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Ms Aileen Fallon

Special Committee on Covid-19 Response

aileen.fallon@oireachtas.ie / covid19@oireachtas.ie

26th June 2020

RE: Cheshire Ireland submission to the Special Committee on Covid19 Response

Dear Ms Fallon,

Thank you for your letter of the 16th June 2020 inviting Cheshire Ireland to make a submission to the Special Committee in relation to people with disabilities and the disability sector more broadly.

I attach Cheshire Ireland's submission and warmly welcome the Committee's consideration of same as part of its work.

Should you or the Committee have any further questions or require any further information please don't hesitate to contact me.

Yours sincerely

Theresa Anderson
Acting CEO

Cheshire Ireland provides services to people with physical disabilities

The Cheshire Foundation in Ireland (trading as Cheshire Ireland) is a company limited by guarantee, registered in Dublin, Ireland.

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SUBMISSION TO THE SPECIAL COMMITTEE ON COVID-19 RESPONSE IN RELATION TO PEOPLE WITH DISABILITIES AND THE DISABILITY SECTOR

1. Introduction

1.1 Cheshire Ireland is a charitable company that provides services to people with disabilities that are generally physical in nature and/or people who have neurological conditions. Cheshire Ireland has been operating in Ireland since 1961 and now provides services in 14 counties across the country.

1.2 In addition to the provision of its services, Cheshire Ireland is also an Approved Housing Body and in that capacity also provides accommodation and is a landlord.

1.3 Cheshire Ireland provides the following services:

- **Residential Services** (there are 12 Cheshire Ireland HIQA registered designated centres in Ireland that supports 120 people);
- **Clustered Housing** (Cheshire Ireland supports 29 people who live within communities of purpose built self contained properties);
- **Stand-alone Homes in the Community** (Cheshire Ireland supports 52 people who live within properties that are located within the community more generally).
- **Respite** (Cheshire Ireland provides respite services in a number of its premises across Ireland);
- **Landlord services** (Cheshire Ireland is a landlord to 18 people with disabilities who do not receive support services from Cheshire Ireland).

1.4 Cheshire Ireland employs over 800 people to provide its services 80% of whom work directly on the front line.

1.5 Cheshire Ireland is primarily funded by the HSE through section 39 of the Health Act 2004.

1.6 Cheshire Ireland welcomes the opportunity to make this submission to the Special Committee on the Covid-19 Response as it has seen first hand the impact of the pandemic on the sector and more importantly on the people it supports on a day to day basis.

1.7A high percentage of the population that Cheshire Ireland works with fall into the definition of 'very high risk' in relation to the virus and as such are, and continue to be, particularly vulnerable to Covid-19. Thankfully, through the hard work, support and cooperation of the people it supports and its staff, the virus was effectively kept at bay and the organisation had an extremely low incidence of positive cases (with only 2 positive cases in the case of service users and a similarly small number in the case of staff) and no Covid-19 related fatalities.

2. Covid-19 Response for People with a Disability

2.1 It is arguable that the national Covid-19 Response had a particularly severe impact on certain sections of society who have disabilities. For those who lived within services that would have been considered as 'congregated settings'¹ originally but for the purposes of the language used during the pandemic fell into the definition of 'Long Term Residential Care' the changes imposed by adherence to Government advice and restrictions was immense.

2.2 Many of the people who received 'residential services' from Cheshire Ireland were all of a sudden cast into isolated living arrangements where they didn't see anybody other than essential health and social care staff.

2.3 For a cohort of people who were already considered to be socially excluded the Covid-19 pandemic magnified and intensified that sense of social exclusion. For many the communities they had shared a large part of their lives with within the service (for example one resident has lived in such a service for almost 60 years) were no longer available. The 'lockdown' meant that a number of people were living within their homes in almost total isolation given that the majority of people who are supported by Cheshire Ireland don't live with their families they were restricted to a household of one and with visitor restrictions in place this continued for a prolonged period of time.

2.4 The Covid-19 Response had a similar impact on others who were supported by Cheshire Ireland but who weren't necessarily living in accommodation that fell within the category of Long Term Residential Care. For those people the responsibility of adherence to Government guidance fell on them directly rather than on the service provider. In this sense people with disabilities who lived outside of a long term residential service were empowered more to adopt the guidance

¹ As understood in the context of the Time to Move on from Congregated Settings, A Strategy for Community Inclusion Report, June 2011

SCC19R-R-0382 (ii)

themselves with support as desired rather than actions being adopted around them.

2.5 The grouping of service types into categories posed certain challenges and it is submitted here that the definition of long term residential care facilities didn't necessarily provide sufficient clarity as to what that included. For example, in Cheshire Ireland it was interpreted to mean those services that were registered as 'designated centres' through HIQA. In essence however that meant that services where people lived in self contained apartments and who had tenancy agreements in place were subject to the same kind of restrictions that were applicable to nursing home type services. This therefore meant that any variance from public health guidance needed to be the subject of detailed risk assessment.

2.6 From that point of view it is submitted that the guidance wasn't sufficiently clear and that posed challenges in sharing accessible information as it was difficult to be categorically clear in relation to how the guidance would relate.

2.7 The lack of clear information left a lot of people supported by Cheshire Ireland in a state of uncertainty and heightened their fear of the pandemic.

2.8 Cheshire Ireland attempted to assimilate the information for the people it supported and create more accessible formats such as direct communications and easy to read resources however the wider public health information (even in its easy to read format) was not directly applicable.

3. Impact of Covid-19 on Daily Life and Services

3.1 Further to the above section it is clear that the Covid-19 Response had a significant impact on the lives of people with disabilities and on their services.

3.2 One of the main focuses in service provision as part of the Covid-19 response was being protective and promoting infection control in that context. Whilst that response was necessary it was resource heavy and didn't readily allow for resources to be allocated to other areas that would usually be provided as part of a holistic service such as social and emotional supports. This approach ran the risk of taking a more paternalistic aspect. This approach doesn't align with more progressive values and principles that align with the requirements of equality and

SCC19R-R-0382 (ii)

non discrimination as enshrined within both domestic and international legislation.

- 3.3 The Covid-19 virus itself thankfully hasn't had a massive impact on the majority of the lives of the people supported by Cheshire Ireland however the impact of the implementation public health restrictions has. In the provision of its supports Cheshire Ireland had witnessed severe reactions on the part of the people it serves which it is believed is in response to the restrictions that have manifested in the decline of people's mental health. In a couple of instances this has led to increased clinical and pharmaceutical interventions.
- 3.4 For many others, effects of the isolation and loneliness that they experienced during the lockdown has been significant. People had contact with their core staff teams but beyond that they often didn't have other non essential interactions (such as personal assistance social supports, family, friends etc).
- 3.5 Now that society is reopening it is somewhat concerning that people who are supported by Cheshire Ireland are still continuing to live as they did during the lockdown. For a high proportion of the people supported by Cheshire Ireland the impact of the lockdown on their lives was akin to their historic experiences of living within institutional settings and their hard work and dedication in combatting the effects of institutionalisation has to some extent been eroded. Cheshire Ireland has the benefit of supporting a number of people to move from congregated settings as part of a Genio funded project a few years ago and is therefore aware of the struggles people often face in overcoming institutionalisation and the type of support that can be provided to assist that process.
- 3.6 In this regard it is clear that resources will need to be allocated to support people with disabilities re-engage with the 'new' normal as it now is.
- 3.7 For some people, the Covid-19 associated lockdown enabled them to make use of technological means to contact their family, friends and community virtually. However, for a lot of the people that Cheshire Ireland supports they don't have the devices to enable them do this and would require additional support and training to use it. Cheshire Ireland made an application to the Social Innovation Fund to commence a project that would address this area but were unsuccessful.
- 3.8 The pandemic has highlighted a number of significant gaps that exists for people who are supported by Cheshire Ireland in relation to

enabling them to connect with society the way others without a disability do.

4. Impact of Covid-19 on the Disability Sector

4.1 The impact of Covid-19 on the disability sector more generally has been significant but it hasn't all been negative.

4.2 Cheshire Ireland has benefitted significantly from the availability of free virtual resources that are sector specific. For example, the Hospice Foundation, the HSPC and a number of other agencies have quickly developed tools that enable disability service providers respond to some of the challenges to the pandemic.

4.3 Equally, as a large organisation that has a number of services across the country the pandemic has enabled the more efficient use of technological devices to work on a day to day basis. Whilst remote working does pose some challenges and can't necessarily fully replace person to person contact it is helpful.

4.4 The pandemic has also showed how committed staff are in providing support to the people they work with. Staff showed incredible willingness to work in ways that were different such as working in smaller teams and in ways that reduced the chance of cross contamination. In addition staff went above and beyond their duties of employment in a number of cases and were perceived by society more generally as particularly valued (as were others in the health care sector).

4.5 In noting the above positive aspects of the pandemic on the sector it is disappointing that these positives are overshadowed by the severe impact that Covid-19 has had on the funding of the sector.

4.6 Financially Cheshire Ireland weren't able to fundraise in the way it would have previously. For example, the Rathfredagh Cheshire Home usually had an annual fete that contributed to the running of the service.

4.7 In addition, Cheshire Ireland had to use its own resources to purchase PPE privately over the first couple of months of the pandemic this had

SCC19R-R-0382 (ii)

an impact on the finances of the organisation but also on the human resources input that was required to source and distribute supplies. More recently these supplies have been provided through local CHO areas.

4.8 Finally and most significantly, Cheshire Ireland has a deficit in its annual funding that was present during the normal course of its service provision. This is not uncommon in the sector as was highlighted in the report of the Independent Review Group established to examine the role of voluntary organisations in health and social care.² The deficit in funding meant that services are stretched at the best of time but that during the pandemic this was even more so the case.

4.9 Given that the people supported by Cheshire Ireland need individualised care and support and that during the pandemic and in moving out of the pandemic the need for such individualised support and risk assessment has never been so important. Whilst Cheshire Ireland continues to work in a deficit it is difficult to facilitate this work in a robust and equal manner. Without this work the rights of people with disabilities in the sector continue to be under threat and need more opportunity to be promoted.

5. Conclusions and Recommendations

5.1 Whilst the Covid-19 Response was successful in stemming the curve of infection in the general population its response in relation to long term residential care was more complex. From an infection control point of view it was successful within Cheshire Ireland specifically but more generally the manner in which it was applied may have unnecessarily contributed to the social exclusion of people with disabilities by grouping them into specific cohorts and identifying them by reference to their living arrangements first and foremost. Furthermore, the response didn't specifically provide for the rights of people in relation to exercising their autonomy and self determination. Cheshire Ireland recommends that consideration be given to establishing rights related resources that will enable people to re-establish their own confidence in identifying and asserting their rights.

5.2 In addition to the above the approach in addressing concerns relating to the pandemic in society more generally centred on the understanding of a 'greater good'. This approach is akin to a 'best interests' approach which is contrary to the spirit and guiding principles of the Assisted Decision Making (Capacity) Act 2015. It is

² <https://www.gov.ie/en/publication/9b5f87-independent-review-group-examining-role-of-voluntary-organisations/>

SCC19R-R-0382 (ii)

recommended that clear guidance is provided that reinforces the State's commitment to the implementation and commencement of the Assisted Decision Making (Capacity) Act 2015.

5.3 Furthermore, it would be very helpful if technological investments were made that enabled people with disabilities access virtual opportunities to connect with others. This will become a central part of the 'new' normal and there is opportunity now to target those who are most at risk of social isolation and exclusion.

5.4 Cheshire Ireland is strongly recommending to the Committee that the recommendations of the Independent Review Group examining the role of voluntary organisations in the provision of health and social care are introduced. By introducing even some of the recommendations in relation to multi annual funding it will enable services in the sector plan strategically and reform their services as needed. It is submitted that for those services in the sector providing essential supports for people with disabilities in circumstances where they have deficits in funding are reaching a breaking point. Staff have shown how willing they are to go above and beyond their contractual duties for the benefit of the people they support but they can't continue to do this especially given the way they so tirelessly responded to the pandemic. It's not sustainable and it is now, more than ever, that people need person centred human rights based approaches to holistic care and support.