National Federation of Voluntary Service Providers
Supporting people with intellectual disability (CLG)

Submission on the Disability Action Plan Framework 2022-2025
October 2021

1. Summary of Key Priorities for the 2022-2025 period:

1.1 Importance of the Capacity Review

The National Federation warmly welcomes the publication of the ***Review of Disability Social Care Demand and Capacity Requirements to 2032***. We commend the Department on its research and the presentation of evidence which is of seminal importance in identifying current and future requirements for people with disabilities. The report will play a key role in guiding the planning and delivery of supports to people with disabilities over the coming decade. The figures presented demonstrate a very significant challenge in terms of the scale of unmet and demographic need of people with disabilities**.** The stark picture provided in the report **validates the evidence from lived experience that our services are reporting for individuals and their families on a daily basis** *(see pg. 5).*

1.2 UNCRPD and Model of support

The UN Convention on the Rights of Persons with Disabilities provides the blueprint for the realisation of the rights of people with disabilities and State parties' role in realising these rights. The commitments under the CRPD Articles, along with the existing positive framework of legislation and policy, should explicitly underpin the *Action Plan Framework* and the vision of how services and supports for people with disabilities should be delivered over the period 2022-2025. This will require a review of the model(s) of support*,* with a focus on ensuring the availability of the full range of options that can support flexible and individualised approaches to meet the very diverse needs of individuals supported by disability services, including those with complex needs.

The priorities of the *Action Plan* should be particularly guided by Article 19 (as a cross-cutting article from which implementation of many other Articles flow); General Comment No 5 of the UN Committee on the Rights of Persons with Disabilities, which provides recommendations on the implementation of Article 19 for State Parties; and Article 12. Each area of the plan should have regard to the relevant article(s) (e.g. Article 7 for Children's services). The inclusion of lived experience in all elements of consultation and planning is required and must form a central focus of the *Plan*.

1.3 Investment in years 2022-2025

The scale of unmet need is very significant and includes individuals remaining in institutional congregated settings; people with significant changing needs requiring additional support; and people living at home supported by elderly parents. These crises indicate the imperative for investment in alignment with the Report's recommendations, in each of the years of the

***Disability Action Plan* from 2022-2025.** This investment should start in 2022, with funding of at least the minimum scenario figures outlined in Table 1a and Table b of the report *(pg. 3 below)*. The funding required by the Disability Capacity Review for demographic and unmet need should be factored into the Existing Levels of Service (ELS) and the annual Summer Economic Statement.

1.4 Multi-Annual Funding and Planning

At present, funding is decided on a year-by-year basis, which represents poor value for money for the State and crisis driven, rushed decision-making that affects outcomes for the individual. Detailed planning for the implementation of a multi-annual funding approach, including capital investment, should be prioritised in Year 1 of the *Action Plan*.

1.5 Collaborative Partnership

70% of direct services for people with disabilities are provided by voluntary / not-for-profit service providers. The voluntary sector are therefore key stakeholders in the delivery of the *Action Plan*. In the context of the requirement for partnership and collaboration between the State and the voluntary sector as set out in the *Report of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services (IRG)*, **the voluntary sector should be represented on the Working Group designing and implementing the Action Plan.** The important insights of the voluntary sector will need to be included on an ongoing basis as the *Action Plan* evolves, and cannot be adequately captured through a point-in-time consultation. The work of the Action Plan should be progressed in alignment with the work of the **Health Dialogue Forum** established on foot of the IRG Report.

1.6 Workforce Planning

Significant recruitment and retention challenges face the disability sector *(see page 6*). In Year 1 of the *Action Plan* a working group should be established to focus on workforce planning to ensure availability of sufficient staff, with the right skills and capabilities, to support people with a disability and implementation of the commitments outlined in the *Action Plan Framework*.

1.7 Inter-Departmental Working

It has become apparent over recent years that where responsibility falls between two or more Government Departments for the delivery of services and supports to people with disabilities, the citizen is often left without the support they need *(see page 7*). Addressing the impact of these gaps should be a priority in the *Action Plan.* There is a need for clear responsibility to be assigned in areas including housing and associated support; transport for day services; and employment and transition planning for young people. It is positive that a wide range of Departments will be involved in the development/implementation of the *Action Plan*. The range of Departments whose involvement is required should remain under review to ensure all needed Departments are included as the work evolves, including the Department of Public Expenditure and Reform.

1.8 Costing Methodology

The current absence of an agreed costing methodology does not support equitable resource allocation; provide for assessment of value-for-money; or support costing of new services and forward planning with confidence. This omission hinders both the State and the Service Provider significantly, while also creating tension between the commissioner and the service provider. The development of an agreed, uniform and consistent national costing methodology should be prioritised in Year 1 so that an equitable, sustainable funding and resource allocation programme can be agreed.

1.9 Sustainable Services

There are a number of key factors that pose immediate challenge to the sustainability of service providers in the disability sector (*see pg. 6*). An overarching workstream should be included in the *Disability Action Plan* to focus on actions to safeguard the sustainability of the high quality, relationship-based supports required to ensure stability and quality of service to people with disabilities.

1.10 Regulatory Impact Assessment

There has been a significant impact on the ability of service providers to provide frontline support by virtue of the increased burden of compliance with a wide variety of regulation from a range of Government Departments. Whilst the majority of regulations themselves are welcome and necessary, the State must assess the impact of new regulation to agree the resourcing required, before implementation. The *Action Plan* should include a review of existing regulations including the HIQA Regulations, and an impact assessment of new regulations and standards such as the *Standards for Approved Housing Bodies*. The resource implications of regulations introduced must be considered in examining the overall allocation of funding and the implications of rising costs of regulation as set against the needs of those who are waiting and have no service due to resource restrictions.

Funding requirements from Disability Capacity Review:

Table 1a: Estimate, additional annual funding required to meet demographic and unmet need – low

	Demography only			Demography + unmet need		
Type of disability service	**2022**	**2027**	**2032**	**2022**	**2027**	**2032**
	€m	**€m**	**€m**	**€m**	**€m**	**€m**
Residential – Minimum scenario	60	120	160	220	280	320
Day services	8	30	60	40	60	90
PA & home help	4	10	15	34	40	45
Therapies	3	5	6	48	48	54
Respite	2	3	4	18	21	25
Community services	3	6	9	3	6	9
Total (rounded)	**80**	**170**	**250**	**350**	**450**	**550**

Estimates are indicative only. Totals may not add up due to rounding

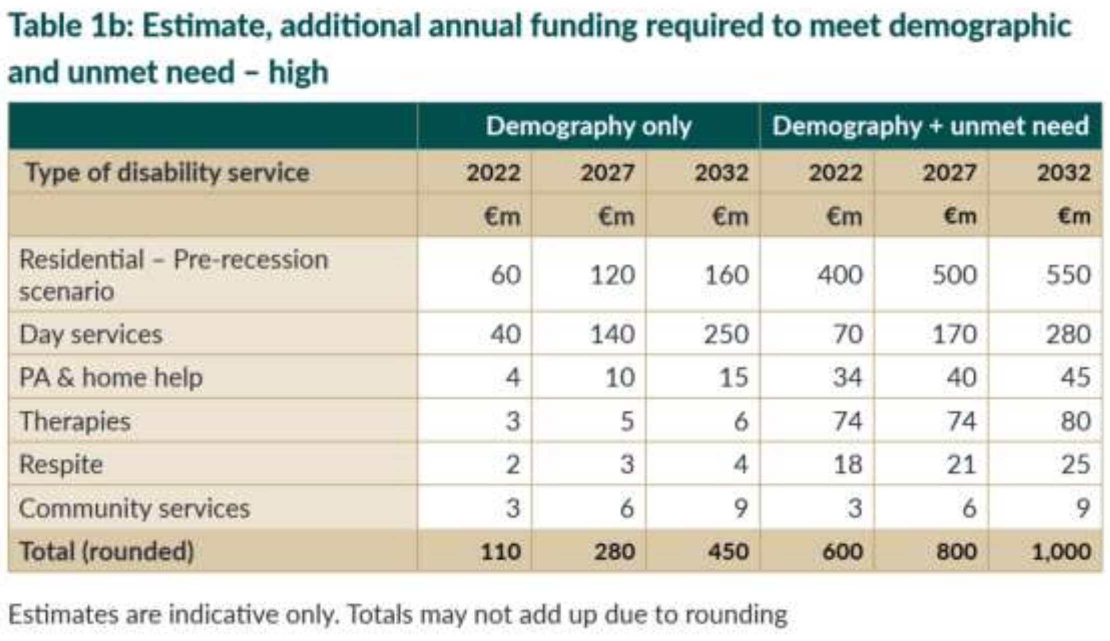

Table 1b: Estimate, additional annual funding required to meet demographic and unmet need – high

	Demography only			Demography + unmet need		
Type of disability service	2022	2027	2032	2022	2027	2032
	€m	€m	€m	€m	€m	€m
Residential – Pre-recession scenario	60	120	160	400	500	550
Day services	40	140	250	70	170	280
PA & home help	4	10	15	34	40	45
Therapies	3	5	6	74	74	80
Respite	2	3	4	18	21	25
Community services	3	6	9	3	6	9
Total (rounded)	**110**	**280**	**450**	**600**	**800**	**1,000**

Estimates are indicative only. Totals may not add up due to rounding

2. National Federation consultation to prepare submission

2.1 The National Federation of Voluntary Service Providers

Approximately 70% of disability support services in Ireland are provided on behalf of the State by Section 38 and Section 39-funded organisations. The National Federation of Voluntary Service Providers Supporting People with Intellectual Disability is the national umbrella organisation of not-for-profit agencies providing direct supports and services to people with intellectual disability in Ireland. Across 57 organisations, our members support more than 26,000 children and adults with intellectual disabilities and their families, providing services and supports throughout the lifespan. Further information is available at www.fedvol.ie.

2.2 Consultation undertaken to develop this submission

The National Federation warmly welcomes both the publication of Disability Capacity Review, and the opportunity to participate in consultation on the new ***Disability Action Plan 2022-2025.*** In preparing this submission, the National Federation has consulted widely with its membership and this document is informed by:

i. A dedicated consultation workshop on the ***Disability Action Plan 2022-2025*** (5th October, 2021);
ii. A discussion on the *Capacity Review* at the National Federation's General Assembly (22 September, 2021)
iii. Written feedback received from National Federation members;
iv. The recommendations of four consultation workshops held in the context of two key relevant submissions by the National Federation:
    - Response to the *Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities* (April 2021)
    - *Housing Strategy for People with a Disability* (September 2021)

3 Key Areas of Unmet Need and Specific Programme Areas

3.1 Key areas of unmet need requiring urgent focus

Our members have confirmed the wide range of areas in which unmet need is impacting on the lives of people with disabilities. At a general level there are some particularly urgent examples affecting people with intellectual disabilities, which include:

- There is no planned pathway in place to access residential support when an adult with intellectual disability (ID) no longer wishes to live with their family, or when family carers can no longer provide support. Over the past decade, provision of residential support has been driven through crisis and emergency responses – at the top 'step of the ladder' of potential supports in terms of funding, and at the most traumatic time for the person supported. Residential supports provided in response to crisis are often considerably more expensive and often result in less favourable outcomes for the person and their family than planned supports, provided at the right time. The *Action Plan* should develop planned supports (at all potential steps along the continuum) and a mechanism for individuals to apply for housing and support together, which in turn will provide a list that can be progressed and monitored.
- There are over 1200 family carers over the age of 70 providing primary care for their loved ones, approximately 400 of whom are over the age of 80 as a result of successive years of underinvestment. As above, the *Action Plan* should address this through a planned approach that supports people with ID to live independent lives in the community, while supporting their families to plan for the future with peace of mind.
- There are at least 2,100 people who remain living in congregated settings, a decade after the publication of the report that set out to close these institutional settings. The *Action Plan* should focus on ensuring that these people are afforded the opportunity to live their lives included in community, in line with the rights set out in Article 19 of the United Nations Convention on the Rights of Persons with a disability (UNCRPD).
- People with intellectual disabilities experience many health inequalities (as outlined in the findings of the IDS TILDA studies to date) when compared with the general population. In particular, a higher level of dementia is present in this population, along with challenges in bone health, obesity levels, and significantly less favourable mental health outcomes than the general population. As a result, many individuals with intellectual disabilities experience changing needs that require adaptations and/or additional supports in their day and residential services. The profile of the younger population accessing supports at school leaving age is also changing, with a higher incidence of autism being reported. The *Action Plan* should factor in changing needs and changing profile of needs as a requirement of planning, delivery and resourcing.
- With the lack of available residential supports, and the additional pressures brought about for family carers during the Covid-19 pandemic, there is a particular need for funding of additional respite – using both traditional and alternative short break models.

A range of support options is needed that encompasses supported independent living, personal assistance, home support, and full-time residential supports - depending on the needs and wishes of the individual and in line with Article 19 (UNCPRD). Similarly, day services must be planned with will and preference underpinning delivery. This will require a review of the model(s) of support as outlined in the initial section of this submission.

3.2 Sustainable supports

High quality services for people with intellectual disabilities are built on a foundation of relationship-based trust and support, maximising the ability, potential and independence of the person. The stability of staff being in place with a long-term commitment to the people they support was a key driver of the low infection and mortality rates from Covid-19 in disability services in Ireland compared with many other jurisdictions. However, there are a range of challenges now threatening the sustainability of the supports provided to people with disabilities, and these require coordinated action to safeguard the future of these supports and services.

- There is a severe shortage of staff making it very challenging to recruit and retain people in many sectors, and this is being acutely experienced in Disability Services.
- For organisations to be able to recruit and retain high quality staff, they must show prospective candidates that they are valued equally; paid equally for the same work, whether they work for a Section 38, Section 39 organisation or the HSE. Citizens with disabilities should not experience differing stability or turnover of their support staff based on the funding model of the service provider.
- The issue of pay parity for Section 39 disability service providers should be addressed to enable services to be equipped to respond to the evolving and unmet need identified by the *Capacity Review*.
- Opportunities for career progression for staff working in the disability sector should be explored, to encourage further take-up of roles and commitment to ongoing staffing. A business case put forward for the areas of behaviour supports should form part of this consideration.
- There are acute underlying and current deficits being experienced by service providers following many years of underfunding of disability services.
- Currently there is an absence of an agreed, uniform and consistent national costing methodology for disability services, which is urgently required to guide equitable investment in the required supports. This will facilitate sustainable planning and resource allocation.
- As noted earlier, there is a need for regulatory impact assessment and resourcing to support services with the significant impact of regulatory costs.
- The *Capacity Review* confirms that 70% of disability services are provided on behalf of the State by not-for-profit service providers. There are legal requirements on services to implement national pay awards, pension entitlements and implement regulation. When these agreements and regulations are made at national level it is essential that the full cost of implementation is equally allocated to not-for-profit service providers who are contracted by the HSE to provide services on behalf of the State, and those provided directly by the HSE.
- To access equal support, the same funding should be provided for the same service, regardless of the type of organisation the person accesses their service from.
- It is concerning that the *Disability Capacity Review* resource requirements do not include '*pay changes, additional staffing for regulatory compliance, and increasing prevalence of intensive support needs'* – all of which the report indicates could all drive unit costs up further. For services to remain sustainable the *Action Plan* will need to respond to these issues.

As noted above, we recommend the establishment of an overarching Sustaining Services workstream in Year 1 of the *Action Plan*, including a Workforce Planning task group, to ensure that the conditions are put in place to attract and retain high calibre staff to support people with ID, valuing their work and contribution over the coming months and years.

3.3 Inter-Departmental working

The National Federation has set out a detailed account of particular areas in which a lack of coordination is causing the citizen to be left without support, in two key submissions:

- Our submission in response to the Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities report; and
- Our submission into the development of the new Housing Strategy for Disabled People

- As set out in detail in our submissions above, there is a need for coordination of housing provision and the required supports in order for people with disabilities to be able to access living options in line with Article 19 of the UNCRPD. This will require significant coordination between the relevant Departments and a joined-up approach to the budgetary allocations in relation to both housing and relevant supports. Currently, opportunities for individuals to access housing are lost when the required supports cannot be allocated in a coordinated approach.
- The allocation of funding to provide transport to day services, upon which many people with ID rely to access their supports, is not currently provided to the HSE. However, this responsibility is not taken up by the Department of Transport. Investment to address the ageing transport fleet in disability services, and clarity of funding responsibility is urgently required to ensure safety and accessibility.
- Special schools are not currently allocated guidance counsellors, in spite of children attending mainstream school having access to this support. A funding allocation to provide access to guidance counselling in the context of transition planning is required to adequately, equitably and positively plan for the future of young people attending special schools.
- HSE has indicated that the Day Services programme does not provide funding for employment supports to those entering its services. However, the mainstream *Intreo* services have not been resourced to take up the specialised requirements for supported employment required by people with ID.

There is a need for detailed work through the *Action Plan* to agree clear Departmental responsibility in these and other areas where gaps arise to ensure that the citizen is not left without support. The *Plan* should include a workstream on coordinated approaches to planning and delivery of the disability programme with a specific focus on addressing areas of difficulty. This should include the development of a mechanism for application for housing and supports together.

3.4 Feedback on the specific programme areas in the *Disability Action Plan Framework*

In addition to the general issues and recommendations above, our members have provided feedback on the specific areas of the *Action Plan Framework,* as presented in this section. This is not an exhaustive list of recommendations for these service provision areas, and further detail is provided in the two National Federation submissions referenced above, the recommendations of which we request to be considered in tandem with this submission.

Children's Services:

- The *National Policy on Access to Health Services for Children with Disability or Developmental Delay*, 2019 ensures equity of access and consistency across the country and makes referral easier for parents and other referrers. Full implementation of this policy in the context of the *Action Plan* should ensure all children have timely access to the most appropriate service, regardless of the support being disability or primary care. This will necessitate stronger links between disability and primary care services and with Child and Adult Mental Health Services.

- The waiting lists for children's services and access to multidisciplinary / therapeutic supports should be prioritised to meet the needs of children with a disability, along with a continued commitment to the full implementation of the PDSCYP programme.
- Transition planning is key to positive outcomes for young people. For instance, there is significant evidence from the *School Leavers Ability Project* highlighting that transition support implemented from the age of 16 (last 2 years of school) is an essential support for individuals with disabilities and their families alike. It provides key tools and knowledge for the individuals and families to transition to their next pathway of choice, setting expectations, learning the language and linking with all relevant adult supports and services. The evidence shows that this support ensures that the majority of individuals are attending the right service, in the right place at the right time. Transition planning should include the provision of Guidance Counsellors in special schools, and an examination of the alignment of the special school curriculum with the regular school curriculum to support access to further education.
- The implementation of the recommendations of significant research and reports published by the Ombudsman for Children is essential, and the 2017 *Joint Protocol for Inter-Agency collaboration between the HSE and Tusla* is key in supporting joint working between the agencies. The development of individual plans to support children and families whose needs cross between the HSE and Tusla is critical.
- The provision of intensive support packages for young people with disabilities experiencing severe distress is very welcome. Consideration should also be given to providing family support – to include formal behaviour support training for family members to provide them with therapeutic intervention skills that can identify, respond, support and de-escalate behaviours.

Day Services

Our members have identified key issues for the *Action Plan* to address in relation to day services, which include: collaboratively reviewing service provision to ensure implementation of models of services that are in line with national policy and the UNCRPD; addressing the changing needs and changing profile of those accessing supports; reviewing the banding system and costing methodologies; and providing resourcing for those who have been accessing services for a long time without having been included in more recent school-leaver investment programmes.

- Members identified a need for the *Action Plan* to be more ambitious in reflecting the requirement to deliver supports that are individualised, rights-based, responsive to changing need and not solely centre-based. A large number of service users enjoy the social interaction that comes hand-in-hand with centre-based provision and should be enabled to continue to access the service provision of their preference. There are also service users who would prefer not to attend a traditional day service and instead receive more individualised supports in the community. Specific actions to cater for this approach are needed.
- An person's needs and wishes change as they go through different stages of their lives, with varying requirements for support at different times of the life cycle. Whilst the *Action Plan* focuses on day service places for school leavers and states that programmes are typically for *'lifelong participation where a mix of activities and supports can change over the person's lifecycle'*, members have indicated that the current funding model does not account for changing needs.

Therefore, if services are to be truly individualised, the people supported should be funded flexibly to account for changing needs throughout their life.

- Many of those supported began accessing services prior to the implementation of banding, therefore their supports receive lower levels of funding that do not adequately fund their needs. Whilst the *Action Plan* has a focus on additional funding for new and additional day places, there is a need for focus on enhancement funding for existing day services in relation to capital, infrastructure, staffing, training, fire compliance and transport.
- Day service supports should be designed and resourced flexibly to encourage employment and 3rd level education opportunities in a manner that is seamless for the individual. As noted earlier, this will require focused work to remove barriers that arise due to gaps in responsibilities.
- The banding process should be reviewed in light of the wide range of recommendations in this submission and the wider context of service provision.
- In relation to the changing profile of those accessing supports, it was recently noted by the NDA in their review of the profiling process that over 50% of school / RT referrals this year had a diagnosis of Autism. This should be considered when planning for future day service provision. A review of service models, and research should be undertaken to ensure appropriate models of support are in place.
- The monitoring of delivery of the day service programme should be sufficiently flexible to ensure that it accounts for community participation and mainstreaming as well as centre-based provision.

Residential supports

The National Federation has recently made a comprehensive submission to the *'Housing Strategy for People with a Disability'*. There is a clear need for a coordinated approach to the implementation of the *Housing Strategy* and the *Disability Action Plan.* In our submission to the *Housing Strategy* we have made 16 summary recommendations *(pages 2 to 4) (also provided in Appendix I of this document)*.

- We request that the implications of these 16 recommendations are considered in the context of the *Disability Action Plan*, due to the linked nature of both strategies as they relate to residential supports for people with disabilities.
- Planned residential supports that respond to the individual's choice and support independence can be provided in a wide range of models including supported independent living; Personal Assistance and home support; supporting individuals to continue living in the family home after loved ones have passed away (where this is their preference); and full-time residential support. We support the implementation of the full portfolio of available options. The *Disability Action Plan* should ensure that each of these models is utilised to best support independence whilst responding to individual care needs for those with more complex requirements. There is a need for planned access to the full range of potential residential supports that respond to Article 19 of the UNCRPD.
- The *Disability Action Plan* in this phase should ensure that a range of all of the 'steps on the ladder' of potential residential supports are funded and delivered, and that there is a plan which responds to people with all levels of need – mild; moderate; severe and profound.
- The planning that takes place during Years 1-3 of the *Action Plan* should therefore focus on meeting a broad range of needs, in a variety of life circumstances, so that there is a reversal of

the emergency-only approach that had been prevalent, and instead a building of capacity for individuals to have their needs met in a planned approach that is not only delivered on the basis of a crisis. As well as providing better, planned and individualised outcomes for people with disabilities, this will also provide evidence to support the delivery of the full range of options – including lower cost where appropriate; and ensuring that the higher cost models are appropriately channeled towards those who have more complex needs.

- The *Capacity Review* highlights a very significant level of need. Meeting these needs through the full variety of planned approaches works better for the individual, their families, the service provider, and the State, as it can be more cost-effective, and person centred. It will also help reduce the risk of people having to live together in a residential setting that are unsuited to living in a shared space. As described from the experience of one our members; *'it enables the individual to stay within their natural community to the greatest extent and achieve a level of independence beyond even their own and their families' expectations'.*
- In planning for de-congregation there is a requirement for additional revenue and transition funding which should be included within the *Action Plan* implementation.
- *Specialist end of life care services* – as we support an aging population of people with ID, there is a need for investment to meet future needs and comprehensive plans as to how these services will be developed. There is also a need for equitable access to specialist gerontological services and end of life care. Aging 'in place' will require investment and additional supports to ensure that people with a disability have the choice to remain in their own home.
- There is a need for continued investment in the safeguarding of adults with an intellectual disability. Implementation of the HSE Adult Safeguarding Policy needs to be adequately resourced, in particular to address challenges arising from people living together whom may not wish or have chosen to live together. Where there are high levels of peer-to-peer issues arising, services should be resourced to address these and this may require identifying alternative living arrangements. There is a need for detailed analysis and learning from the safeguarding reports notified to both the HSE and HIQA e.g. the levels/types of notifications, patterns emerging and how these can be effectively addressed. The *Action Plan* should therefore include an analysis of safeguarding reports and link these to the prioritisation of those individuals who urgently require a response.
- The development of a pathway for applying for housing and supports together should be included in the *Action Plan*, with the development of an application to be considered so that a list can be formed and data gathered which will support monitoring and clear targets for coordinated action.
- In the context of the considerable unmet needs outlined in the *Capacity Review* report, there is a need for inclusion within the *Action Plan* of significant investment in respite/short break supports – using both traditional and alternative models. There are many respite places currently in full time use by people who are in crisis need of residential support, thereby increasing the need for short breaks or respite for those living at home. The Covid-19 pandemic has further stretched the resilience of those families for whom a planned residential support has not yet been possible, and this further underlines the importance of this strand of the *Action Plan*.

<u>A coordinated approach to the *Disability Action Plan* across domains</u>

Our members recognise that supports in different domains (e.g. personal assistance/home support/day services/respite/residential places) can have connectivity and relativity to each other. We call for a co-ordinated approach to the actioning and prioritising across each domain which delivers a menu of support options, optimises the opportunities for the relevance and strengths in each type of support to complement the other and avoids a sense of competition for resources.

There is a considerable body of research being undertaken within the disability sector by third level institutions, statutory bodies and disability organisations. The *Action Plan* should seek to support the translation of high-quality research to inform future planning and priorities for practices.

There is a need for coordination with service providers in the transition of disability services from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth, whilst acknowledging that people with disabilities will still require many services e.g. access to primary care that will remain funded within the health budget.

There will be a need for joint working between Government Departments, state agencies and voluntary Service Providers to support full implementation of the *Disability Action Plan Framework* 2022-2025.

It is essential that the Action Plan is underpinned by measurable targets and clear timeframes for action. These measurements should be developed in collaboration with all key stakeholders, including those with lived experience.

We request that a review of the *Action Plan Framework i*s scheduled after Year 1, with all stakeholders consulted.

4 Conclusion

The National Federation welcomes this initial opportunity to participate in the consultation process for the *Disability Action Plan Framework 2022-2025*. We believe the actions agreed under the *Disability Action Plan Framework* for the period 2022-2025 will provide an opportunity for increased focus on the rights and needs of people with an intellectual disability and will be an important driver in achieving the rights of people with a disability as set out in the UNCRPD and we look forward to further engagement in the planning and delivery of the *Action Plan*.

Appendix 1 – Recommendations from National Federation Submission to Housing Strategy

The key recommendations for the new Housing Strategy contained in this submission are:

1) The vision of the new Housing Strategy should be underpinned by the UNCRPD, and in particular Articles 19 and 12; and should take account of the recommendations contained in the General Comment on Article 19;

2) The Strategy should build an integrated approach to the provision of housing and supports for people with disabilities;

3) The Strategy should recommend increased joint/interdepartmental working at three levels:
   a. Between Government Departments;
   b. At Housing Agency and HSE national operations level;
   c. At Local Authority/CHO level.

Structures should be put in place to resolve any gaps in responsibility between Departments/ agencies in a timely manner;

4) Sufficient, multi-annual investment in housing and supports should be put in place to meet the housing and associated support needs of people with disabilities, in line with the population of people requiring support identified through the Disability Capacity Review to 2032 (July 2021);

5) Our members have identified three groups of people with intellectual disabilities, for whom housing with supports are urgently required. It is our recommendation that the housing and support needs of these three cohorts should be a key priority in the new Strategy:
   a. Supporting people who remain living in congregated settings to move to community living should be prioritised and addressed as a matter of urgency, as there is evidence of significantly worse quality of life outcomes and rights restrictions for those living in congregated settings. The pace of change over the past decade has not been sufficient to ensure access to community living for all citizens as envisaged by the Time to Move on from Congregated Settings (2011) policy. Within the vision of the new Strategy should be included measures to ensure that those citizens with disabilities who have the highest levels of need, many of whom are living in congregated settings, should be enabled to live their lives in the community, with access to appropriate housing and supports.
   b. There are approximately 1250 people aged 70 years and over, more than 400 of whom are over the age of 80, who remain the primary carers for their adult son or daughter with an intellectual disability. Currently there is no avenue for the citizen with a disability in this situation to apply for housing together with support, unless the family carer becomes seriously ill or dies. This leaves the person with an intellectual disability and their family members in extremely distressing circumstances, without future planning available to offer reassurance.
   c. People with intellectual disabilities experience many health inequalities (as outlined in the findings if the IDS TILDA studies to date) when compared with the general population. In particular, a higher level of dementia is present in this population, along with challenges in bone health, obesity levels, and significantly less favourable mental health outcomes than the general population. As a result, many individuals with intellectual disabilities experience changing needs that require adaptations and/or additional supports. The Strategy should factor in changing needs as a requirement of planning, delivery and resourcing of housing and supports;

6) It is important that the models of support and accommodation provided through the Strategy avoid over-reliance on standardised approaches that cater for specific numbers of individuals living together in a group home. The Strategy should provide for models that are diverse and individualised (for example offering

choice for individuals to live alone, or with others who have/do not have a disability) and that are based directly on the housing and support needs of the person;

7) Whilst ensuring that individualised approaches are implemented for each person seeking housing support, it would be useful at a national level to gather shared learning through the Strategy on a range of built environment models that enable and facilitate supported independent living;

8) Input from disability service providers should be sought at an early stage of housing planning and development to ensure that at a minimum, a proportion of housing in each development is accessible and wheelchair livable, and to avoid necessity of retrofitting for adaptation at a later stage;

9) Shared data gathering should be established to ensure the extent of housing and support need is understood and addressed through clear KPI's on an ongoing basis;

10) All funding streams should be examined to ensure fit for purpose (for instance, members provided feedback that use of the CAS funding has become less practical on the ground in more recent years, in part due to the absence of associated revenue funding for the individual and due to the timeframes for approvals);

11) The Housing Strategy should include a process to develop clear guidance nationally on the support needs of individuals who have a particular requirement to access additional space – for instance to accommodate additional equipment, staff sleepovers, or for a small number of people with particularly complex needs, the requirement for lone living along with staff accommodation due to behavioural support needs;

12) The Strategy should seek to foster inclusive communities (more accessible for people with disabilities, more accessible for all citizens including older people; parents of young children, etc.);

13) At local and national levels, the Strategy should encourage the use of accessible and alternative methods of communication; and sufficient time and support where required for people with intellectual disabilities to understand and respond/participate.

14) The Strategy should recommend that all legislation and regulation affecting the housing and support requirements for people with disabilities should undergo an impact assessment. The intersection of regulatory requirements from different Departments should be factored together and appropriate resourcing provided to allow regulation to be implemented effectively. The impact of regulation on people's lives should be examined, to ensure that proposed new measures do not become a barrier to living an ordinary life.

15) The Strategy should seek to identify mechanisms to support the engagement of mainstream AHB's and should examine challenges present for AHB's that are linked with disability service providers in order to maximise the ability of AHB to support the delivery of housing to people with disabilities.

16) A clear set of measurable deliverables should form the cornerstone of the Government's overarching approach to meeting its housing and support obligations under the Convention, through the new Housing Strategy; with clear monitoring and oversight processes put in place.