NDA submission to the Department of Health to inform the development of a Disability Action Plan

# Summary

The NDA welcomes the publication of the Disability Capacity Review and the opportunity to inform the Disability Action Plan (2022-2025). In the table overleaf we have summarised a number of actions under thematic headings arising from our more detailed submission document below. We suggest that these items would be targeted as areas for focus in the initial implementation phase. An indicative timeline as to when we advise each should be actioned is included. The eight action we deem to be priorities are highlighted in yellow and are bulleted below.

* 1.1 Evaluate the progressing disability services programme with a view to developing a pathway to reducing waiting lists for early intervention to a sustainable level.
* 2.2 Set a target date and develop a plan for all sheltered work to cease
* 5.2 Develop a plan to prevent new inappropriate admissions to nursing homes of people less than 65 years of age
* 5.4 Accelerate decongregation with due regard to the availability of housing and avoid new admissions to congregated settings
* 5.7 Consider the housing needs of people living in residences with five to nine people in parallel with decongregation
* 7.3 Develop a national framework of assessment of need. Select and use a resource allocation tool for disability services.
* 7.4 Fund and support services to develop the requisite expertise, resources and interest to ensure good measurement, interpretation and use of outcome data to guide policy and practice
* 7.6 Review the role of regulation for each area of the Disability Capacity Review

| No. | Action | Timelines |
| --- | --- | --- |
| 1 | Early Intervention and specialist therapy teams |  |
| 1.1 | Evaluate the progressing disability services programme with a view to developing a pathway to reducing waiting lists for early intervention to a sustainable level.  | Evaluation Q3&4 2022 followed by a plan to sustainably reduce waiting lists.  |
| 1.2 | Consider the investment in therapy posts under Disability Social Care in relation to how these will align with the needs of the School Inclusion Model | Ongoing throughout |
| 1.3 | Develop and implement a training plan for allied health professionals in multi-disciplinary team working.  | 2022-2023 |
| 2 | Day Services and Supports to Participate in the community |  |
| 2.1 | Use the self-evaluation of interim standards for New Directions to identify the further training needs to ensure that services constantly improve and provide a person-centred service. | 2022-2023 |
| 2.2 | Set a target date and develop a plan for all sheltered work to cease  | 2022-2023 |
| 3 | Personal Assistance and Home Support |  |
| 3.1 | Develop a standardised and comprehensive method of gathering data on PA services at CHO level | 2023 and ongoing  |
| 4 | Respite services |  |
| 4.1 | Develop a pathway for a seamless transition from child/adolescent respite services to adult respite service | 2023 and ongoing  |
| 4.2 | Enhance the availability of alternative types of respite and evaluate the different methods to determine whether they reduce the need for traditional overnight respite | 2022 and ongoing |
| 5 | Supported housing and residential care |  |
| 5.1 | Update and maintain the emergency/urgent waiting list | 2022 and ongoing |
| 5.2 | Develop a plan to prevent new inappropriate admissions to nursing homes | 2022 and ongoing |
| 5.3 | Develop ambitious targets to reduce the number of under 65 year olds in nursing homes. | 2022 and ongoing |
| 5.4 | Accelerate decongregation with due regard to the availability of housing and avoid new admissions  | 2022 and ongoing |
| 5.5 | Limit the direct expenditure of the HSE on housing and explore the benefits of moving to tenancy arrangements.  | 2022 and ongoing |
| 5.6 | Develop and implement a plan to harmonise systems that collect cost data across disability services.  | 2023 onwards |
| 5.7 | Consider the housing needs of people living in residences with five to nine people in parallel with decongregation and explore ways to release funding so that more appropriate housing solutions can be identified.  | Planning during 2022 and implementation from 2023 |
| 5.8 | Develop services for people with complex behavioural issues so that they do not have to be cared for abroad.  | Planning during 2023 and implementation from 2024 |
| 5.9 | All new houses procured or retrofitted should follow a Universal Design approach. | Ongoing throughout |
| 6 | Multidisciplinary therapy teams |  |
| 6.1 | Develop clear pathways and protocols in relation to who should be accessing a specialist multi-disciplinary team and who should be accessing primary care support. | Develop pathways in 2022 |
| 6.2 | Develop and implement awareness raising and training to ensure that primary care professionals are equipped to meet the needs of adults with disabilities  | Planning in 2022 and implementation from 2023 forwards |
| 6.3 | Develop plans for how Part 2 of the Disability Act will operate for adults and what cohorts will be eligible for an assessment under the Act  | 2023 |
| 7 | Cross-Cutting issues |  |
| 7.1 | Adequately resource NASS, HSE and Services to build the long term completeness of the NASS system.  | Ongoing throughout |
| 7.2 | Consider using the opportunity of the expansion of services included in the Review to examine the possibility of a commissioning model.  | Examine and develop a model in 2022-2023 and implement in 2024 and 2025 |
| 7.3 | Establishment of a national framework of assessment of need. Select and use a resource allocation tool for disability services. | Decide on framework and tool in 2022 and make preparations for roll out, commence roll out in 2023 |
| 7.4 | Fund and support services to develop the requisite expertise, resources and interest to ensure good measurement, interpretation and use of outcome data to guide policy and practice | 2022 and ongoing |
| 7.5 | Fund awareness training around the Assisted Decision Making Capacity Act and responsibilities around staff determining the capacity of individuals to make decisions.  | 2022 and ongoing |
| 7.6 | Review the role of regulation for each area of the Disability Capacity Review (e.g. day services, PA services, review of existing regulations for residential)  | 2022 and ongoing (perhaps start with review of residential regulations, then day services and then look at PA services) |
| 7.6 | Assistive technology services and staff training need to be planned and provided to maximise client independence and subsequently minimise disability care costs. | 2023 and ongoing |

# Introduction

The National Disability Authority (NDA) welcomes the opportunity to make a submission to inform the development of a Disability Action Plan for the period 2022-25 based on the Disability Capacity Review to 2032.

The NDA is the independent statutory body with a duty to provide information and advice to the Government on policy and practice relevant to the lives of persons with disabilities, and to promote Universal Design. Much of the advice given in this submission is based on advice we have previously provided to the Department of Health and the HSE.

In the summary section above we have laid out the priority level that we give to each proposed action with the higher priority actions requiring action sooner than those of a lower priority.

Although the submission instructions clearly laid out what is in and out of scope for submissions on this matter, the NDA notes that due consideration will need to be given to areas that are currently deemed out of scope but which we advise will be important to address when taking a systems wide view.

We have organised our input following the main headings outlined in the review and added an additional section at the end to cover cross-cutting issues.

# Early intervention and specialist therapy teams

The Capacity Review estimates the shortfall in the number of professionals who will be required to provide early intervention and children’s therapy services by 2032 to be 350 - 400 higher than they will be when the 100 new posts provided for in the 2019 Budget are in post, based on demographics and available data on unmet need. The Capacity Review notes the UNCRPD Article 26 obligation to provide timely therapy and early intervention and notes the economic cost of not providing these.

The NDA recognises that significant progress has been made in terms of reconfiguring children’s disability services into area-based, multi-disciplinary teams. Of the planned 91 progressing disability services teams, 83 are now fully reconfigured and it is anticipated that the remaining teams will be reconfigured by the end of November. The NDA notes that there has been considerable progress on the clearing of waiting lists for assessments of need under Part 2 of the Disability Act. 2005. This however has prompted concerns about increasing the already long waiting lists for intervention.

It is clear that based on the Capacity Review and previous analysis completed by Transforming Lives Working Group 1[[1]](#footnote-1) and the NDA[[2]](#footnote-2) that there will be a requirement for the numbers of therapists to increase up to 2032. To ensure that further investment in children’s therapy services maximises children and family outcomes the NDA advises that there is a need for more evidence around unmet need for therapy services and more evidence around the impact of reconfigured children’s multi-disciplinary services on outcomes for children and families.

The NDA notes that there was a commitment in the NDIS Programme of Action on Autism (2015) that the progressing disability services programme would be evaluated when the programme was fully operational. With all areas expected to be reconfigured at the end of 2021, the NDA advises that the second half of 2022 may be an appropriate time to conduct an evaluation which would establish issues around the

* quantity of service available, in particular for those who are “in service” but who may not be receiving an adequate or timely service due to availability of staff (to inform future forecasting)
* quality of service (the impact of service children and families).

The timing of such an evaluation may need to be aligned with progress on work on establishing a common IT system across the disability network teams and the adoption and progress on implementing elements of the Outcomes for Children and Families Framework Implementation Plan as both of these developments could assist such an evaluation. Such a review will help in the development of a pathway to reduce waiting lists for early intervention to a sustainable level.

The Capacity Review necessarily focused on ‘Disability Social Care’ and did not set out to look at the broader range of mainstream and specialist supports that people with disabilities use. The Capacity Review’s projections therefore relate only to ‘Disability Social Care’. However, there may be areas where ‘Disability Social Care’ provision and other areas of provision are best considered together. In relation to children’s therapy services the supply and retention of therapists in disability services and in the education sector (under the School Inclusion Model) should, the NDA advises, be considered together. More fundamentally, how the School Inclusion Model and progressing children’s disability services will align to maximise child outcomes and best use of resources should be part of the consideration for increased investment in therapist posts under Disability Social Care, therefore requiring improved mechanisms to support cross-departmental working in this space.

Another issue not covered in the Capacity Review is the issue of training. Third level training of OTs, Physiotherapists, and Speech and Language Therapists is largely focused on one-to-one assessment and intervention. The NDA advises that it may be timely to consider how that training could be reconfigured to place a much greater emphasis on how to work as part of a multi-disciplinary team. This will require working collaboratively with education professionals in the education sector. Continuous professional development in this area may also be required.

# Day services and support to participate in the community

## Day services

The Capacity Review highlights that investment will be needed due to demographic changes (increased in flows up until the late 2020s), addressing the needs of those with no day service or a partial day service and those with an inadequate day service such as those who are transitioning out of congregated settings. The Capacity Review analysis does not include any investment to meet the needs of those who may be in a day service but who may not be receiving an appropriate service. Ace Communications’ evaluation of the PCP demonstration projects[[3]](#footnote-3) highlighted significant disparities within services in relation to the supports provided.

This report was not an evaluation of adult day service provision and it was only based on a very small number of organisations. Nonetheless, it suggests that there may need to be a consideration of whether there is a need for investment in enhanced quality of day service places as well as enhanced quantity. The first reporting (across all themes) on Interim Standards for New Directions is to be completed later this year may shed some further light on this issue but there may be a need to further investigate the extent of those present in day services but not receiving a person centred service which meets their support needs.

The inequity of provision also raises the issue of whether or not adult day services should be regulated. The Interim Standards for New Directions were designed so that they could be easily adopted by HIQA. However, to date there are no indications that HIQA will be asked to regulate adult day services. In the short term it may be useful to consider what an appropriate model of external regulation might be (learning from the experiences of regulation of residential disability services) and what the costs and benefits of external regulation of adult day services might be. The NDA advises that this piece of work is conducted during 2022-23 and that a clear action in relation to regulation of adult day services is then instituted. This will require earmarking some funding in the 2022-25 action plan for this purpose.

The Capacity Review and other previous reports make reference to the fact that Sheltered Work placements are being phased out. The NDA advises that it is important that phasing out Sheltered Work is progressed and therefore the Disability Action Plan Framework 2022-2025 should address this issue. There may be a cost involved in finding alternative placements so this needs to be considered. The alternatives will likely require collaboration with other sectors outside of health and cross-departmental collaboration to ensure appropriate transitions to an appropriate work employment environment. Work around transitions is already going on between the HSE and multiple departments although it is focused on young people leaving school. The NDA advises that there may be merit in having a shared action in the Disability Capacity Review Action plan and the Comprehensive Employment Strategy related to this action.[[4]](#footnote-4)

# Personal assistance and home support

The NDA welcomes the acknowledgement in the Capacity Review that the unmet need for people who use a personal assistance service or a home support service is largely unknown.

The NDA, through a partnership agreement with the ESRI, is conducting research into PA services. The preliminary findings from both those using the service and those who manage the service have highlighted unmet need – particularly latent unmet need where those with an existing PA service require more hours than they are currently receiving. The Capacity Review clearly shows the low number of hours that many people who use a PA receive and the NDA welcomes the proposals to increase these hours.

The ESRI study has also found significant gaps in relation to data with no standardized approach to data gathering across CHO areas. The National Ability Supports Service database (NASS) had potential to improve the data in this area. However, the NDA advises that further work is required in relation to data completeness and that extra resources for the HSE to facilitate same is not included in the capacity review. We would recommend that the action plan clearly outlines how the NASS, HSE and services will be resourced to improve the completeness of data particularly for people with a physical and sensory disability. While the issue of data is relevant to PA and home supports services, the NDA advises that it applies throughout all service areas discussed in this document.

NDA recommends that the action plan includes clear steps for a standardised approach to gathering data in relation to PA services across all CHO areas. This will include the use of a standard resource allocation tool. This is discussed later under the section on developing a framework for assessment of need.

The NDA recognises that work is ongoing by the Department of Health and HIQA on the development of National Standards for Home Support Services. These standards will complement the primary legislation and minimum requirements (regulations) currently being developed by the government to meet the Programme for Government (2020) commitment to support people to live in their own homes. This commitment involves providing access to high-quality, regulated home care. The standards aim to promote progressive quality improvements in home support services.

The NDA notes that the boundary between PA and home care supports for people with disabilities is often not clear at local level. The Programme for Government commitments to the establishment of a statutory home care scheme and work on same is progressing. However, we advise that putting home care on a statutory footing will require a clearer articulation of what a PA service is, what its objectives are, and what it aims to support. Therefore, the NDA advises that in tandem with the work on a statutory home care scheme a national policy on PA supports should be developed in consultation with people who use PA services and other relevant stakeholders.

# Respite services

The NDA commissioned research on respite that was published in 2019.[[5]](#footnote-5) The research explored the experiences of users of disability respite services in Ireland. There are a few findings from that research report that have relevance to the action plan.

Some respondents spoke about the lack of a seamless transition to respite services before and after the age of 18. People who had been in receipt of regular respite services during their teenage years were suddenly on a waiting list for respite when they turned 18, with some reporting that they were still waiting after two years.

The Disability Capacity Review notes that there will be an increase in young people entering day services over the next decade due to the demographic increase in under 18s. This will also be true of respite services and the NDA advises there is scope for an action to be developed that would plan for a seamless transition to adult respite services that does not require a waiting period.

The NDA study found that respondents were unclear as to how respite was allocated. There was a feeling that the system was non-transparent and that criteria varied from services to service.

The NDA recognises that such disparities are likely due to resourcing constraints, but it highlights the fundamental problem that is not discussed in the Disability Capacity Review of the lack of entitlement, eligibility criteria, or national guidance on who should be offered respite. The absence of these criteria means that measuring unmet need is very difficult. It is also worth noting that unmet need applies not only to people who are not receiving any respite services but also to those who may be receiving some service but not enough for their needs.

The NDA study also showed that many people interviewed were not aware of alternative forms of respite with the majority only being aware of overnight respite. The NDA advises that there is scope to enhance the availability of alternative respite and evaluate the different methods to determine whether they reduce the need for traditional overnight respite from the perspective of users of respite services and their families. This will also increase choice for those who use respite services.

One thing that is unclear from the Review is whether the NASS data adequately captures the needs of people with autism without a concurrent intellectual disability. These individuals might be linked in with educational services and maybe some services from multidisciplinary teams but may not be registered on the NASS. Some people with autism and their families may have a need for respite that is currently not being met. The NDA suggests that early support and intervention for some of these individuals may reduce the need for high cost behavioural support therapy when they are older.

In summary, we suggest that respite should be considered in the context of being a protective measure against higher cost care by supporting families and users of respite care so that people can live at home for longer, while at the same time providing choice and a person-centred service for individuals.

# Supported housing and residential care

## Emergency/urgent waiting list

The Capacity Review mentions the existence of an emergency/urgent waiting list for residential supports. The NDA advises the importance of updating this list, and ensuring it is fully comprehensive as otherwise the level of unmet need is very difficult to measure. The NDA therefore advises that resources are assigned to keeping this list updated. The Review also acknowledges the unsustainable situation in many homes where older parents are caring for their adult son or daughter. This links to the point on eligibility to services that is expanded below and the NDA advises that consideration is given to this issue particularly in relation to older parents.

## Younger people in nursing homes

The NDA welcomes the recognition of the situation regarding nursing home residents under 65 years of age in the Capacity Review and is aware that the HSE are doing a piece of work to determine the numbers of people involved and an assessment of how many are inappropriately placed. The NDA advises that the estimate of one third being inappropriately placed be revised if relevant and appropriate.

The issue of a continuous inflow of younger people to nursing homes is not addressed in the Capacity Review. The NDA advises the importance of further work in this area, to ensure appropriate placements, and to prevent any new inappropriate placements to a nursing home of people under 65 years of age.

The Review questions whether the ‘10% funding envelope provided in this exercise for residential support places for people with a physical, sensory or neurological disability’ will be sufficient. The NDA advises that options such as PA support at home should be further explored in this context and it should not be assumed that a residential support place will be required for all. The NDA also advises that ambitious targets will need to be set in order to reduce the numbers of under 65 year olds in nursing homes, and support transitions to more appropriate placements.

## Residential care

The Moving In, Moving On study, commissioned by the HSE and soon to be published by the NDA, is a mixed method study examining the costs and benefits of newer models of disability service provision. It provides detailed information on the support needs, profiles and outcomes achieved by 426 individuals – including those who moved directly from a congregated setting to a home within the community. The findings show the extent of positive outcomes associated with person-centred and tailored models of support – which can be described as ‘newer’ models, as well as the potential for further improvements over time as individuals have greater opportunity to exercise choice and control, and build independence and associated life skills.

The findings of the comparative analysis of service delivery unit costs pre and post decongregation indicate significantly increased costs post decongregation for people with high support needs, and lower costs for those with low support needs. Once the level of support need among residents has been accounted for the estimated cost uplift associated with transfer of the remaining residents from congregated settings to community housing is estimated to average €1,703 per resident per week (around €89,000 p.a.) – a cost uplift of around two thirds. This reflects the fact that most of the residents still living in congregated settings have high support needs, requiring very high staff-to-resident ratios in the context of community housing serving no more than four individuals living together, and sharing support resources.

In addition to calculating the unit costs of service delivery pre and post decongregation, the analysis modelled the practical and fiscal implications for the full achievement of decongregation. This was done while considering three potential timelines for the completion of decongregation – 2030, 2027 and 2025. Earlier completion of decongregation would involve a greater number of residents being supported to transition to the community in the four year period covered by this plan.[[6]](#footnote-6)

The cost findings of this report are not out of line with those in the Capacity Review. However, the projections in the Review are to 2032 and we would advise that the action plan includes decongregation and closure of congregated settings as a priority and that it is completed in the shortest time possible, noting the resource implications of same. The NDA also notes the difficulties in obtaining comparable data on costs and advises that improvements are made to the way cost data is collected and managed.

The NDA notes that there is no mention in the Review of people living in the community in houses with between five and nine residents. The estimates in the Review seem to be based only on settings of 10 or more residents. However, we note that the Time to Move on from Congregated Settings report states that ‘home-sharing arrangement should be confined to no more than four residents’.[[7]](#footnote-7)

The NDA advises that it would not be in line with person-centred practice to wait to deal with this issue of people living in residences with five to nine people until all congregated centres are closed. The NDA recommends a dual approach in that decongregation and transition of people living in houses with five to nine people to smaller residences are advanced in parallel. While this is not costed there may be an opportunity to realise some funding to make this a reality. Four possible ways of doing this are briefly outlined below.

* It is likely that on average, people still living in congregated settings have a higher level of need than people living in community residences with five to nine people. It may therefore be easier to meet the housing need of the latter group as a purpose built or adapted house is less likely to be required.
* While the Review accounted for deaths in congregated settings in the projection of the number of people remaining to be decongregated it would seem that deaths in the community were not accounted for and could lower costs to some extent. For example if 100 people are to decongregate this year there is a need for 100 new residential places in the community. However, if 10 people in existing community houses die during this year then there will only be a need for 90 new places. The NDA advises that it may be worth investigating any potential impact this may have on costs. [[8]](#footnote-8)
* The NDA study did not include capital costs and we note they are included in the Capacity Review and are substantial. Over time it will be important that the costs in relation to housing are met more by the Housing Agency, Local Authorities and the Capital Assistance Scheme so that they are not coming directly from the HSE’s budget. Some housing may also be funded through the sale of congregated settings.
* Currently many residents of community houses do not have tenancy arrangements and this may affect their rights (sometimes people are moved to facilitate another resident) and their entitlements to rent allowance or other supports. There may be advantages for community residential housing to move to tenancy arrangements to benefit from the various financial supports available from the state.

## Young people with complex behavioural issues

The Capacity Review notes the very high needs of a small group of younger people with complex behavioural issues. Although not mentioned in the Review, the NDA is aware that on occasion residential support has been sought outside the jurisdiction for some young people. We would be interested to know whether the development of highly specialist placements has been factored into residential costs so that people can be supported to live in Ireland to maintain family ties. The NDA considers that it would be important to develop these services if this gap remains.

## UD housing

In relation to all procurement and retrofitting of residences, the NDA advises that a Universal Design approach is taken. Universal Design is the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability. The NDA is currently conducting a cost benefit analysis of UD housing and will share these results with the department when finalised.

# Multidisciplinary therapy teams

### Adult Therapy

As the Capacity Review notes there is currently unmet need for adult multi-disciplinary therapy services and demographic pressure will mean that demand for these services will grow considerably up to 2032. The Capacity Review also notes that access to mainstream therapy services via primary care is variable and sporadic. While the NDA concurs with the analysis in the Capacity Review we would advise that investment to meet the demand for adult multi-disciplinary therapy services should take a number of factors into consideration such as –

* The need for clearer pathways and protocols in relation to who should be accessing a specialist multi-disciplinary team and who should be accessing primary care support (similar to the National Policy on Access developed by under Progressing Children’s disability Services)
* The need for awareness raising and training to ensure that primary care professionals are equipped to meet the needs of adults with disabilities
* The investment in increased numbers of multi-disciplinary services for adults should be aligned with the broader reforms in Disability Social Care. For example, the NDA understands that access to therapies is being raised as a barrier to people accessing the HSE Personalised Budgets Demonstration Project. This raises a questions about how adults with complex needs could access multi-disciplinary teams should they wish to self-direct their support
* How Part 2 of the Disability Act will operate for adults and what cohorts will be eligible for an assessment under the Act would be an important consideration in relation to future investment in multi-disciplinary services for adults. While Assessment of Need (AoN) for adults may operate quite differently to AoN for children (it is unlikely to be driven by demand for a diagnosis) it is still likely to impact on demand for in multi-disciplinary services for adults.

# Cross-cutting enablers

This section deals with a number of issues that do not naturally fit under the headings above but which are important to enable the successful implementation of all actions. Some issues discussed below may be considered to be out of scope but they are necessary to a systems wide approach and if implemented should contribute to the value for money of the increased resources outlined in the Capacity Review.

## Data

As noted in several places above (and in the Capacity Review itself) the absence of appropriate data impedes evidence based policy-making and investment decisions in a number of Disability Social Care areas. While it is noted that ongoing developments, such as the NASS and the Children’s Management Information System have the potential to address some these issues, other challenges will remain. The NDA understands that service providers have cited lack of funding to update older IT systems as one of the key reasons for not being able to ensure that their local system is fully compatible with NASS (i.e. not able to automatically transfer relevant data). Gaps in NASS data have also related to relevant HSE personnel being in post at local level. The NDA advises that while investment in data infrastructure and personnel does not directly increase frontline provision of services, it is critical for creating a better planned, more responsive service delivery approach.

## Commissioning Framework

The National Disability Authority has previously advised the Department of Health and the HSE on the importance of establishing a commissioning framework. A commissioning framework includes the following key elements:

* **A national framework for assessment of need** which would generate adequate data to inform service planning and specification of service requirements
* **A national eligibility framework for social care**
* **Standards to inform service specification**
* A system to monitor delivery of agreed services to the required standards including **measurement of outcomes**

Each of these is described in more detail below.

The 2018 Day Report (Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services) recommended a new approach to the funding and governance of health and social care services that is broadly similar the commissioning framework described above.

## National Framework for Assessment of Need

Disability service capacity planning should be underpinned by establishment of a national framework for assessment of need. This would include a standard resource allocation system. Resource allocation tools provide a valuable way to ensure adequacy and cost efficiency of services, improve planning and enable comparison across regions, services, service units and over time. The recommendation of the ‘Value for Money and Policy Review of Disability Services in Ireland’ report to this effect has been supported by the NDA through reporting on assessment of a range of possible tools for use.[[9]](#footnote-9) The NDA advises that a resource allocation tool for disability services is selected at the earliest opportunity. The NDA recognises that there may be some interest in ensuring that the tool used for disability services is the same tool used for elder care services. However, it would be important to ensure that the tool selected reflected person-centredness and a move away from the medical model of disability.

There will be costs associated with the training and roll out of any resource allocation tool and advises that these are taken into consideration. The NDA has also previously advised that while a resource allocation tool is valuable in terms of standardization of the allocation of resources across services it should not be the only method used and the will and preferences of individuals with regard to how they want to live their lives should also be considered in the allocation of resources.

### National eligibility framework for social care

This was discussed earlier in this report in relation to the lack of clear criteria around eligibility for respite care. However, this also applies to some extent to access to residential supports, day services, personal assistance and home support services. In many cases the level of natural supports available is a significant factor in considering whether someone gets a service, but the NDA recognises that the preference of the individual may be that they do not want their supports to be provided by family members.

### Standards to inform service specification

With the proposed expansion of services the NDA advises that the role of regulation and non-statutory quality assurance processes for each area of the Disability Capacity Review is examined. Funders should have clarity on what constitutes a good service. Standards (whether underpinned by regulations or not) and service specifications should be developed based on identified need and engagement with people who use disability services and their supporters.

The Health Information and Equality Authority (HIQA) started regulating designated centres for persons with disabilities from 2013. Since the regulations were developed the process of deinstitutionalisation has accelerated and the same regulations for congregated settings are now being used for small community residences. The NDA advises a need for a review of the HIQA regulations in relation to homes in the community. Any new regulations could have an impact on costs, for example, in relation to staffing required or some capital costs.

As mentioned earlier there is a question as to whether day services should be regulated and what the impact of this might be. The regulation of Home Care Services is currently being developed and as mentioned previously there will be questions as to how this may impact PA services and whether they in turn should be regulated.

### Measuring outcomes

The implementation of three interrelated frameworks ‘Quality of Life Outcomes Domain Framework for Disability Services’, ‘Person-Centred Planning Framework’ and ‘Quality Framework: supporting persons with disabilities to achieve personal outcomes’ need to be supported by funding and evaluating services until they are embedded and so that personal outcomes for individuals with disabilities improve. The NDA advises that consideration of approaches to outcome measurement will then be required.

Outcome measurement requires a carefully-considered combination of quantitative measures and accountability with qualitative methods such as interviews and observation. Results/data should feed into the disability services quality improvement system in order to improve the provision of appropriate supports and opportunities.

The NDA advises that services are funded and supported to develop the requisite expertise, resources and interest to ensure good measurement, interpretation and use of outcome data to guide policy and practice.

## Assisted Decision-Making (Capacity) Act 2015

The Assisted Decision-Making (Capacity) Act 2015 is due to be commenced in mid-2022. This legislation represents a shift in society from a medical model of disability, where ‘best interest’ decisions are made on behalf of individuals and towards a social model of disability, whereby people are empowered and supported to make their own decisions. Health professionals working in disability services will have new responsibilities in determining the capacity of individuals to make decisions. While the HSE has done a lot of preparatory work and awareness raising around this issue there will be a need for more training and support for staff as the Decision Support Service becomes operational. The NDA advises that this will need to be adequately supported and funded.

## Assistive technology

The NDA advises the importance of ensuring adequate and efficient access to assistive technology (AT) as part of forecasting disability service capacity and optimising its cost effectiveness. The Review does not estimate costs for AT, noting that it is funded under Primary Care. While this is true for aids and appliances it is less true for more recent technologies such as self-monitoring tools for health, falls detection technology, safety related technology such as personal alarms and voice activated or timed technologies for routine home activities such as turning on lights.

AT has the potential to reduce dependence on staff including Personal Assistants and home support staff. It also has the potential to delay the need for residential care.[[10]](#footnote-10) [[11]](#footnote-11) Research has shown that AT is underutilised within disability services, there is an absence of staff capacity to optimise its use, and delays for assessment and supply inhibit access.[[12]](#footnote-12)

AT services and staff AT training need to be planned and provided to maximise client independence and subsequently minimise disability care costs. There are currently working groups within HSE and DCEDIY focused on AT access and there may be learning from those groups to help inform this planning.

# Timetable for the plan

In the summary section above we have proposed the timelines for each of the actions we have proposed are included in the 2022-2025 action plan. In some cases there will be initial work to be completed before the action can be implemented. For example, a resource allocation tool will need to be selected and staff trained in same before the implementation of the tool can be rolled out. The NDA recognises that some of the actions outlined are likely already underway, for example training on the ADMA, but suggest this should be accelerated before the implementation of the Act in the middle of next year.

# Conclusion

The importance of staff training and capacity building is a common theme throughout this submission, particularly in relation to AT, ADMA and training allied health professionals to work as part of multi-disciplinary teams. Equally important, is the ongoing training of staff and managers in relation to providing person-centred support. Ongoing training and professional development of staff is essential to achieve good outcomes for persons with disabilities in receipt of disability services and needs to be adequately planned for and resourced.

Another pervasive theme relates to data. There is a need to invest in data collection systems at the service and HSE level and to ensure that a systematic approach is used across all services.

We realise that difficult choices have to be made in relation to prioritising what needs to go into the action plan and hope that our comments and advice above are useful in this regard. We have highlighted eight actions that we consider to be priorities. We are available to discuss any aspects of this submission and to provide ongoing support and advice on the implementation of the Disability Action Plan.

1. Transforming Lives - Working Group 1 Report on Future Needs for Disability Services, 2018 [↑](#footnote-ref-1)
2. Children’s Disability Services in Ireland, 2015 [↑](#footnote-ref-2)
3. Supporting the Implementation of the National Framework for Person-Centred Planning in Services for Persons with a Disability: A Report on the Demonstration Project, 2019 [↑](#footnote-ref-3)
4. The final three year action plan for the CES is currently being developed. [↑](#footnote-ref-4)
5. Exploring the Experiences of Users of Disability Respite Services in Ireland <http://nda.ie/Policy-and-research/Research/Research-Publications/Exploring-the-Experiences-of-Users-of-Disability-Respite-Services-in-Ireland.html> [↑](#footnote-ref-5)
6. Achieving decongregation by 2030 (Scenario 1) would require an average of 134 individuals to transfer to the community per annum over the 2022-2030 period. Completion of decongregation in 2027 (Scenario 2) would require an average of 215 individuals per annum to transfer to community housing over the 2022 to 2027 period. Completion of decongregation in 2025 would require an average of 337 individuals to transfer per annum over the 2022-2025 period. [↑](#footnote-ref-6)
7. <https://www.hse.ie/eng/services/list/4/disability/congregatedsettings/time-to-move-on-from-congregated-settings-%E2%80%93-a-strategy-for-community-inclusion.pdf> (Recommendation 9, 8.3) [↑](#footnote-ref-7)
8. It should be noted here that the NDA in its calculations in the Moving In, Moving On also did not account for this issue but acknowledged that it would be worth exploring. [↑](#footnote-ref-8)
9. NDA Resource Allocation Research <http://nda.ie/Publications/Disability-Supports/Resource-Allocation-Project/NDA-Resource-Allocation-Research.html> [↑](#footnote-ref-9)
10. Enable Ireland/ Disability Federation of Ireland (2016). Assistive Technology for People with Disabilities and Older People. <https://www.enableireland.ie/sites/default/files/publication/AT%20Paper%20final%20version.pdf> [↑](#footnote-ref-10)
11. Work Research Centre, 2012. Research on the provision of Assistive technology in Ireland and other countries to support independent living across the life cycle. <http://nda.ie/research-on-the-provision-of-assistive-technology1.pdf> [↑](#footnote-ref-11)
12. ibid [↑](#footnote-ref-12)