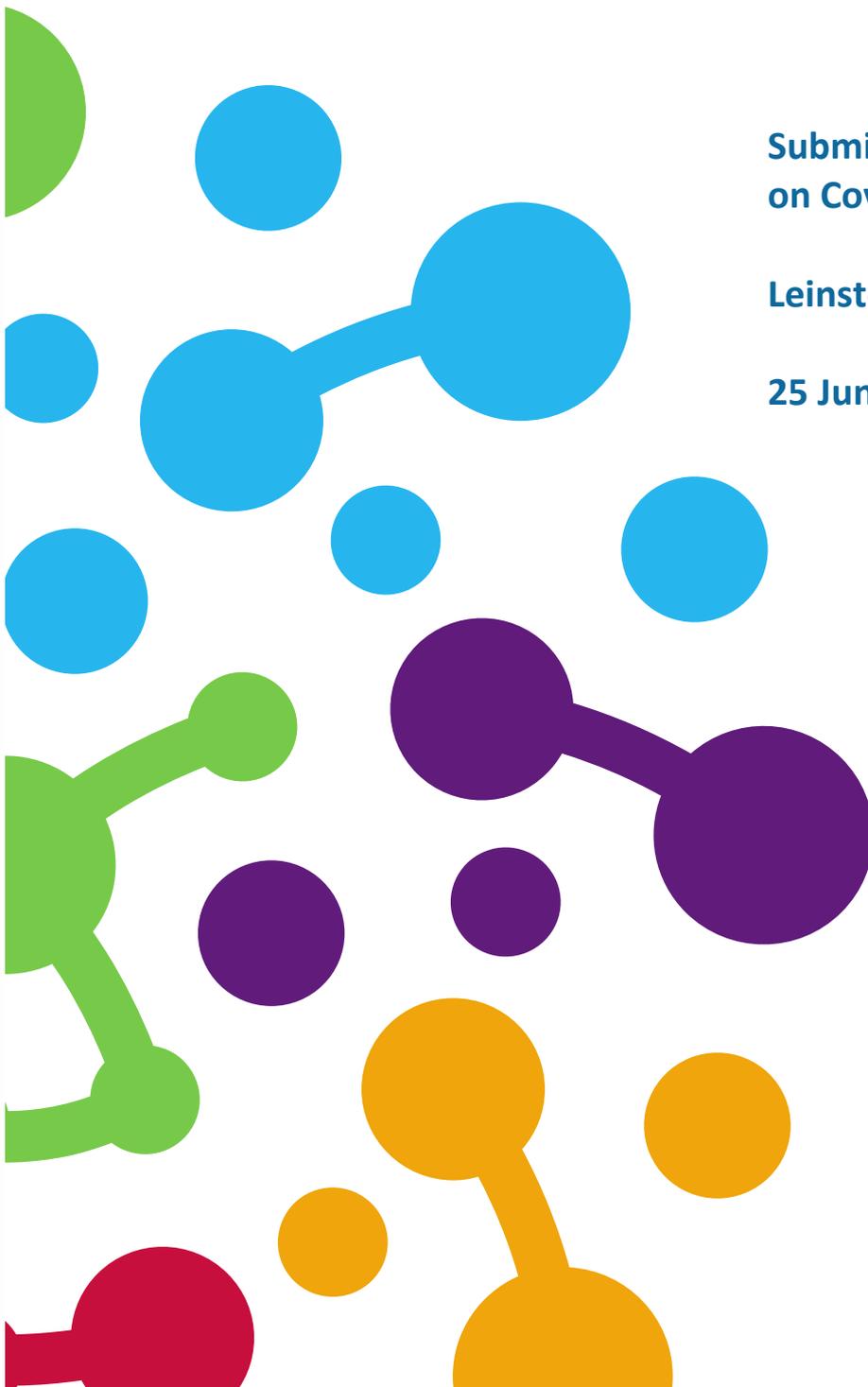


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**Submission to Special Committee
on Covid-19 Response**

Leinster House

25 June 2020



1. Introduction

Acquired Brain Injury Ireland welcomes the opportunity to make a submission to the Special Committee on Covid-19 Response as it considers the impact of Covid-19 on people with disabilities. The submission follows the guidelines as set out by the Special Committee. It also contains a set of recommendations for the Committee to consider.

2. Impact of the Pandemic on People with ABI and families

2.1 Impact of COVID-19 on our clients

People with acquired brain injury (ABI) in our rehabilitation services are severely impacted by the Covid-19 pandemic. With over 1,200 clients, Acquired Brain Injury Ireland witnessed first-hand the direct impact on people with ABI and their families of the physical closure of some of our services, in particular our day resource and home/community rehabilitation services. Given the cognitive, emotional and psychological impact of brain injury, the lack of a daily routine and structure is particularly challenging for the individual as well as their family. Considering the need for social distancing and cocooning as a vulnerable group, the progress on rehabilitation plans slowed down as the opportunities to engage become more limited. Communication with our clients became paramount to avoid social isolation as well as providing information to them around Covid-19 and how to manage their health and well-being and cope with cocooning.

Acquired Brain Injury Ireland's, Clinical Psychologist, Dr. Lorraine Crawley wrote an article¹ about her reflections on working with clients during the pandemic. She says in the article that one of the most interesting reflections that is emerging from her recent clinical work is clients' perceptions of the current way in which we are living. While there is of course individual differences in this, there are two emerging themes that could be categorised as 'I've been practicing living like this for years' and 'Now people will understand what it's (brain injury) been like for me'. In talking about this with her clients, they have highlighted that many of the restrictions we have been adjusting to over the past two months, have been significant issues for them for years, such as loss of employment, social isolation, lack of access to the wider community (related to loss of driving license) and lack of access to family/relationships. This can all lead to a sense of having reduced self-worth, a loss of identity, and long days ahead to fill. A common experience that clients generally report in therapy is a feeling of an ongoing sense of threat and that the brain injury which was sudden and unexpected has changed their perception of their own safety and the safety of the world around them. Many of these aspects resonate to some extent with what the general population has experienced recently.

¹ Dr. Lorraine Crawley (2020) living with restrictions: Perspectives from a neuro-rehabilitation service. The Psychologist. British Psychological Society. <https://thepsychologist.bps.org.uk/living-restrictions-perspectives-neurorehabilitation-service>

2.2 Impact of Covid-19 on our family carers

For families of people with ABI, the impact of the Covid-19 pandemic has been significant. Acquired Brain Injury Ireland runs a family carers' programme, *On With Life*² (funded by Pobal). The experience from this programme sees both an immediate impact on families as well as concerns over the long-term impact on their health and well-being. While the latter still must be evidenced, there is little doubt that this group will be disproportionately affected as a result of the measures put in place by the Government to slow down the spread of the virus.

Our families, who are already isolated, struggle with the increased isolation and sense of helplessness in knowing how to respond to their family member. The role of the family is crucial in achieving rehabilitation goals for the individual with the brain injury. This role became increasingly difficult during the cocooning phase. Families also express their fear that the family member may cease making progress on their rehabilitation goals or worse still, may regress if the rehabilitation interventions were not possible.

Managing their own mental health and well-being is particularly challenging for our family carers. As well as caring for their loved one, many of our family carers are also parents to children, the main wage earner in the household and caring for older members of the family. Any one of these roles is difficult in "normal circumstances" but put them together they are massively challenging and add in the lockdown restrictions due to the pandemic, it becomes an extremely pressurised situation with very few safety valves for the family.

Families also struggled with not being able to visit their loved one in residential settings. Communications tools such as Facetime are useful, but in some circumstances, it may lead to further stress and confusion for the individual and their family. Such technology is also a challenge for people with ABI with speech and language issues.

3. Providing neuro-rehabilitation services during a pandemic

Covid-19 has greatly impacted on our frontline service delivery and has required us to be an agile and solution focused organisation using innovation and creativity in every aspect of our organisation's structure and service delivery.

3.1 Sustaining our clinically lead neuro-rehabilitation services

Our residential services remained open serving a population of 68 people in 16 residences across the country. We believe our success in keeping our clients safe is that we acted early and decisively and had clear lines of communication with our teams working in our services. Furthermore, our services are internationally accredited by CARF, the Commission on Accreditation of Rehabilitation Facilities. This ensures a strong foundation and adherence to the highest standards for delivering rehabilitation services. As a result, there have been no cases of Covid-19 in our residential services to date.

Being Covid-19-free to date is due largely to the critical role played by our frontline staff. Their work involved delivering services in a safe, yet person-centred manner and they

² <https://www.abiireland.ie/services/family-carer/on-with-life-project/>

continue to follow a whole range of newly implemented policies and procedures that had to be developed as a response to the Covid-19 outbreak. The organisation's management team played a vital role in interpreting and analysing the sometimes daily guidance that was issued by the HSE and HIQA and continue to play a vital role in policy formation, implementing procedures, providing staff information, communication and training, building capacity and maintaining the rostering level of staffing required to ensure the 24/7 service in all our 16 residential sites across the country. In addition, the human resources function is vital in proactively responding to the raft of human resource measures that are required to be in place to respond to the crisis.

Day resource services as well as home and community rehabilitation services had to move online and continue to do so until it is safe to return. Overnight, our clinical teams and service staff continued to provide their range of interventions and therapies using telerehabilitation. This ensures that the 1,200 brain injury survivors in our services continue to receive neuro-rehabilitative and clinical support during the pandemic. Like so many organisations, Acquired Brain Injury Ireland has turned to technology for solutions to maintain essential rehabilitation services and continue as a lifeline to brain injury survivors and their families across the country.

Our use of telerehabilitation has been borne out of necessity during this health crisis but it is already proving its worth as an invaluable experiment. Neuro-rehabilitation is not a quick fix and the process centres around making plans and setting goals with our clients along with guidance and support from a range of professionals. Telerehabilitation has allowed our clinicians, case managers and teams to continue to deliver neuro-rehabilitation right into the client's home via video call or other remote means without breaking compliance with national Covid-19 restrictions. While this unplanned exploration into telerehabilitation has shown many positive results for the organisation so far, it is not suitable for all brain injury survivors in the community nor all aspects of neuro-rehabilitation. Our biopsychosocial model of neuro-rehabilitation means that we take the whole person into account. We look at their environment where they live, their abilities, support needs and we consider the life they had before their brain injury. Community visits are also essential for people living by themselves so we can check that they are managing well independently running their own home, cooking meals, taking medications and so on. In addition, when communication is remote only, the communication is less nuanced, and difficulties may go unnoticed until such time as a crisis unfolds.

There are additional costs incurred in our services because of Covid-19. These include the replacement cost of residential staff where staff who were symptomatic had to self-isolate for significant periods, particularly when there was significant time between testing and results, sometimes up to two weeks. Until the HSE could supply PPE we had to source that ourselves. In order to remain connected to our community and day service clients in particular, we equipped staff with tablets so they could Zoom individuals providing telerehabilitation and support, not only to the clients but also to families too in what was a very uncertain and stressful environment. The household budgets for services also had to increase to take into account the additional cleaning and disinfection.

3.2 Supporting families and carers

Our carers support service, *On With Life*, provides support to over 100 family carers across the country and when the lockdown happened we moved all the carer support services online. With no face to face meetings allowed, support group meetings are now operated online, as well as virtual coffee mornings, yoga classes and music therapy. Telephone contact and text messaging services are also utilised as regular means of communication. However, for some family carers, accessing and utilising such technology is not always an option.

3.3 Supporting and sustaining our staffing levels

Crucial to all our services are our highly trained and skilled staff. Their health and well-being continues to be of paramount importance. Clear protocols, policies and procedures and communications and training for staff are crucial to ensuring their own safety and well-being. Our success at keeping our services operating in a safe manner is due to the commitment, flexibility, and expertise of our staff teams across the country.

4. Issues for Acquired Brain Injury Ireland

Acquired Brain Injury Ireland is a Section 39 HSE funded organisation. Since our foundation, we have continually proven our agility, ability to innovate, responsive and highly creative. However, as a Section 39 organisation there are many issues that are of major concern to us in coping and adapting to the challenges of the pandemic as well as immediate and longer-term concerns around our sustainability:

- We are massively concerned about our future financial sustainability. Our organisation is not sustainable currently and given the uncertain future we are facing this sustainability crisis is only going to deepen.
- Throughout the pandemic, Acquired Brain Injury Ireland had to continue deal with a 1% cut to our funding from the HSE announced in January 2020. As a frontline service provider, this situation became extremely difficult during the Covid-19 crisis. We continue to face the reality of this cut despite assurances from the Minister for Health in the Dáil recently, that it would be reversed.
- We face core funding issues every year and continue to be funded via cash acceleration from the HSE.
- Our staff are currently disadvantaged in their wages compared to their counterparts in the HSE. We want to have public sector pay parity for our staff as they are carrying out the same work as HSE frontline staff in the same Covid-19 risk environment. Finding and retaining staff with this disparity is a constant challenge.
- We anticipate a massive dip in our fundraising capacity in 2020 and beyond given the very uncertain economic future.

- We want our sector to be recognised by the state as a vital component of the health service in the fight against Covid-19. The voluntary sector continues their frontline work to keep so many vulnerable people safe and well.
- There is a huge lag in policy implementation with an eight-year gap between the publication of the Neuro-rehabilitation Strategy in 2011³ and the Implementation Plan⁴ for the strategy in 2019. A policy paper published this year by Dr. Sara Burke et al⁵ from Trinity College Dublin on the extent of implementation of neuro-rehabilitation policy in Ireland indicates that rehabilitation services are low political priority which has resulted in poor policy implementation in Ireland. As a result, there is poor access to fragmented rehabilitation services. Burke et al present the case and that better data, visibility of people with brain injury and advocacy is needed to bring about change in rehabilitation policy and services. The paper's analysis indicates that despite the publication of the 2019 Neuro-rehabilitation Implementation Framework by the HSE, key challenges remain for people with ABI in Ireland, including the absence of services across the 'pathway', the under-resourcing of specialist rehabilitation services, the negative impact on the lives of people with brain injury of poor or no access to services, and the lack of good data on this population. The paper concludes with recommendations on how increased political priority of the rehabilitation needs of people with ABI could enhance implementation of the neuro-rehabilitation implementation framework.
- Pre Covid-19, community rehabilitation was vastly under-funded and now with Covid-19 cases added to the waiting lists and with more people needing rehabilitation, there is no mention by the HSE of building capacity in the current rehabilitation services. This needs to be on the agenda for Government. While the evidence is only emerging, it is clear now that there will be a need for rehabilitation for some people who have been impacted significantly by Covid-19 and what is being referred to as Covid brain.⁶ (Brain injury as a result of lack of oxygen to the brain, inflammation of the brain as well as an increased risk of strokes and other neurological effects). This will undoubtedly place an increased demand on community-based rehabilitation services which are currently, over-stretched, under-developed and under-resourced.

³<https://www.lenus.ie/bitstream/handle/10147/200892/NeuroRehabServices1.pdf?sequence=1&isAllowed=y>

⁴ <https://www.hse.ie/eng/services/list/4/disability/neurorehabilitation/national-strategy-policy-for-the-provision-of-neuro-rehabilitation-services-in-ireland.pdf>

⁵ Burke, S, McGettrick, G, Foley, K, Manikandan, M and Barry, S (2020) The 2019 neuro-rehabilitation implementation framework in Ireland: Challenges for implementation and the implications for people with brain injuries. Health Policy, Volume 124, Issue 3, March 2020 Pages 25-230

<https://www.sciencedirect.com/science/article/pii/S0168851020300051?via%3Dihub>

⁶ <https://www.bbc.com/future/article/20200622-the-long-term-effects-of-Covid-19-infection>

5. Recommendations

The following are recommendations that need to be implemented to ensure that the future of Acquired Brain Injury Ireland as a vital frontline service provider is secured and our funding sustained in the short and long term:

- **Immediate removal of the 1% cut imposed by the HSE to our organisation's budget for 2020.**
- **Address the funding crisis facing Acquired Brain Injury Ireland and other Section 39 organisations.** We need an annual investment of an additional €2m to make us sustainable and for us to deliver the services at the actual cost of providing them.
- **Implement public sector pay parity for our staff.**
- **Implement the recommendations of Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services⁷** relating to Section 39 organisations (Chapter 8). This includes overhauling the nature of the relationship between the state and Section 39 organisations and to address the flawed process for how the HSE currently decides to allocate funding to the sector.
- **Invest in the expansion of community-based neuro-rehabilitation services including an urgent investment to expand our brain injury case management service.** An investment of €500,000 per annum would provide an additional 7.5 case managers and a basic case management service across the country. This would ensure that the delivery of some key elements of the Implementation Plan for the National Strategy and Policy for the Provision of Neuro-rehabilitation Services in Ireland.⁸
- **Invest in research to understand the impact of the pandemic on people with ABI and their families.** Funding for research to generate this evidence is vital to understand the short and long-term impact of Covid-19.

⁷ The Government commissioned an independent review of the sector and a report was published in February, 2019 called the [Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services](#), also known as the IRG report, chaired by Dr. Catherine Day

⁸ <https://www.hse.ie/eng/services/list/4/disability/neurorehabilitation/national-strategy-policy-for-the-provision-of-neuro-rehabilitation-services-in-ireland.pdf>

Appendix 1

Supporting Information – About Acquired Brain Injury Ireland and brain injury

ABI Ireland

ABI Ireland is a dedicated provider of community-based neuro-rehabilitation services for people with an acquired brain injury (ABI) and their families. As a brain injury can affect a person's ability to manage their own life, ABI Ireland works in communities across Ireland to support and empower people to rebuild their lives. ABI Ireland also campaigns, educates and advocates for the rights and needs of this hidden group in society.

ABI Ireland Services

ABI Ireland provides a diverse range of clinically lead, accredited neuro-rehabilitation services. The core services include:

- Residential rehabilitation
- Transitional living
- Day resource/clubhouse
- Home and community rehabilitation
- Case management

Additional support services are also provided and include ABI information, psychology (Cognitive Behaviour Therapy/family therapy), social work, (family support services) and carer supports.

What is an ABI?

There are many ways in which a person can acquire a brain injury. These include, among others, a fall, assault, accident, infection, stroke or tumour. People's lives can change suddenly and significantly following an ABI. Having a serious brain injury is totally life altering for both the person and their family due the effects of brain injury. The brain is a complex organ. Depending on what part of the brain is injured, and the extent of the injury, the person will have to live with different consequences. Many of these consequences may be hidden, others not. They range from physical and sensory to cognitive and psychological.

Key Facts and Figures on ABI in Ireland

- Each year it is estimated that 19,000 people in Ireland acquire a brain injury
- There are over 100,000 people living with ABI in Ireland today
- ABI is one of the leading causes of disability and can have life-long consequences for people with the condition, their carers and families.

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