



Údarás Náisiúnta Míchumais
National Disability Authority

01 July 2020

Aileen Fallon,
Clerk to the Special Committee on Covid-19 Response,
Leinster House,
Dublin 2,
D02 XR20

Dear Ms. Fallon,

I write on behalf of the National Disability Authority regarding the invitation extended by the Special Committee on Covid-19 to make a written submission on the topic of Ireland's COVID-19 Response, and in particular the impact of COVID-19 on non-COVID healthcare services.

As the statutory body with functions to provide independent, evidence-informed advice to Ministers and officials on policy and practice relevant to the lives of persons with disabilities, the National Disability Authority is grateful for this opportunity. I enclose now a copy of the written submission, as requested by you.

Should you require any further information in this regard, please do not hesitate in contacting me.

Yours sincerely,

Siobhan Barron
Director
National Disability Authority

Special Oireachtas Committee on the COVID-19 Response – NDA Submission on Non-COVID-19 Healthcare

Executive Summary

The National Disability Authority (NDA) is an independent statutory body with a duty to provide information and evidence-informed advice to Government and officials in the public sector on disability matters, and to promote Universal Design. The NDA welcomes this opportunity to provide a submission to the Oireachtas Special Committee on Ireland's COVID-19 Response, and in particular the impact of COVID-19 on non-COVID healthcare services. Attention to this matter is particularly important in light of Ireland's obligations under the UN Convention on the Rights of Persons with Disabilities.

The COVID-19 pandemic has had a dramatic impact on the capacity of the healthcare system to deliver health and social care services. While the majority of persons with disabilities do not require routine access to health and social care services, COVID-19 has had significant adverse consequences for those who do. The NDA notes that the reduction or suspension of some healthcare services, such as dental services, mental health services and therapies, may have had a disproportionate impact on persons with disabilities, in particular where they have greater health needs than the general population. Additionally, along with the general population, persons with disabilities have been adversely affected by restrictions on health screening programmes, such as cancer screening. As normal health and social care services resume operation, the NDA advises that consideration is afforded to addressing increased need across a range of different areas and services.

Some persons with disabilities have been particularly affected by restrictions on the provision of disability services, which are also considered "health services" under Irish law, such as the temporary suspension of respite, the closure or partial closures of adult day services and the reduction in home support services.

The COVID-19 experience has underlined the importance of long-term health and social care planning and the need to accelerate progress across a range of areas. In this regard, the NDA acknowledges the considerable efforts by health and social care services to meet the challenges faced by persons with disabilities, in particular through the use of technology and remote support. The NDA advises that there is much learning to be captured from the response to the COVID-19 pandemic, which can inform future planning.

For its own part, the NDA is currently considering a number of COVID-19-related health and social care projects which could be progressed over the coming months, within available resources. The NDA will also be in direct contact with relevant departmental and agency officials to discuss the issues and the proposals detailed in our submission, as well as advising the Minister for Health.

Introduction

At the outset, the NDA notes that it has provided separate input into the Special Committee's review of the impact of COVID-19 on persons with disabilities and the disability sector, and this submission draws on the health and social care-related content contained therein. The term "health service" under Irish legislation incorporates both health care and personal social care services, and the submission below refers to the impact of COVID-19 on both.

The NDA would also like to highlight some key points from our previous submission that have application across the health service, such as:

- The need for effective communication between healthcare staff and persons with disabilities accessing healthcare, in particular those who may find it challenging to communicate with staff who may be wearing PPE such as face masks e.g. persons who are deaf
- The need for all health information to take into account needs of users who might have communication difficulties, and the need for accessible communications on all health-related matters (The Customer Communications Toolkit for the Public Service - A Universal Design Approach co-published by the Centre for Excellence in Universal Design and the Department of Public Expenditure and Reform may be instructive in this regard)
- The need to build the participation and consultation of persons with disabilities into all future considerations regarding the configuration and provision of mainstream health services
- The need for a Universal Design approach to healthcare to ensure that health care services are accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability
- The need for healthcare data to be disaggregated by disability

Regarding the latter point, the NDA advises that healthcare data should be disaggregated by disability to enable monitoring of the impact of COVID-19 on the health of persons with disabilities and future healthcare planning. For

example, it is essential for accurate data on numbers of cases and deaths to be available for the disability sector in order to enable tracking of the virus, and effective management thereafter. The NDA understands that the IDS-TILDA study, and possibly others, plan to collect data on the impact of COVID-19 which may support this work.

The NDA also notes that the majority of persons with disabilities live in the community rather than in specialist services. In this regard, if we consider the percentage of those who have died from the infection (as of 22nd June) having 'underlying conditions' (92.35%), it is likely that a significant number of these people would have described themselves as having a disability in Census 2016.

Information is available on underlying medical conditions for 18,935 confirmed cases of COVID-19 for notifications up to and including 17/06/2020. 9,782 (51.7%) of these cases were reported to have at least one underlying medical condition. 21% (n=3,977) of cases were reported to have one of these conditions, 7.8% (n=1,485) of cases have two of these, and 3.9% (n=736) have three or more of these. The five most commonly reported conditions were chronic heart disease, chronic respiratory disease, diabetes, chronic neurological disease, and cancer/malignancy.

The NDA advises that the above data will be useful in terms of identifying where additional healthcare needs may arise over the coming months and years owing to the effects of COVID-19 on persons with underlying medical conditions.

Provision for persons with disabilities

Impact of COVID-19 on Access to Healthcare Services for Persons with Chronic Health Conditions

Some persons with chronic health conditions, such as neurological conditions, cancer and heart disease, who typically require access to a wide range of health and social care supports, experienced disruption to services during the COVID-19 pandemic, including outpatient appointments, diagnostic tests and ongoing treatments which are delivered in a hospital setting. The NDA is also aware that some persons decided not to access healthcare services, especially during the initial stages of the pandemic, due to concerns regarding the potential risk of contracting COVID-19 in a healthcare setting, especially as people with such conditions were considered at most risk.

A report of a nationwide survey carried out by the Neurological Alliance of Ireland examined the impact of COVID-19 on persons with neurological conditions and family carers. An analysis of patient comments showed that 25%

had significant issues in accessing services/treatment for their condition. Most were concerned about the implications for their health and unsure when services would return to normal. Patients reported a range of challenges in accessing services and treatment including:

- Cancellation of outpatient appointments with neurology services
- Cancellation of infusion/injection treatments
- Delays in commencing new treatments, changes in medication postponed
- Postponement of routine MRI scans and delays in getting results from MRI
- Challenges in getting prescriptions renewed
- Cancellation of physiotherapy and other allied health services

A similar percentage of family carers (26%) reported a significant impact on access to services through their qualitative responses, raising most of the same issues as the patient respondents. Additionally, almost 20% of family carer respondents reported that they were experiencing delays in accessing allied health professional services such as physiotherapy or speech and language therapy in the community. The NDA notes that while this study focuses on persons with neurological conditions, it might also give a sense of how other persons with chronic conditions may have experienced the pandemic in relation to accessing healthcare.

Impact of COVID-19 on waiting times for health services particularly relevant for persons with disabilities

One of the key contextual factors to take into consideration when thinking about how the impact of COVID-19 will affect the lives of persons with disabilities is the fact that there were in many areas waiting lists in accessing the health services prior to COVID-19. In September 2019, there were 569,498 on a waiting list for a hospital outpatient appointment and 67,985 for a hospital inpatient appointment.

The NDA notes IDS-TILDA findings that there are higher levels of use of specialist health and social care services for people who moved to a more restrictive setting (movement from a community group home or from family/independent living to a campus setting or institution or to a nursing home or mental health unit; or from family/independent living to a community group home), though it is unclear whether movement to these settings was influenced by the need for such services or that placement in such settings means that specialist services will be offered and availed of. While waiting list figures are not

disaggregated by disability, the NDA advises that there are a number of services which are more likely to be specifically relevant to persons with disabilities, and in a number of these cases there were already significant waiting lists as of September 2019, which are only likely to have increased on foot of the pandemic and associated lock-down:

- 1876 on the CAMHS waiting list nationally
- 40,799 on the Physiotherapy assessment waiting list
- 33,343 on the Occupational Therapy assessment waiting list including 9,296 waiting more than 52 weeks
- 12,760 on the Speech and Language Therapy waiting list and 7,586 on the Speech and Language Therapy treatment waiting list
- 9,276 on the Psychology treatment waiting list
- 7,252 were on the waiting list for funding for Home Support hours

In relation to children with disabilities, there was, prior to COVID-19, significant delay in access to health services. Though children with disabilities have a right to an assessment of need under Part 2 of the Disability Act 2005, there were over 4,600 overdue (that is not completed within the statutory timelines) assessments of need in December 2019. Of these, over 3,200 were more than three months overdue.

While acknowledging that there is an overlap with the overall figures quoted above, the NDA notes that in December 2019 the HSE reported that there were 90,000 children waiting for community health care services, including 19,000 children waiting for speech and language therapy and over 7,000 children waiting to see a psychologist. Research findings consistently show the importance of children with disabilities or developmental delays getting early access to appropriate therapies.

The impact of COVID-19 means that there is likely to be increased challenges for persons with disabilities accessing many of the health services which are important to their wellbeing because existing waiting lists are likely to have grown because of disruption to many aspects of health service delivery in the first half of 2020.

Impact of COVID-19 on Adult and Child Therapy Services

While in the initial phases of the outbreak, many HSE therapists were redeployed to COVID-19-related work, some therapists (both adult and child) in HSE funded service providers have continued to provide therapies using video conferencing. As mentioned above, there were substantial waiting lists for accessing therapies prior to COVID-19. Given the disruption to therapy services related to COVID-

I9, it appears inevitable that these waiting lists are likely increase, although it may be some months before the relevant HSE Performance Reports can confirm this. The NDA advises that it will be critically important that the post-COVID-19 waiting lists are addressed across all age groups but for children in particular. The NDA, in its Children's Disability Services in Ireland report (2015) and through its work on the Transforming Lives Working Group I Report on **Future Needs for Disability Services**, has highlighted the need for additional therapist to meet demand.

The NDA acknowledges that there was funding provided in Budget 2020 for additional therapists for disability network teams and acknowledges that the HSE has developed a Training and Team Development programme for Children's Network Team Managers which will be delivered in the autumn when the new team managers take up post. The NDA also notes that the HSE now has an agreed Standard Operating Procedure for Assessments of Need. The NDA understands that plans for the resumption of face-to-face therapy services within public health guidelines will be finalised in the coming weeks. Notwithstanding the above, the NDA advises that there is likely to be significant challenges in meeting demand for therapy provision in the post-COVID-19 period.

The NDA has not been in a position to gather evidence on the experience of therapists or persons with disabilities or their families of their experience of therapists delivering services using video conferencing, but is currently planning a project to explore same to inform considerations for future models of service provision. However, from speaking with stakeholders, the NDA understands that for some people the experience was positive, though this may be influenced by certain factors such as the person's age (in particular in the case of children), the person's needs or the type of therapy availed of.

While pre-COVID, the HSE had developed e-Mental Health initiatives such as CAMHS Connects, there had been no such developments in relation to disability services. It would be important that the HSE try to gather information on experiences of therapy being delivered remotely to inform possible developments in the case of any future COVID waves and/or to consider the extent to which therapy services could be delivered remotely in the future.

Impact of COVID-19 on Disability Services

The HSE provides and funds a range of health and social care services for persons with disabilities. These services include health care services provided in acute settings, and those provided in the community, such as therapies. According to the HSE National Service Plan 2020, social care services seek to support and enable persons with disabilities to live ordinary lives in ordinary places as independently as possible. Social care services include adult day services, respite

services, residential services, home support services and personal assistant services.

The NDA notes that there is significant unmet need for disability services and is concerned that the COVID-19 pandemic has exacerbated the situation. In addition, the proportion of the adult population requiring specialist disability services and supports is increasing, due principally to demographic change and the growing numbers of adults aged over 60 living with family members. The Transforming Lives Working Group I Report on **Future Needs for Disability Services** (which was based on research and analysis jointly carried out by the NDA and the Chairperson of the Working Group I) highlighted the growing numbers of adults with intellectual disabilities (and in particular the growing number of older adults with intellectual disabilities, e.g. those aged 60 plus, who are also at greater risk of dementia) living with family members. A recent NUIG study analysing carer burden among family carers of people with and without dementia in Ireland found that dementia diagnosis and dependency level were significantly associated with carer burden (Teahan, Á, Lafferty, A., Cullinan, J., Fealy, G., & O'Shea, E. (2020). An analysis of carer burden among family carers of people with and without dementia in Ireland. *International Psychogeriatrics*, 1-12).

For instance in the residential care context, in order to cater for demographic changes, the lack of sustainability of arrangements whereby persons over the age of 60 live with family members and if there was a return to pre-recession use of residential services, it is estimated that an additional 1,900-2,000 residential care places for persons with an intellectual disability would be required by 2020, and 2,300-2,400 places by 2025. This indicates both a need for more residential places but also supports for older parents (respite, home support, etc.) supporting their adult child to live at home.

Overall, the report highlights the need to increase both current and capital spending in order to meet forecasted demand. Current spending needs to increase by approximately 19-35 percent. Capital spending requirements are likely to increase by between €100m and €300m.

Impact of COVID-19 on Home Support and Personal Assistant services

The NDA advises that the majority of persons with disabilities do not reside in specialist disability settings, but rather live in their own homes in the community, either individually, or with their families. Many of those living alone or with their families rely on social care supports to live independently, either in the form of personal assistant hours or a homecare support package.

Information indicates that the decision to temporarily reduce home help hours for some persons with disabilities was related to both public health measures of

physical distancing and ‘cocooning’, and the redistribution of home care workers to residential care arising from a rapid rise in the number of clusters of COVID-19, and staff shortages. In some cases, this reduction may have been in addition to an already existing insufficiency with regard to support hours due to budget and resource constraints in this area.

Similarly, a proportion of that reduction resulted from persons with disabilities opting not to avail of PA hours because of the risk to their health, or because a family member was now available to support them. However, some of the reduction also related to HSE guidance which focused on those with the greatest level of need. The HSE has pointed out that the reason it prioritised the service was in line with the public health message, to reduce numbers of people entering homes and risking the spread of the virus. The HSE developed a contingency plan for home support services which outlined different approaches to support people to remain in their own homes under different scenarios during the COVID pandemic.

The HSE also developed guidance for alternative models of care which include online support to family carers, one to one online support, face to face services, greater use of community supports, and technology etc. They encourage services to be innovative. It would be important that the HSE seeks to learn from how some of these innovative practices worked. It would be particularly important that the opinions of persons with disabilities, and where appropriate their families, are gathered to ensure that learning is used to inform arrangements in any future COVID waves but also in future service design.

The NDA advises that as the public health guidance is changing, it is important persons with disabilities are supported to re-engage with services when they are ready to do so. The NDA is aware that some service users who for example did not use their PA hours during the lockdown because of concerns about their health now fear that if they do not use up the hours allocated to them they may have them reviewed and lose them. It would be important that reassurance in this regard is communicated clearly to those with concerns about their health, with due regard to current capacity in the system.

The NDA also advises that the COVID-19 pandemic has further highlighted the need for work on a national personal assistance policy and home care standards to be expedited. The NDA notes that the Department of Health has progressed some work on a statutory home care scheme, including a public consultation on home care services and an evidence review by the Health Research Board on **Approaches to the regulation and financing of home care services in four European countries**. The **Sláintecare Implementation Strategy**

commits to the introduction of the new scheme in 2021. The NDA further notes the absence of a national policy for provision of personal assistance support.

The NDA welcomes the commitment in the new Programme for Government – **Our Shared Future** – to introduce a statutory homecare scheme, deliver increased home support and Personal Assistance hours, and also ensure that home support is adaptable and responsive to the needs of those with dementia.

Impact of COVID-19 on Adult Day Services

Adult Day Services have been closed since the beginning of the lockdown and remain closed. While some providers have sought to remotely support their adult day service users by conducting, for example, daily telephone or video calls, by distributing relevant activity-packs and by conducting one-to-one socially distanced wellbeing walks, there is a recognition that the closure of adult day services has been very disruptive to the lives of those who use these services and their families. The NDA understands that the HSE is planning to seek information from Adult Day Service providers on what service level was delivered over recent months during the lockdown. However, the NDA advises that, in addition to seeking information on the quantum of service that was delivered, the HSE should also seek to capture information on what models of support were used and what was the experience of persons with disabilities of those services.

Some adult day services users live with elderly parents who have been ‘cocooning’ and therefore this period away from their adult day services has been particularly isolating for them. Other day service users may be living with parents who have been working from home and who may therefore face challenges in providing the level of engagement that their adult children may receive as part of their day services.

Feedback from adult day service providers suggests that some individuals and some families have really struggled during the COVID-19 lockdown. While technology and developing innovative means of supporting adult day services users remotely has helped, there is a concern that some day service users will have had very limited social engagement over the lockdown period. There is a concern that some people who access adult day services will have lost skills which they have developed but haven’t had an opportunity to use during the lockdown (such as using public transport independently) and some others may have difficulty readjusting to a ‘new’ routine of attending an adult day service when they reopen.

The NDA notes that the HSE has produced guidance on returning to adult day services (**Reshaping Disability Services From 2020 and beyond in line with COVID-19 restrictions**). Given the potential impact of social distancing rules, this may mean that adult day services will have to operate at reduced

capacity in the medium term, meaning that some people may continue to receive their service or part of their service remotely during that period. These circumstances could present an opportunity to make progress in moving towards the more personalised and community-based service model outlined in the New Directions policy. However, operating service locations with reduced numbers and operating a more remote and community-based model of support will have resource implications given the levels of existing resources required. In this context it may be useful to look at investing in strategies which integrate the use of natural supports (local community and family and supporters) to meet some of the support needs. The NDA notes there may be learning that could be adapted in this regard from initiatives sponsored by Department of Community and Rural Affairs via the National Public Health Emergency Team (NPHE) sub-group for Vulnerable People during the crisis, whereby community assets (e.g. voluntary groups and clubs) were mobilised to ensure that necessary supports were provided to older persons or persons with disabilities who needed assistance with everyday tasks and activities such as shopping, social interaction, etc.

The NDA advises that another matter meriting serious consideration in the context of the phased reopening of day services is the need to address transport issues. In line with public health advice, transport capacity has been greatly reduced. Effectively addressing this issue may involve higher transportation costs for service providers and it would be important to ensure that these costs can be met without impacting on the quantum of day service supports individuals are in receipt of.

Impact of COVID-19 on the School Leavers Process

In addition to those currently receiving adult day services, COVID-19 restrictions have impacted both school leavers (the term used to refer to those applying for adult day services places post education or a period of rehabilitative training) referred in 2019 and school leavers to be referred in 2020.

The School Leaver Profiling Process for 2019-2020 was completed for most service users and funding allocated prior to the lockdown. There are always a few late referrals or delays in profiling individuals, but a small number of service users remain who were unable to be profiled. The NDA notes that this is a direct result of the profiling process requiring face-to-face interviews, which have been impossible due to COVID-19 restrictions. Fully completing the profiling process for those individuals has clearly been delayed, but we are unaware of how this delay is affecting families.

In order to address the delay in completing the last of the profiles and also to provide resources for the coming 2020-2021 process, the HSE is developing guidance and training to allow for remote profiling using the **Attend Anywhere**

platform. The NDA feels that such guidance should provide the opportunity to safely interview service users, families, teachers and service providers using tools (remote and in-person) applicable to each situation. To facilitate this change in the profiling process, additional resources may be needed and stakeholders may have to be supported to fully engage in the process.

The 2019-2020 School Leavers have been further affected by the inability of CHOs to directly negotiate placements with service providers, and service providers have been unable to meet with the service users themselves or offer placement visits. This may potentially affect close to 1,200 school leavers. The NDA is aware that the HSE has tried to address this by flexibly negotiating agreements with service providers and notes the impact of COVID-19 on this area of service provision will need to be monitored ongoing.

The NDA advises that in light of the potential for added costs to services, the current funding allocation system for specialist disability services may need to be reviewed in order to ensure that increased staffing costs, cleaning and equipment costs do not disproportionately impact the quality of services received by service users. Such impacts may include reduced access to services in order to facilitate social distancing. Smooth transitions from schools to adult day services are vitally important to school leavers and their families. Service users with autism, mental health issues and more challenging behaviour may struggle with these changes. School leavers who may have not had any previous experience in their new service may be at an added disadvantage.

With the new guidance from the HSE providing leeway for interviews to be conducted remotely or in-person, profiling for the 2020-2021 School Leaver process is set to begin in September 2020. Profiler training is set to commence in August or September and at least part of the training will be held via online webinars. The NDA will support the HSE process through independent quality assurance of the profiling process, as it has in previous years, with due regard to the new approaches being considered.

Impact of COVID-19 on Respite Services

COVID-19 has meant that many disability services have stopped providing respite services. Social distancing rules may mean that existing respite provision may not be delivered at full capacity for some time. Prior to the lockdown there was unmet need for respite services. In the NDA publication **Exploring the Experiences of Users of Disability Respite Services in Ireland**, about half of participants indicated that they would like an enhanced service with more sessions/visits or longer stays. Some participants seemed resigned to the fact that they had little choice in the type of respite they received, or in the frequency of their respite service. Participants were aware that there is a demand for respite

which is unmet. They talked about the need to ‘share services’ and ‘take your turn’. Those on waiting lists also stated that they would like a quicker response and access to services, and to be able to move from children’s to adult services more easily.

The post-COVID context may provide an opportunity for more flexible, personalised forms of respite to be developed. The NDA advises that the HSE and providers engage with persons with disabilities, and where appropriate their families, and look at the types of respite that could be delivered as alternatives to centre-based respite, which may be disrupted because of COVID or may be unsuitable for people who have particular health concerns.

Impact of COVID-19 on Residential Services for Persons with Disabilities and Older Persons

Both residential services for persons with disabilities and older persons, many of whom have disabilities and which also care for younger persons with disabilities, have experienced high numbers of clusters of COVID-19. The NDA understands that in congregated settings, where there are higher numbers of staff and fewer opportunities for self-isolation, the potential for transmission of the virus can increase.

There is anecdotal evidence to suggest that there has been a decrease in challenging behaviours amongst persons with disabilities living in residential services during the COVID-19 period, and that this may be linked to the provision of individualised supports to such persons. This may for example be related to some residents receiving a personalised support during the day in the lockdown instead of attending a group-based Adult Day Service. The NDA advises that the reasons for the apparent reduction in such challenging behaviours be explored further.

The NDA also notes that guidance produced by the HSE and the Health Protection Surveillance Centre on the phased reopening of residential care facilities, entitled **Interim Public Health, Infection Prevention & Control Guidelines on the Prevention and Management of COVID-19 Cases and Outbreaks in Residential Care Facilities**, covers all types of residential centres, but is primarily designed for residential centres for older persons. However, residential centres for persons with disabilities are more likely to be smaller and situated in the community, and persons living in such settings tend to be younger and may not have any underlying health issues. The NDA emphasises the importance of providing specific advice and guidance on the phased reopening of residential services for persons with disabilities in light of the different context.

In particular, Appendix H of the interim guidelines provides that all persons admitted to a residential care facility must isolate in a single room for a period of

14 days, a measure which has impacted negatively on the ability of such centres to provide respite care to adults with disabilities in recent weeks. The NDA understands that the HSE is developing guidance on providing residential care facilities with some flexibility in this regard.

The NDA notes that in 2012, government published the **Time to Move on from Congregated Settings Report**, in which a policy to decongregate persons with disabilities from institutional settings was set out. At the time the policy was published, there were approximately 4,099 individuals living in congregated settings of 10 or more people. A commitment was made to transition all these individuals to the community by 2021. By the end of 2018, the most recent year for which figures are available, there were approximately 2,100 individuals remaining in 83 congregated settings. While COVID-19 may in the short-term impact on efforts to support people to move out to the community, the NDA advises that acceleration of progress should be considered in light of the obvious benefits in terms of infection prevention and control.

Regarding those persons with disabilities living in congregated residential services for older persons, the NDA advises that meaningful consideration is afforded to providing more community-based living options for older people, including small, community-based residential centres or supported living in self-contained housing units. The NDA further advises that the current situation regarding persons with disabilities under the age of 65 years living in nursing homes for older persons needs to be urgently addressed. Effectively addressing this issue requires that appropriate housing, care and supports can be provided to such persons in the community, and planning to ensure that the practice of inappropriate placements of persons with disabilities in nursing homes in the future can also be addressed. It also requires co-ordinated working between the relevant authorities and actors, particularly the HSE and local authorities, as well as other stakeholders in the community to enable same.

Furthermore, in order to ensure such persons can live independently in the community, they must be able to access mainstream health services. This may require health services in the community to improve their accessibility for all users. An omnibus survey carried out by Ipsos MRBI for the NDA in 2011 examined the accessibility of community facilities. The research revealed that community facilities that had the lowest perceived access among disability households was the doctor's surgery. 34% of physical disability households reported that they could not access their local doctor's surgery without having to go up or down steps. The NDA's work to evaluate the costs and benefits of new models of residential service for persons with disabilities has also underlined that not all General Practitioner surgeries are accessible and as a result some persons with disabilities require home visits from GPs. Additionally, some GP services

have indicated they are unable to take newly decongregated service users onto their books. The NDA underlines the importance of not just accelerating the process for providing more appropriate accommodation, care and support to this cohort of young people in the community, but also ensuring that the community is prepared to adapt and integrate this group of individuals.

The NDA further advises that retrofitting and redesigning homes following Universal Design guidance produced by the Centre for Excellence in Universal Design at the NDA, would enable persons with disabilities and older persons to remain in and return to their homes for as long as possible, which would in turn reduce pressure on residential settings.

Impact of COVID-19 on Assistive Technology provision

Assistive technology plays a key role in fostering inclusion, participation, autonomy and independence for persons with disabilities by maintaining or improving their functional capabilities. The COVID-19 pandemic has underscored the importance and potential of assistive technologies in enabling persons with disabilities to live independently in the community, away from residential facilities, where the virus has shown to be readily transmissible.

Previous research commissioned by the NDA suggests that policy and delivery systems for assistive technology in Ireland are not effective and may not be reaching many people who need such technology. While publicly-funded assistive technology provision processes exist in Ireland across a range of settings, some of these processes can be fragmented, involving a number of different statutory and non-statutory stakeholders. The NDA notes that assistive technology provision processes are likely to have been disrupted by COVID-19, arising from restrictions on therapy, primary care and hospital services, which typically make referrals for HSE “aids and appliances”, and advises that this matter requires further examination, particularly in light of a possible second wave of COVID-19 or future pandemics.

The NDA advises that a comprehensive assistive technology provision system that is integrated into current service delivery systems would enable greater numbers of people to access assistive technology and to live independently in their own homes. Additionally, the NDA has committed to developing advice on national policy and practice relating to assistive technology.

Impact of COVID-19 on Section 38 and 39 service providers

Disability services are delivered through a mix of HSE direct provision as well as through non-statutory Section 38 and 39 service providers, and private providers. While operating costs for some Section 38 and 39 service providers may have reduced during the early stages of the COVID-19 pandemic, all providers are having to adjust to a new model of service delivery as they gradually reopen their

services, which has entailed higher expenditure. The NDA notes that some Section 38 and 39 service providers had raised concerns about the budget allocated to them for 2020 prior to COVID-19, indicating that it was not sufficient to deliver services at the same level or quantity as had been the case heretofore.

For instance, the National Federation of Voluntary Service Providers (FedVol) have noted that the cost of providing residential and respite services has increased due to changed staff-client ratios and rostering of additional support hours. FedVol also note that other costs need to be factored into consideration including the supply and cost of PPE; ongoing deep cleaning; additional occupational health services, redesign of living spaces where necessary; (and in some cases sourcing of alternative accommodation where respite facilities are in use for isolation purposes), insurance costs and IT investment. The NDA advises the need for discussions on funding Section 38 and 39 service providers for the additional costs associated with COVID-19.

Impact of COVID-19 on Access to Other Health Services

Impact of COVID-19 on Access to Oral Health Services

Oral health services have been significantly affected by the COVID-19 pandemic, with many HSE dental services suspending all non-urgent or routine treatments, although emergency treatments in large part continued. While many dental services are currently undertaking a phased reopening of services, the NDA is concerned that the prolonged suspension of routine dental services may have exacerbated the oral health challenges faced by persons with intellectual disabilities.

The **National Oral Health Policy, Smile agus Sláinte**, recognises that oral health issues are more prevalent among those with intellectual disabilities than the general population. The Intellectual Disability Supplement to TILDA and earlier work conducted in residential care settings show that, among persons with intellectual disabilities, oral healthcare was, and still is, poor by comparison with the remainder of the population in Ireland. For instance, more than one-third of older people with intellectual disabilities in residential settings suffer total tooth loss, whereas less than one-fifth of those with disabilities living at home or living independently and accessing mainstream local oral healthcare services suffer such tooth loss. As dental services gradually reopen, the NDA advises that the importance of addressing inequalities in oral health experienced by persons with disabilities are taken fully into consideration.

Accelerated provision of Telehealth and Telecare services during COVID-19

General Practitioner and many hospital services have moved to telephone consultations only. This move can be very helpful in terms of enabling persons with mobility difficulties to access healthcare services, but it can make it potentially difficult or impossible for Deaf people or persons with a hearing or speech difficulty to conduct a consultation. The NDA advises that technology should be available to facilitate accessible telehealth provision, e.g. through video calls, conferencing tools and even SMS. While the NDA is not aware of evidence being gathered in the Irish context, some international reports have shown how the COVID restrictions have highlighted the lack of availability of video calling options in many doctors' surgeries and hospitals and that many health practitioners are unaware of remote signing arrangements. The NDA advises this area be given further consideration, as telehealth provision would have a wide range of benefits for persons with disabilities and older persons, not least in future waves of COVID-19.

However, in addition to GPs, telecare and telehealth services have also been utilised by other health and care professionals during the course of the COVID-19, in order to mitigate the risk of infection. In the telehealth sphere, the unprecedented circumstances surrounding the outbreak of COVID-19 have led many healthcare professionals to undertake consultations, assessments and interventions remotely. The NDA is aware also of a number of new telecare initiatives, including a COVID-19 support line for older people, established by ALONE, working in collaboration with the Department of Health and the HSE. While such services can assist people to live more independent lives, it is acknowledged that older persons and persons with disabilities can encounter difficulties accessing and using such technologies.

The NDA has previously undertaken research to explore learning from telecare/health systems to guide national policy and advises that there may be further valuable learning from current implementation of solutions in this regard that could be applied in the future as a route to maximising the independence of persons with disabilities living in their own homes in the community. This research should also explore the barriers to accessing and utilising such services and technologies, for instance whether barriers relate to a paternalistic attitude of some disability services not allowing internet access for users, inadequate or lack of access to broadband, or other difficulties in accessing or using such technology. The NDA advises the importance of considering any potential solutions from a Universal Design perspective, which takes a broader approach to ensuring all people can access and use the technologies.

Healthcare Considerations for Persons with Disabilities in the context of COVID-19

Advance Healthcare Directives

The NDA reiterates and emphasises the need for the commencement of the Assisted Decision-Making (Capacity) Act 2015, and in particular Part 8 of said Act at the earliest opportunity. Part 8 allows for the creation of Advance Healthcare Directives, a legal document in which individuals may make advance expressions of his or her will and preferences in respect of treatment decisions. In such a case where an individual falls ill and lacks capacity to make a treatment or healthcare decision at that time, the decision made will still be informed by the person's will and preferences. The NDA advises the relevance of this for any future waves of COVID-19, where individuals may be severely impacted and may lose capacity to express their preferences with regard to healthcare interventions such as ventilation etc.

Ethical Decision-Making in the context of COVID-19

In April, the National Public Health Emergency Team (NPHE) approved the guidance document “**Ethical considerations relating to critical care in the context of COVID-19**”. The aim of that document is to support clinicians in their challenging roles and to ensure that, in the event of a surge where critical care capacity is exceeded, decisions regarding the allocation of finite critical care resources are made in a consistent and fair way. The document followed the previously published Ethical Framework for Decision Making in a Pandemic, and deals with specific measures for critical care units and intensive care beds.

The document stipulates that, in deciding who should be prioritised for intensive care, a range of factors should be considered including the presence of comorbidities and frailty. It further states that no single factor (e.g. a person's age) should be taken, in isolation, as a determining factor and decisions should not be made arbitrarily or in such a way as to result in unfair discrimination. In response to concerns that persons with disabilities may not receive equitable healthcare in the event of a COVID-19 surge, the Department of Health published a two-page Supplementary Information document. It explains that one of the key messages of the original guidance document is that safeguards against unfair discrimination are required to ensure that there will be no systematic de-prioritisation of any group, including those with a disability. It also notes that caution should be exercised when interpreting frailty scoring systems in the case of persons with a disability. According to the Supplementary Information document, the terms disability, frailty and comorbidity are often conflated and, while they may be inter-related, they are distinct.

While the possible COVID-19 surge has not yet happened, there is still a concern that the health service could be overwhelmed in event of a second wave

coinciding with winter flu season etc. While welcoming the Supplementary Information document provided by the Department of Health, the NDA underlines the importance of ongoing, effective communication with persons with disabilities and their families in the context of the COVID-19 pandemic, particularly where concerns exist that they may not receive equal access to healthcare.

Consultation with Persons with Disabilities on COVID-19-related Healthcare measures

The National Public Health Emergency Team (NPHE) COVID-19 Subgroup - Vulnerable People was set up “to provide guidance around the specific preparedness, measures and actions that need to be taken to protect vulnerable groups and individuals in society.” According to NPHE’s Terms of Reference, the term “vulnerable people” includes persons with a disability and mental health service users. Membership of the Subgroup includes a representative of the Mental Health Commission and a voluntary sector representative for the disability umbrella groups. Whilst acknowledging the inclusion of a disability perspective, the NDA advises that the Subgroup could benefit from broader engagement with disability stakeholders, and persons with disabilities facing a diversity of situations during the COVID-19 pandemic. In this regard, the Department of Health may wish to reflect on membership of the Subgroup.

Catch-up programme for missed care and services

Census 2016 show that there is a stark difference in the percentage of persons with and without disabilities with regards to how they report their general health (92.7% without a disability vs 51.2% of persons with a disability). The Healthy Ireland Framework has a number of actions related to improving the health outcomes of persons with disabilities. The lockdown has impacted on health promotion strands such as screening and physical activity. It will important that as programmes under these strands are recommenced that they are made accessible to persons with disabilities, including those with underlying health conditions.

The NDA has previously noted that in some cases, persons with disabilities may access such routine healthcare services to a greater degree than their non-disabled counterparts, but that their health outcomes may not necessarily have been as positive as might be expected in this context. This is often due to the fact that healthcare professionals have not had the training or capacity to provide healthcare information in a way that is tailored and accessible to the individuals in question. The pause in these services that was forced by COVID-19 could offer a

valuable opportunity to consider approaches to building capacity in the system in this regard.

Cancer screening programmes have been paused during the course of the pandemic, though it is anticipated that such services will resume during the course of July. Additionally, the NDA understands that due to public health requirements, there is reduced capacity for carrying out certain diagnostic tests, in particular colonoscopies. The NDA notes that the Irish Cancer Society has highlighted the need for additional healthcare capacity to deal with a growing backlog of tests.

Mental Health and Wellbeing

Mental Health Services

The NDA notes that the COVID-19 pandemic has negatively affected many people's mental health and, for some, may have exacerbated their pre-existing mental health issues. Mental health issues, such as anxiety and stress, may have arisen due to the effects of the COVID-19 virus itself or concerns regarding family and friends contracting COVID-19, or indeed the fear of transmitting the virus to such persons. Such issues may also have resulted from social isolation, disruption to everyday life and loss of employment.

Research undertaken on behalf of the Department of Health by Amarach showed that the COVID-19 outbreak has led to a significant impact on Irish people's mental health and wellbeing. This research showed that:

- Isolation is likely to cause distress and mental health problems
- Overall level of worry scored consistently high at almost 7/10
- Four out of five people were worried about their friends and family, and almost as many are worried about the economy
- One-third of people were worried/believe they will get the virus

Previous research undertaken by the NDA on access to mental health services for persons with an intellectual disability found that the separation of mental health services from disability services resulted in difficulties for those persons availing of disability services, who also required access to mental health services. In this regard, the NDA notes that 50% of people with severe and profound learning disabilities experience mental health issues at some point in their lives. The NDA notes that the difficulties experienced by those persons availing of

disability services who are also seeking access to mental health services may have been exacerbated during the pandemic.

The NDA welcomes the mental health wellbeing campaign launched by the Department of Health and the HSE in April, entitled 'Together'. The initiative directs people to the HSE's 'Your Mental Health' supports and resources, including online and telephone services, and provides tips and advice from cross-Government and Healthy Ireland. Another welcome service launched during the initial stages of the pandemic was the Crisis Text Line, a free, 24/7, confidential messaging service for people in crisis.

The NDA notes that the COVID-19 crisis has accelerated the provision of telemental health services by both the HSE and state-funded organisations, including telephone and online therapy sessions. The NDA understands that HSE Community Mental Health Teams are providing most of their services online or via telephone, though some face-to-face assessments and interventions are still facilitated, albeit at a much reduced level. The NDA advises that the eMental health experiences of services, professionals and service users are captured in order to inform future policy developments and service delivery.

The NDA understands that some mental health services, such as the National Forensic Mental Health Service and acute admission units, have continued to operate normal services during the course of the COVID-19 pandemic, though some were challenged by staffing issues and the necessary infrastructure to facilitate isolation and social distancing. Relevant primary care services, namely counselling and psychology services, also continued, but at a reduced capacity. However, some mental health services, in particular day services, encountered significant disruption. In addition, a number of programmes falling within the remit of the HSE's Mental Health Engagement and Recovery Office were adversely affected by COVID-19, owing to restrictions on face-to-face meetings and the redeployment of staff. These include the Individual Placement Support (IPS) model, the Advancing Recovery initiative and community living programmes.

The NDA is aware that the HSE has commenced planning for a resumption in mental health services. The HSE is also coordinating a Psychosocial Response Project Group to address the impact of COVID-19 on mental health through the development of a framework for psychosocial structures and responses. Groups that will be prioritised under the framework include those who have been bereaved during the pandemic, healthcare workers and "more vulnerable groups of the population". The focus to date been on providing immediate psychological first aid and bereavement supports.

Furthermore, the NDA welcomes the recent publication of the refreshed mental health policy, **Sharing the Vision – a Mental Health Policy for Everyone**,

in particular the focus on community supports. The NDA notes that one of the issues which hindered effective implementation of the previous policy, **A Vision for Change**, was lack of sufficient resources, particularly during the economic crisis. As Ireland faces another period of economic uncertainty in the wake of COVID-19, the NDA underlines that effective implementation of the refreshed policy will require adequate human and financial resources, particularly in the context of a likely increase in demand for mental health services and supports arising from the negative impacts of COVID.

The work of the Mental Health Commission has also been challenged by the pandemic. Physical inspections by the Commission have been paused during the COVID-19 outbreak, though plans are under development to resume inspections. However, the NDA notes that the Mental Health Commission developed a COVID-19 Risk Assessment Framework, at the request of the Department of Health, to contact and assess services in terms of their preparedness, environment and disease progression. While these assessments are not publicly available, the NDA notes that they contain a range of valuable data, such as the number of residents considered to be “at-risk”, whether the physical environment facilitates separation of residents and whether residents are accommodated in shared accommodation.

The NDA advises that while these assessments are invaluable in terms of directing necessary resources to services with the greatest level of COVID-19-related need and controlling the spread of any outbreak, they may also be valuable in terms of long-term planning, particularly as regards prioritisation of people moving from mental health congregated settings to homes in the community. The NDA notes that a 2020 discussion paper on **Access to Acute Mental Health Beds** published by the Mental Health Commission revealed a low number of community mental health supports across the State, resulting in the protracted placement of individuals experiencing mental issues in acute mental health units.

The NDA noted that the Mental Health Commission expressed concern regarding the length of time taken for staff to receive test results, despite the introduction of guidance in April requiring all staff to be tested. At the end of May, 32 out of 181 services reported that they were awaiting one or more staff test results. While acknowledging the challenges which can be involved in mass testing facilities, the NDA underlines the importance of communicating test results to staff working in health and social care services within a short timeframe. Another concern raised by the Mental Health Commission related to guidance for approved centres, some of which provide both acute and residential services. While COVID-19-related guidance was published for both acute and residential services, the Mental Health Commission reported at the end of May

that some approved centres remained confused as to which public health guidance document they should be following.

Finally, the Emergency Measures in the Public Interest (Covid-19) Act 2020 amended provisions in the Mental Health Act 2001 concerning the review procedures for those who are involuntarily admitted to an approved centre. Changes introduced included:

- The possibility of appointing a lawyer to convene a one-person mental health tribunal, instead of a typical three-person panel. The lawyer reviews the same documentation as the three-member panel and can have access to an independent psychiatrist for further guidance in relation to certain specific matters
- The independent consultant psychiatrist can carry out the examination of the patient remotely
- If the treating consultant psychiatrist is not able to attend the tribunal hearing then they shall be required to submit a report within a day of the tribunal hearing
- A tribunal may adjourn a hearing on its own motion if satisfied that this is required due to the public health emergency and having due regard to the interests of the patient
- Tribunal hearings can be conducted remotely

The NDA notes that these measures are due to expire no later than 9 November 2020. While acknowledging that such measures may be required in the short-term to deal with the continuing effects of COVID-19, it is important that they do not last any longer than is necessary. It is the NDA's understanding that research will be undertaken to ascertain the experiences of those who have used the temporary review procedures.

Wellbeing and Persons with Autism

The NDA notes that COVID-19 has resulted in many sudden changes in people's daily lives, including the closure and reduction of services. We know that disruption to routines, such as the closure of schools and day services, can be particularly challenging for persons with autism, including children with autism, and adversely impact their mental health and wellbeing. In addition, we note that some families and carers are experiencing increases in challenging behaviour from persons with disabilities, including autism, who are finding it difficult to adjust to new routines. These challenges can also negatively impact on the resilience and mental health of carers.

Wellbeing and the Employment of Persons with a Disability

Another relevant consideration is the link between employment and positive mental health and wellbeing, and the impact of COVID-19 on unemployment levels and in turn psychological wellbeing. The NDA notes the progress was being made to date towards improving the employment outcomes for persons with disabilities in Ireland (the rate work for persons with disabilities aged 20-64 as a percentage of the whole population rose from 33% in 2011 to 36.5% in 2016), including through actions committed under the Comprehensive Employment Strategy for Persons with Disabilities (CES). We are concerned, and are also aware of concerns of stakeholders in this space, that the progress achieved to date may be reversed on foot of employment lay-offs owing to COVID-19, particularly as large numbers of persons with disabilities in employment are in sectors vulnerable to the economic downturn, such as retail, catering and hospitality.

We advise the importance of continued commitment from all relevant actors to implementation of the CES once the immediate crisis has passed, noting that employment is a valuable route to social inclusion, as well as physical and mental well-being. Restoring employment levels and the economy will be critical areas for attention as the COVID-19-related restrictions are lifted. It will be important that any planning such as the provision of new activation and employment support measures for same always have due regard to the employment of persons with disabilities, as they continue to experience low employment levels and may be most likely to be impacted by any downturn. In particular, there is a need for employer engagement in relation to employing persons with disabilities and for addressing issues in relation to developing the skills of persons with disabilities for a labour market which is likely to have more of a focus on a digital-virtual world - where technology and remote working practices will be key components of future work practices.

Physical and Mental Wellbeing in the context of Physical Exercise for Persons with Disabilities

The Social Impact of COVID-19 survey was undertaken by the Central Statistics Office (CSO) to measure the impact of COVID-19 on Irish society in April 2020. More than 95% of survey respondents said they exercise. Of these, 37.1% stated that their frequency of exercising had increased since the introduction of COVID-19 restrictions, 33.2% of respondents said that it had decreased and 29.8% of respondents reported no change. The data are not disaggregated by disability.

The NDA notes that while some disability service providers conducted one-to-one socially distanced wellbeing walks with persons accessing their services, and

thereby ensured that some persons continued to engage in physical activity, it is possible that, for others, physical exercise was reduced on account of lack of access to structured physical activities, such as swimming pools and dance classes. The NDA advises the importance of ensuring persons with disabilities can physically exercise, particularly in light of the benefits for mental and physical wellbeing.

The NDA also notes that one way in which residential centres for persons with disabilities sought to prevent and control the spread of COVID-19 in their facilities was to restrict residents from undertaking normal social activities, such as certain forms of physical activities. The NDA advises that any such restrictions will need to be reviewed to ensure that persons with disabilities are not treated less favourably than the general population with regard to social and physical activities, especially in the context of the World Health Organisation's view that some public health restrictions related to COVID-19 will be in place for another two and a half years.

Children with Chronic Health Conditions and Education

While many children may go back to school in August, there may be some who cannot return or some who may encounter greater difficulties returning because of their own health situation. While some of these children may need to engage with schools remotely, it may be possible for some of them to return to school with adequate supports, including healthcare supports.

The NDA notes that one of the key components of the new School Inclusion Model is a new national nursing service for children with complex medical needs in schools. The School Inclusion Model was to be piloted in 75 schools, both primary and post-primary, in Kildare, Wicklow and South Dublin. The NDA understands that work in relation to a National Nursing Scheme element has been paused due to COVID-19 restrictions. The pilot has been extended for another year and will be evaluated by the ESRI. The NDA advises that this evaluation could examine how the new national nursing service, and the wider School Inclusion Model, can best support children with chronic health conditions to access the physical school environment.

Conclusion

The NDA recognises that the circumstances created on foot of the COVID-19 pandemic are unprecedented and challenging for all involved in the health and social care sector, in particular the Department of Health, the HSE and all

providers. We also acknowledge that there will be a significant impact on the State finances when the initial crisis has passed. However, we advise the continued importance of meeting the health and social care needs of persons with disabilities over the short, medium and long term, particularly in light of Ireland's ratification of the UNCRPD, Article 25 of which guarantees a right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

While public expenditure may be constrained in the immediate future, we advise the necessity of exploring innovative ways of working and leveraging available funding so that any improvements to date in the health of persons with disabilities are not reversed, leading to a failure to comply with the provisions of the Convention. The NDA also underlines that additional health and social care capacity may be required across a number of fronts to deal not only with the immediate adverse impacts associated with COVID-19, but also to ensure that the necessary, long-term changes required to deal with any future pandemic are put into place.

The NDA will be embarking on research to establish learning from some of the innovative health and social care practices put in place during the crisis, and also to understand the impact of the pandemic on persons with disabilities, whether in specialist disability services or accessing mainstream services. We will be happy to update the Committee on this work as it progresses.