

NDA's submission to the Oireachtas Special Committee on Covid-19 Response on the impact of COVID-19 on persons with disabilities and the disability sector

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**Údarás Náisiúnta Míchumais
National Disability Authority**

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 persons with disabilities and the disability sector. 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 disproportionate impact on persons with disabilities in Ireland. There have been high numbers of COVID-19 clusters in residential care facilities, and high rates of mortality in some centres, particularly nursing homes. Persons with disabilities have also been adversely affected by the closure of schools, the temporary suspension of services, such as respite, and the reduction of others, such as home support and adult day services.

However, the NDA recognises that, beyond specialist services, persons with disabilities have also experienced challenges in their daily lives. In the employment context, large numbers of persons with disabilities work in sectors adversely affected by COVID-19. The NDA is also concerned that changes to transport schemes and sanitation facilities in the post-lockdown context may have adverse consequences for persons with disabilities requiring access to these public services to go about their daily lives.

The COVID-19 experience has underlined the importance of long-term planning and the need to accelerate progress across a range of areas. This includes the decongregation process and embedding the involvement of persons with disabilities in the design and delivery of emergency interventions. However, the NDA also acknowledges the considerable efforts undertaken to meet the challenges faced by persons with disabilities. Examples of this include the creation of a Summer Education Programme, with expanded eligibility, and innovations in the use of technology and remote support in areas such as education and healthcare. 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 suite of COVID-19-related 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 Ministers concerned.

COVID-19 Infections and clusters in disability settings

The NDA notes that congregated settings such as nursing homes for the elderly have seen clusters of the COVID-19 virus, and that significant numbers of individuals living within these settings have contracted the virus, with a further number dying from it: 14 COVID-19-related deaths associated with residential disability services (as of the 22nd of June); 884 COVID-19-related deaths associated with nursing homes for the elderly (as of the 26th of May); and 17 COVID-19-related deaths associated with mental health services (as of the 22nd of May).

The NDA advises that, while much of the media focus on clusters of COVID-19 has been on nursing homes, congregated settings for the provision of disability services – e.g. residential, respite, or day services – similarly pose risks to controlling the spread the virus as those settings for the care of the elderly. In referring to residential disability services, the NDA includes congregated or ‘institutional’ settings with 10 or more residents, but also homes within the community where a number of individuals may live together in groups with staff support. There are approximately 8,000 individuals in residential services. The staff and residents within these centres may not have the same opportunities for self-isolation in the event of illness or exposure to the virus as the general population, and this can accelerate the spread through the relevant facility. It is also the case that there are a mix of staffing arrangements in such centres, with some staff ‘living-in’ and others attending on a rota over the course of the day. Changeover in rosters and the attendance of staff can also give rise to further opportunities for cross-contamination between the community and the residents in the centre.

There are around 1,100 residential centres for persons with disabilities nationwide. The NDA notes that to date there was no COVID-19 outbreak in 75% of those settings. To date, there have been 105 COVID-19 outbreaks associated with disability services. There were 623 cases of illness and 488 laboratory confirmed COVID-19 cases associated with these outbreaks. Disaggregate data are available on 405 of the notified COVID-19 cases linked with the 105 outbreaks. Of these, 222 were reported as being a health care workers and 107 were reported as not being a health care worker. Disaggregate data was not available for the remaining 76 cases. There have been 14 confirmed deaths linked to COVID -19 among persons with disabilities in residential settings.

It appears that staff turnover in disability services may have been less pronounced than in residential care settings for older persons. It is also the case that many of those living in designated residential facilities are less mobile than the general population due to the severity and complexity of their disabilities. This has meant that their level of exposure to community transmission may have been reduced. The HSE also developed Coronavirus (COVID-19) guidance for vulnerable group settings, including residential settings for persons with disabilities, which offered clear information and advice on how to manage infection spread. The Department of Health has reported that where there were outbreaks in residential settings, 25% were COVID-19-free after 28 days.

The HSE and individual service providers also moved swiftly to pause those services where individuals move in and out at regular intervals, and therefore where there would be increased risk of introducing infection to a particular centre e.g. adult day services or respite services. While this may have been beneficial in slowing the transmission of the COVID-19 virus, the NDA advises that there are other consequences to this cessation of services, which will be discussed in further detail below. The NDA also recognises that disability services have sought to respond innovatively within the constraints of COVID-19.

The NDA also notes that a number of persons with disabilities under the age of 65 are resident in nursing home facilities for older people, and so may be at risk of contracting the COVID-19 virus in such locations where there is an outbreak. While exact numbers are not available, it has been estimated that there could be as many as 1,200 individuals in this category. The NDA advises that the availability of appropriate supports within the community is required to ensure that persons under the age of 65 are not inappropriately placed in facilities for older people.

Availability of data disaggregated by disability for COVID-19

While the NDA welcomes the regular publication of data on the number of cases of COVID-19 in the community, we wish to emphasise the importance of data disaggregated by disability. We note challenges in accessing and validating this data, and in particular instances where designated centres have been identified as having an outbreak when this is not the case. 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 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.

COVID-19 response for persons with a disability

PPE - Supplies and supports for disability sector and carers

The NDA notes the importance of ensuring that health and social care staff can access personal protection equipment (PPE) as required throughout the duration of the pandemic, and that training and guidance is provided on the use of this equipment as appropriate.

The NDA further advises the importance of ensuring that PPE allows communication with persons with visual or hearing difficulties, or persons who might find the wearing of PPE challenging for a number of reasons, such as a mental health issue, autism, facial disfigurement, claustrophobia or other health conditions.

The NDA notes that face masks which are provided to consumers in the course of commercial activity must meet “Standard Written in Fast Track” (**SWiFT**) **I9 specifications**, which have recently been developed by the National Standards Authority of Ireland (NSAI). The NDA participated on the NSAI committee responsible for developing SWiFT technical specification titled “SWiFT-I9:2020 Barrier Masks for Consumers” to represent design considerations for persons with disabilities and the wider population through applying Universal Design principles.

SWiFT-I9 defines requirements related to regulating Barrier Masks for consumers in Ireland, as explained by the Competition and Consumer Protection Commission (CCPC) on their website. While the NDA notes that some disability support providers initially experienced difficulty obtaining adequate PPE supplies, this was addressed by the HSE and disability service providers have since been able to access HSE centrally procured PPE supplies.

Accessibility of public health information on COVID-19 for persons living with disabilities

The HSE has developed Coronavirus (COVID-19) guidance for vulnerable group settings, including residential settings for persons with disabilities, which is welcome. Where persons with intellectual disabilities are resident in such communal settings, it is important that information on requirements regarding social distancing, self-isolation measures, and the use of PPE is communicated in a variety of ways, so that the residents are as aware of and comfortable with new arrangements as possible. Staff may also need to review protocols for how individuals who are diagnosed with COVID-19 are transferred to hospital if necessary, including whether they need to be accompanied in order to ensure healthcare information is clearly communicated and understood by the individual in question, with due regard to the safety of both staff and those in need of treatment.

Impact of COVID-19 on daily life and services

Impact on educational supports for persons with a disability

The closing of schools because of the COVID-19 has had a significant impact on children with disabilities and their families.

Many public bodies developed guidance and resources in this area. For example,

- The Department of Education and Skills produced guidance for schools (**Guidance on Continuity of Schooling: Supporting Pupils with Special Educational Needs For primary and special schools**)
- The National Council for Curriculum and Assessment hosted a webinar '**Vital for some, good for all - Supporting students with Special Educational Needs (SEN) remotely**' on Tuesday, 28 April
- NEPS developed a range of advice and resources for keeping children and young people well during COVID-19
- The National Council of Special Education developed a range of supports material for both teachers and parents called **Online resources for home learning during the COVID 19 restrictions**. The NCSE has also developed the capacity to continue to deliver elements of its Continuous Professional Development (CPD) programme online during the lockdown

In addition to developing support material the NCSE's SENOs, advisors and Visiting Teachers have continued to provide support to schools and parents. The NDA is also aware that principals, teachers and Special Needs Assistants are also

providing learning materials and carrying out live and recorded Zoom classes with many students, individually and as small class groups.

Despite all of the above efforts to support schools and families to maintain progress in the learning of children with special educational needs during the lockdown, the reality on the ground appears to very mixed. Stakeholders who the NDA spoke to indicated that a high proportion of the families who were feeling overwhelmed because of home-schooling during the lockdown were families of children with disabilities. A survey by Inclusion Ireland with families of children with intellectual disabilities and autism (**The Implications of COVID-19 on the Education of Pupils with Intellectual Disabilities and Autism**) highlighted the various barriers faced by families in trying to support their child's learning while they were out of school. Some of the barriers potentially apply to families of children with or without disabilities such as parents working, access to appropriate technology or adequate broadband but others were particular to children with disabilities, such as, access to appropriate guidance and resources.

Similarly, an INTO commissioned report by researchers in NUI Maynooth (**Covid-19 Practice in Primary Schools in Ireland Report**) highlighted that teachers found providing support remotely to some children with special educational needs particularly challenging. The ESRI's report (**Second-level students impacted by a lack of access to technology during COVID-19 school closures**) which was based on a nationally representative survey and in-depth qualitative research with school leaders found that children from socio-economic disadvantaged backgrounds and those with special educational needs have been particularly impacted by the shift to distance learning and that the lockdown will have contributed to widening pre-existing educational disadvantages.

In the context of the above, the NDA advises that it will be very important that evidence, training and support materials are gathered in relation to how children with disabilities and their families can best be supported in relation to online learning. The NDA understands that the NCSE 2020 research conference will focus on the topic of remote learning for children with special educational needs. However, more is likely to be needed in the short to medium term to develop the knowledge and resources around remote learning for children with special educational needs. While many children may go back to school in the autumn, there may be some who cannot return because of their own or a family member's health situation. Some of these children may have special educational needs and may therefore need to continue to engage with schools remotely.

The NDA welcomes the 2020 Summer Education Programme, in particular the expanded eligibility criteria, and also the cooperation between the health and

education sectors in developing a joined up programme. The NDA accepts that, in the time available, pragmatic solutions had to be found in order for the Programme to be delivered in summer 2020. We note that as of the 25th of June approximately 200 schools have registered to run the school-based summer education programmes, which will benefit an estimated 3,400 children. 9,200 children are registered for the home-based programme. Also, in allowing SNAs to deliver the home-based programme the scheme, we note that the 2020 Summer Education Programme has moved beyond the education focus of the July Provision scheme.

There are however concerns about the current eligibility rules. Given that school years in the short to medium term may be disrupted, the NDA advises that work should commence on developing an evidence base on the impact of school loss (what children are most at risk of regressing from periods out of school) to inform 2021 and future eligibility rules and look at the evidence around the costs and outcomes of providing educational supports and/or of providing opportunities for social participation (in mainstream summer activities or programmes for example).

The Association for Higher Education Access and Disability (AHEAD) surveyed students with disabilities in the Further Education and Higher Education Sectors and found that many students with disabilities in those sectors felt that they were not coping well with remote learning (**Covid-19 Learning from Home Student Survey Report**). As there appears to be a degree of consensus that remote learning will play a greater role in how the Further Education and Higher Education Sectors will deliver their services in the future, the NDA advises that it will be important for those sectors to gather evidence and engage with students with disabilities to begin to understand how students with disabilities can be supported to have better experiences of remote or blended learning provision. In particular, we would advise that a Universal Design for Learning (UDL) approach may be usefully applied to considerations for how blended further and higher education programmes could be delivered so that the content and delivery mechanism (including the technology and Assistive Technology) is accessible, understandable and useable to all students.

Impact 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 child 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.

Impact 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. 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 on Home Support, Personal Assistance and Respite

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.

Impact on Respite

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.

Child Therapy Services

While in the initial phases of the outbreak, many HSE therapists were redeployed to COVID-19-related work, some child therapists in HSE funded service providers have continued to provide therapies using video conferencing. 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 age of the child, the child'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.

Services for persons with a disability post COVID-19

Home Support and Personal Assistance

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 home care 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.

The NDA notes that the HSE had to pause the process of recruiting new entrants to the Demonstration Project on Personalised Budgets during the lockdown. However, it was welcome that the HSE continued the project for those already in receipt of a personalised budget. The NDA notes that in the post-COVID environment, where some centre-based services will face restrictions in how they operate, a personalised budget may be of interest to some people who may not have considered a personalised budget in other circumstances. The NDA advises that the HSE completes the recruitment of all 180 Demonstration Project participants as quickly as is possible given the current circumstances, as the learning from the evaluation of the Demonstration Project may be highly relevant for some persons with disabilities in the post-COVID context for whom more group based supports will not be appropriate.

Education

The NDA advises that it is extremely important that lessons are learned from the COVID-19 period on how all children, but children with special educational needs in particular, were supported to continue their education. Understanding what worked for different groups of students with disabilities will obviously be crucial in terms of dealing with any future waves of COVID-19, but also important because one of the longer-term impacts of the COVID-19 pandemic is likely to be an increased use of remote learning in the education sector.

As noted above, the National Council for Special Education has chosen online learning for students with special educational needs as the topic for their 2020 annual conference. This should be an important first step in drawing together the experiences of teachers, school managers, students and parents on the provision of remote learning for students with special educational needs. In the short to medium term, it will be important that there is access to training and CPD for teachers, carers and families on approaches to providing remote learning for students with special educational needs.

As noted above, the NDA acknowledges that the Department of Education and Skills significantly expanded the eligibility for the Summer Education Programme 2020 (compared to the previous July Provision eligibility rules) and acknowledges that the Department worked with the HSE and the Department of Health to produce a joined up programme of supports around the Summer Programme 2020. However, in preparation for potential disruption in future years related to COVID-19, and also for a scheme to replace the July Provision scheme, the NDA has advised that the Department look at the issues around summer / education loss in order to devise eligibility rules based on those most at risk of summer / education loss. The NDA has also advised that a future summer scheme should look at coordination across relevant Departments (the Department of Education, the Department of Health and the Department of Children, Disability, Equality and Integration) to design a scheme which best meets the educational and social needs of children with disabilities and their families over the summer months.

Residential Services for Persons with Disabilities and Older Persons

As discussed in greater detail above, 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.

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.

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, which would in turn reduce pressure on residential settings.

Housing

The NDA welcomes commitments in the recently published Programme for Government regarding construction of social housing units, and particularly a mix of housing design type, including universally designed units, accommodation for older people and persons with disabilities.

Universal Design in housing is a route to supporting people to live independently within their communities for as long as possible. While not only relevant to persons with disabilities or older persons, Universal Design in housing would play a part in reducing the flow of individuals to congregated care settings, whether on account of disability or increasing age and frailty. UD houses are constructed with

accessibility considerations designed in from the outset, e.g. ample level circulation space, wider door access etc., to cater for those of all ages who may need to use mobility aids such as walking frames or wheelchairs. These design features have many other benefits for family living generally. They may also be relevant to families who may be spending more time in their homes than previously on account of social distancing and remote working requirements. Universal Design also incorporates infrastructure required for the use of assistive technology that can be of benefit in supporting people to remain in their homes, or to access telehealth and telecare solutions, each of which have increased relevance in the context of a pandemic. Additionally, and as mentioned above, by retrofitting and redesigning existing homes following UD guidance, there can be a significant positive impact on the quality of life of persons with disabilities and older people, while at the same time reduced costs to the exchequer.

In this regard, the NDA notes a number of telecare and telehealth solutions were put in place during the COVID-19 pandemic, which may be relevant to longer term provision. However, in considering future policy direction in this area, it is important to consider the design of same to ensure accessibility and usability for all users, for instance as regards Universal Design that take persons with disabilities and older persons needs and preferences into account. Training and education to build the capacity of users and healthcare providers would also be important. The NDA published **Effective implementation and monitoring of telehealth and telecare in Ireland: learning from international best practice** report in 2018 which may be useful in this regard.

The NDA has prepared policy advice for the Department of Housing, Planning and Local Government with regard to Universal Design in new social housing, as a significant aspect of supporting people to live independently in sustainable communities, and therefore reducing pressure on congregated settings where transmission of infection such as COVID-19 is an increased risk.

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.

Impact of COVID-19 on carers and families of those with disability

Impact on those caring for persons with disabilities in an informal capacity (e.g. families taking over from carers)

The NDA is aware from engagement with carer representative bodies and media reports of the difficulties and increased demands faced by families and carers during the COVID-19 situation arising from the closure of day and respite services and restrictions on some home care services. We also note that some families and carers are experiencing increases in challenging behaviour from persons with disabilities who may not fully understand the change in their routine or the requirements for social distancing.

We also recognise that some key frontline disability staff, such as therapists in children's services, have been moved within the HSE to roles supporting COVID-19 work, e.g. contact tracing. While dealing with the pandemic is the most important issue the HSE is currently facing, the NDA advises that where frontline disability staff have been redeployed, alternative plans are put in place to try to provide some level of support to families and carers. This may include maintaining a level of contact between services and all families and where families who are facing particularly challenging circumstances are identified, that tele-support and other appropriate methods of engagement are put in place.

It has also been reported that carers and families have experienced increased levels of stress and anxiety during the pandemic, linked to a combination of factors including fear of transmitting the virus to the person they care for or fear of being unable to care for a person if they themselves contract COVID-19. Entitled **Caring Through Covid: Life in Lockdown**, a survey carried out by Family Carers Ireland and which received over 1,300 responses, found that 60% of family carers worried about a decline in their own mental health and wellbeing. In addition, carers and families also expressed concerns about the impact of the COVID-19 crisis on those they are caring for, including social isolation and fears that normal services will not be reinstated after the crisis.

Transforming Lives Working Group 1 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 1) 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) living with family members. To cater for demographic changes, the lack of sustainability of arrangements whereby persons over the age of 60 live with family members and 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. Such families are likely to have been significantly impacted during the lockdown because Adult Day Services were not operating as normal and because many respite services have not been able to operate as normal. As many of these family members are older themselves, how they will be supported in the post-COVID period will require careful planning.

The NDA notes that the Carers Alliance have highlighted the benefits of people being cared for at home, with low numbers of such individuals contracting COVID-19, underlining again the need for enhanced home care provision. However, the NDA advises that carers and families must be effectively supported to care for people at home, including through targeted information and communications, and the provision of PPE. At the outset of the pandemic, difficulties accessing PPE and appropriate information resulted in some persons with disabilities, together with their families and carers, deciding to suspend their home care service.

Impact on disability sector

Impact on funding and services provided in disability sector (e.g. Section 39 disability providers)

Residential services for persons with a disability

The NDA notes that residential centres for persons with a disability have been vulnerable to the spread of the COVID-19 infection. The staff and residents within these centres may not have the same opportunities for self-isolation in the event of illness or exposure to the virus as the general population, and this can accelerate the spread through the facility. In referring to residential centres, the NDA includes congregated or 'institutional' settings with 10 or more residents, but also homes within the community where a number of individuals may live together in groups with staff support. While national policy indicates that funding should only flow to centres with a maximum of four residents, the NDA notes that there are still a number of designated centres with between 5 and 9 individuals with disabilities living as a group, together with support staff.

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 are 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.

Residential centres for older persons

In addition to residential centres for persons with a disability, the NDA notes that HIQA regulates 581 designated nursing homes for 31,250 mostly older persons, the majority of whom have a disability and many of whom will have acquired that disability in older years (**HIQA, Overview report on the regulation of designated centres for older persons – 2018, 2019**). As noted above, it is estimated that there are approximately 1,200 persons with disabilities under the age of 65 also resident in nursing homes for older persons, including persons with long-term disabilities, such as those with acquired brain injury (**Transforming Lives Working Group I Report, Report on Future Needs for Disability Services, 2018**).

The NDA notes that persons living in nursing homes have been disproportionately affected by the COVID-19 pandemic in Ireland. The NDA has provided separate input into the Nursing Homes Expert Panel rapid consultative exercise on the COVID-19 pandemic and nursing homes, and can make this contribution available to members of the Committee should they consider it useful to their work.

Providers of Personal Assistants/Homecare support workers

The NDA understands from discussions with providers in this space that the initial period of the pandemic was very challenging, for many of the same reasons identified above, e.g. staff absences due to need for self-isolation or caring duties, requirements to reduce quantum of service provision to manage social distancing and hygiene measures, and access to PPE etc.

One service provider indicated their awareness that individual PAs could visit with five or six different service users in the course of a day and service users could receive support from up to 3-4 different staff members in the course of a week. To address these concerns, staff rostering was adjusted in so far as possible and staff were 'silo-ed' to limit the number of service users they were in contact with. In this particular case, 30-35% of hours delivered were suspended in the early stages of the pandemic, as many service users cancelled their services as they did not want people coming into their home and family members who would normally have been at work or in college were on hand to assist them. The number of hours delivered has currently recovered to 85-90% of the normal level. Access to PPE has also been facilitated at the level required to deliver services safely.

In light of the above experiences, the importance of continued access to adequate supplies of PPE, as well as to rapid testing and results is relevant to enabling service providers maintain current levels of support, but also planning for any future waves of COVID-19.

The NDA also recognises that in some cases the original levels of support provided pre-COVID, may only have been sufficient to meet very basic care needs – e.g. washing and dressing – rather than supporting activities that could foster independence and participation in the life of the community, which should be a key aim of PA services.

Health Promotion

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.

Employment

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). While more remains to be done, the NDA recognises some developments and innovative approaches that have been implemented both in the public sector and among disability service providers in recent years, including remote working practices, supported employment and internship models. 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.

Data available from the Citizens Information Board regarding the cases they have dealt with indicates the impact of COVID-19 on individuals in receipt of Disability Allowance (DA) between March and May of 2020:

- The number of persons in receipt of DA at the end of April was 149,395. Of DA recipients, 4,442 have received at least one Pandemic Unemployment Payment (PUP).
- The number of DA recipients who have received at least one Temporary Wage Subsidy Scheme (TWSS) payment as at the end of May was 2,739.

The NDA advises there may be further individuals with disabilities who are not in receipt of an allowance from the Department of Employment Affairs and Social Protection, but who nevertheless have been furloughed or made redundant on account of the COVID-19 pandemic and therefore are not reflected in the above figures. The NDA emphasises the importance of ensuring the disability status of

anyone accessing a COVID-related payment is captured as part of the application process for these payments, as measuring and tracking the scale of the issue is important in considering mitigating and remedial actions.

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.

Other

Technology

Technology has played an important role for persons with disabilities in maintaining personal relationships and supporting wellbeing during the course of the COVID-19 pandemic. For instance, the NDA is aware that residential services have supported and facilitated persons with disabilities to use mobile technologies such as tablets and smart phones which have enabled them to maintain contact with their families and friends. While acknowledging the considerable efforts of staff in this regard, the NDA is aware of some situations where technology was not sufficiently available or expertise was lacking, and advises that there is a need for digital skills of persons with disabilities and for learning and developing the skills of disability service staff to support persons with disabilities to engage with family and friends.

Telecare and telehealth supports have also become increasingly important over the course of the COVID-19 outbreak, where people may prefer not to visit health centres or GP surgeries 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 the paternalistic attitudes of 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.

Transport and the Urban Environment

The NDA has raised a number of concerns regarding the Interim Mobility Intervention Programme for Dublin City developed by Dublin City Council and the National Transport Authority (NTA) to address the new and urgent needs which have emerged as a result of the COVID-19 Public Health Emergency in Ireland. The programme includes alterations to streetscapes to facilitate businesses to continue operating in light of social distancing requirements, as well adjustments to transport routes and infrastructure to facilitate same. The NDA is also concerned about similar Interim Mobility Programmes that are in the process of being developed and rolled out by local authorities across the country in response to the crisis.

While recognising the urgency of the current situation, these programmes are being progressed in the absence of consultation with a diverse range of users, including persons with disabilities and older people, who may be particularly impacted by the remedial works proposed in urban landscapes and in transport provision. The users' perspectives, especially in time of emergency, are crucial to inform the development and delivery of integrated universally designed public transport services, which can be accessed and used by all, regardless of whether or not they have a disability.

The NDA advises the importance of continued focus on the development and provision of integrated and universally designed public transport services so that they are easy to access, easy to understand and easy to use. This includes the exterior and interior design of public transport vehicles; the location and design

of bus stops/shelters and stations; the accessibility of public transport information; and the disability awareness of public transport operator staff.

Public Sanitation

The NDA recognises the challenges in provision of safe and hygienic public toilet facilities during the COVID-19 pandemic, and notes that many locations where public facilities were previously available have been closed during the lock-down. However, the NDA advises that access to public facilities is a critical part of enabling persons with disabilities to go about their daily lives in public, and suggests the following considerations in this regard:

- Universally designed public sanitation facilities should be provided at regular intervals in town and cities. These facilities should have an appropriate means of access, such as a pathway and ramp suitable for wheelchair and stroller use or by those with walking aids with clear identification and with a regular programme for cleaning and maintenance.
- The location of portable sanitary facilities should also take into account the need for vehicle access for delivery and emptying, as well as having an appropriate water supply and drainage. This will enable direct connection to mains services and avoid the need for chemical-based toilets, which many people find less desirable to use.
- Interim Mobility Programmes should include actions to ensure that all equipment and modifications including accessible public toilets are regularly checked and maintained to address concerns regarding vandalism.

Accessibility of public health information on COVID-19 for persons living with disabilities

The NDA notes a number of trends and impacts in relation to access to public health services and information as a result of 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.

The NDA welcomes the moves to ensure provision of Irish Sign Language (ISL) interpretation in government and NPHET televised announcements during the pandemic, and advises continued commitment to provision of information in various formats, including ISL. This may include a need for awareness training for a range of professionals involved in broadcasting these announcements and briefing sessions to ensure that the interpreter is captured on screen in a way that facilitates ease of understanding by those viewers who use ISL.

The NDA notes that a large amount of public health information during the crisis was published in short-form video format such as YouTube clips provided by the HSE, which has the capacity to reach a wide audience. The NDA advises that a high level review of these videos shows that they contain captioning, which is essential for viewers with hearing difficulties. However, as these captions are auto-generated, there can be issues with regard to accuracy when compared with manually prepared captioning. The NDA also advises the importance of including ISL interpretation in these videos, in addition to captioning.

The NDA also advises that where information is provided through public sector websites, that these websites are required to meet web accessibility standards as provided for in the EU Web Accessibility Directive, which is currently overdue for transposition into Irish legislation. As well as the websites achieving accessibility, it is also important that any documents contained on them (e.g. PDF guidance or factsheets) equally achieve accessibility standards. This would include using alt-text for images, and ensuring documents can be read by those using assistive technology, e.g. screen readers.

The NDA notes that guidance prepared by the HSE for disability service providers and persons with disabilities in specialist services is available in a range of accessible formats, including Plain English, Easy-to Read, ISL videos etc. As noted above, however, the majority of persons with disabilities in Ireland are resident in the community, either alone or with their families. It is therefore important that **all** public health information is prepared and published in a range of formats to maximise accessibility.

NDA guidance on Clear communications

The CEUD has co-published with the Department of Public Expenditure and Reform (DPER), guidance on the Universal Design of communications that can improve consultation for persons with disabilities. The Customer Communications Toolkit for the Public Service - A Universal Design Approach,

has guidance to inform the design and procurement of customer communications in the Public Service.

The Toolkit has sections on the design of Written, Spoken & Signed and Digital Communication. The Toolkit sections contain selected statements, examples, tips, checklists and links to learn more. It contains information that will be useful to many organisations, both public and private for planning, training and informing staff and contractors. The NDA recommends that, where possible health information follows a Universal Design approach so that it is accessible to everyone from the outset.

COVID-19 Discourse

The NDA also notes concerns raised by persons with disabilities regarding public discourse during the COVID-19 pandemic, particularly the positioning of disability in a discourse of vulnerability. While some persons with disabilities are at greater risk of severe complications arising from COVID-19, such as those with underlying health issues, many persons with disabilities are at no greater risk than the general population. The NDA underlines the importance of communicating COVID-19-related messages in an appropriate way, which does not stigmatise particular groups of people, such as persons with disabilities. For instance, changing the terminology of COVID-19-related risk from “vulnerability” to “at greater risk” would be more consistent with the social model of disability, and may avoid assumptions regarding the inherent vulnerability of persons with disabilities or older persons.

Consultation and Participation

The NDA advises that including persons with disabilities in the development of policies likely to impact them is a key provision of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This includes consultation, but also ensuring individuals and representative organisations are involved in the design and delivery of interventions such as those implemented to address the COVID-19 pandemic. The NDA notes that in the immediate emergency, a number of measures were implemented without due consultation, and while recognising the urgency of the situation, we advise the importance of developing mechanisms to be able to rapidly consult and ensure participation of persons with disabilities for any future waves. The Centre for Excellence at the NDA has developed Guidance on Accessible Online Meetings – a supplement to the “Customer Communications Toolkit for the Public Service - A Universal Design Approach”.

Additionally, I.S. EN 17161:2019 'Design for All - Accessibility following a Design for All approach in products, goods and services - Extending the range of users' is a European process Standard is about using a Universal Design (Design for All) approach at all levels in organisations so as to continuously improve and manage the accessibility and usability of the products and services they provide.

The standard specifies requirements and recommendations that enables an organization to extend their range of users by; identifying diverse user needs, characteristics, capabilities, and preferences, by directly or indirectly involving users, and by using knowledge about accessibility in its procedures and processes.

Conclusion

The NDA recognises that the circumstances created on foot of the COVID-19 pandemic are unprecedented and challenging for all. We also acknowledge that there will be a significant impact on the State finances when the initial crisis has passed. However, we advise the importance of continued work to progress independent living, equality and inclusion for all persons with disabilities, particularly in light of Ireland's ratification of UNCRPD. 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 lives of persons with disabilities are not reversed, leading to a failure to comply with the provisions of the Convention. The NDA will be embarking on research to establish learning from some of the innovative 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 within the community. We will be happy to update the Committee on this work as it progresses.