Supporting people with disabilities and significant residential support needs

Report of the
Time to Move On from Congregated Settings Review Group

October 2019

TRANSFORMING LIVES
Programme to Implement the Recommendations of the 'Value for Money and Policy Review of the Disability Services in Ireland'

Acknowledgements

The Review Group would like to thank the family members who engaged in and supported the Focus Groups convened as part of this review.

The Review Group would also like to thank the Disability Services personnel and the experts and leaders in the disability sector and the wider health services who engaged in and contributed to this review process. Particular mention goes to those that facilitated the Review Group during site visits.

Finally the Review Group would like to thank all those involved in drafting the case studies contained within this report, that demonstrate and support the findings of the review and most importantly, reflect the commitment and dedication of staff across disability services who are enabling people to live a life of their choice in their community, “ordinary lives in ordinary places”.

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1. Glossary of Terms

Community cluster
Clustering can be defined as where a number of individual houses and/or apartments are grouped close together in the community. Cluster housing typically consists of a relatively small number of homes in close proximity to each other, for example some or all of the homes are on a particular street or located within a block. A community cluster can be differentiated from a small campus, in that the homes can be accessed and run independently and are not notably different from the surrounding housing.

Community Health Organisation (CHO)
The HSE manages the delivery of the community health and social care services across the country through nine separate administrative areas, known as Community Health Organisation (CHO) Areas. Each CHO Area is led by a Chief Officer and there is a Head of Social Care in place with responsibility for the services for older persons and people with disabilities.

Congregated Settings
The *Time to Move on* Report defines congregated settings "*as where ten or more people with disabilities live together in a single unit or on a campus*".

Dispersed Housing
Dispersed housing may be defined as apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods.

Intentional communities
These are settings that have a particular ethos of communal living and intentional life-sharing. People with disabilities residing in these settings, may live in a group with others who need support as well as with co-workers. The co-workers who support the individuals often live with the people with support needs, sharing the homes.

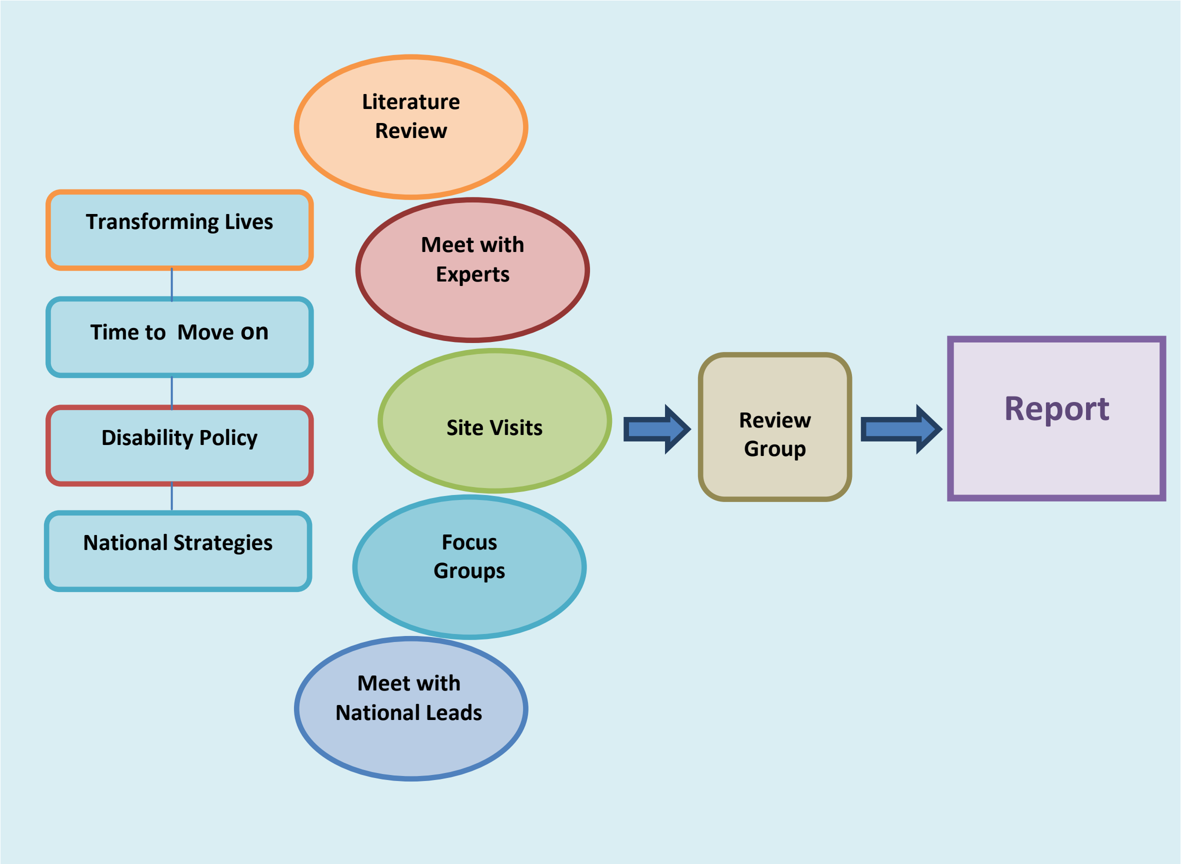
2. Executive Summary

This report aims to inform the development of support services for people with disabilities with significant specialist support needs who currently reside in congregated settings and for the broader disability sector based on evidence-based good practice. The report identifies key guiding principles to underpin the development of services and specifies a best practice model of care and associated care pathway. The report makes a number of recommendations to support the delivery of this model of care, which are structured into three delivery strands with specific priority actions to allow progress to be made incrementally.

Under the umbrella of the *Time to Move On* working group, a review group was established to review specialist residential support services for people with disabilities and to make recommendations in relation to the development of and or the retention of specific specialist services. The review group chaired by the HSE included representatives of voluntary sector, the Department of Health, the NDA, Inclusion Ireland and a representative of the HSE Head of Service for Social Care.

Review process

The process followed by the review group to develop the report was multi-faceted, in or to ensure that the views of stakeholders were taken into account alongside the evidence gathered from literature and other resources.



Informing the Report

This report is underpinned by a number of policy developments and reports including:

- Transforming Lives
- Time to Move on from Congregated Settings
- A Quality Framework: Supporting persons with disabilities to achieve personal outcomes
- Report on the Future Needs
- Shaping the Future of ID Nursing
- Neuro-rehabilitation Strategy
- Autism policies

Literature Review

An extensive literature review was undertaken to gather evidence on best practise in the provision of support for people with disabilities that have significant specialist support needs. The review focussed on recently published material and literature under a number of search topic headings:

The material reviewed gathered information on the provision of support for people with specific specialist needs, with and without a disability, service user experience, family perspective, staffing and capacity building. Documentation from Ireland and other jurisdictions were reviewed. The literature confirmed a changing landscape in disability residential specialist services to reflect a growing ageing population and a shift to community based care with an increasing focus on a social care model.

Key Guiding Principles

Seven themes emerged from the literature. These themes were agreed as the Guiding Principles to underpin the development of services and models of support.

It is noteworthy that these themes are equally applicable as principles for the wider disability services as well as those focused on supporting people with significant and complex needs.

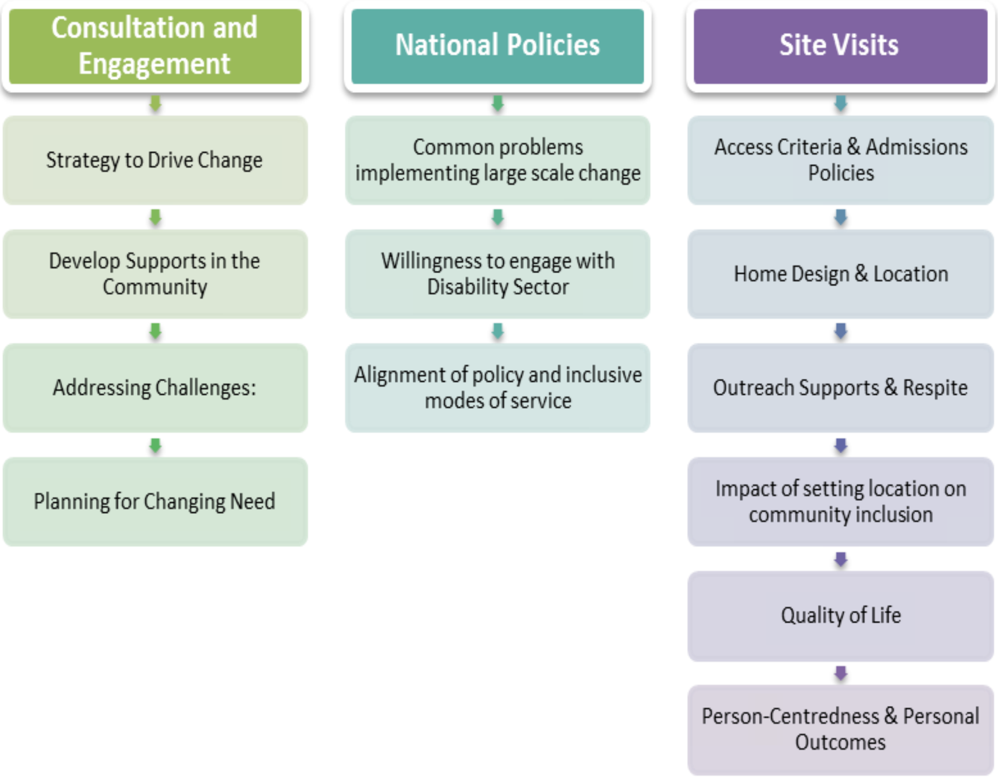
Research Projects

A number of research projects focussing on models of best practise were underway while the review was being undertaken. The progress, findings and recommendations of these projects were taken into account and inform the recommendation of the review.

Consultation and Engagement

The final report is produced following extensive consultation with service providers across the HSE and the voluntary sector, cross sectoral engagement meetings with researchers, experts and family focus groups.

A series of meetings and engagements were held with families, leaders and experts in the provision of specialist services, national policy leaders, service providers CHO Disability Service Teams and research teams. Cross sectoral engagements included the National Dementia office, the Palliative Care National Lead and the Mental Health of Intellectual Disability Lead. Site visits took place to a number of community based homes where people with behaviours that challenge, complex medical needs and significant physical and intellectual disability are now living. The key findings from the consultations can be summarised as follows:



Case Studies

A number of case studies are included that highlight how service providers are supporting people who present with significant specialist support needs. The case studies outline the challenges in providing these services, the service response and learning.

Data

A number of recent reports and data sources provide information on the demand for disability health services and disability health service spending. These reports provide information on current services and future demographic requirements and highlight the impact of population changes and existing gaps in provision that need to inform the planning of services.

Discussion

The report found there is a broad consensus on the direction that any approach to supporting people with disabilities needs to take. Enabling people to stay at home and in their own communities for as long as possible, meeting people's needs at the lowest appropriate level of complexity and when required, providing specialist supports that may in some cases include a residential component.

The implementation of the *Time to Move on* policy is driving the development of community-based residential placements where people with disabilities are enabled to exercise their will and preference over the way they are supported and care is provided. The *Time to Move on* policy recognises and identifies that in order to support people to live well in their own homes; the capacity of a wide range of community-based services must be developed to respond appropriately. This includes primary health care and social care supports as well as local amenities such as housing, transport services, community groups, education, business and leisure facilities.

Key drivers will be:

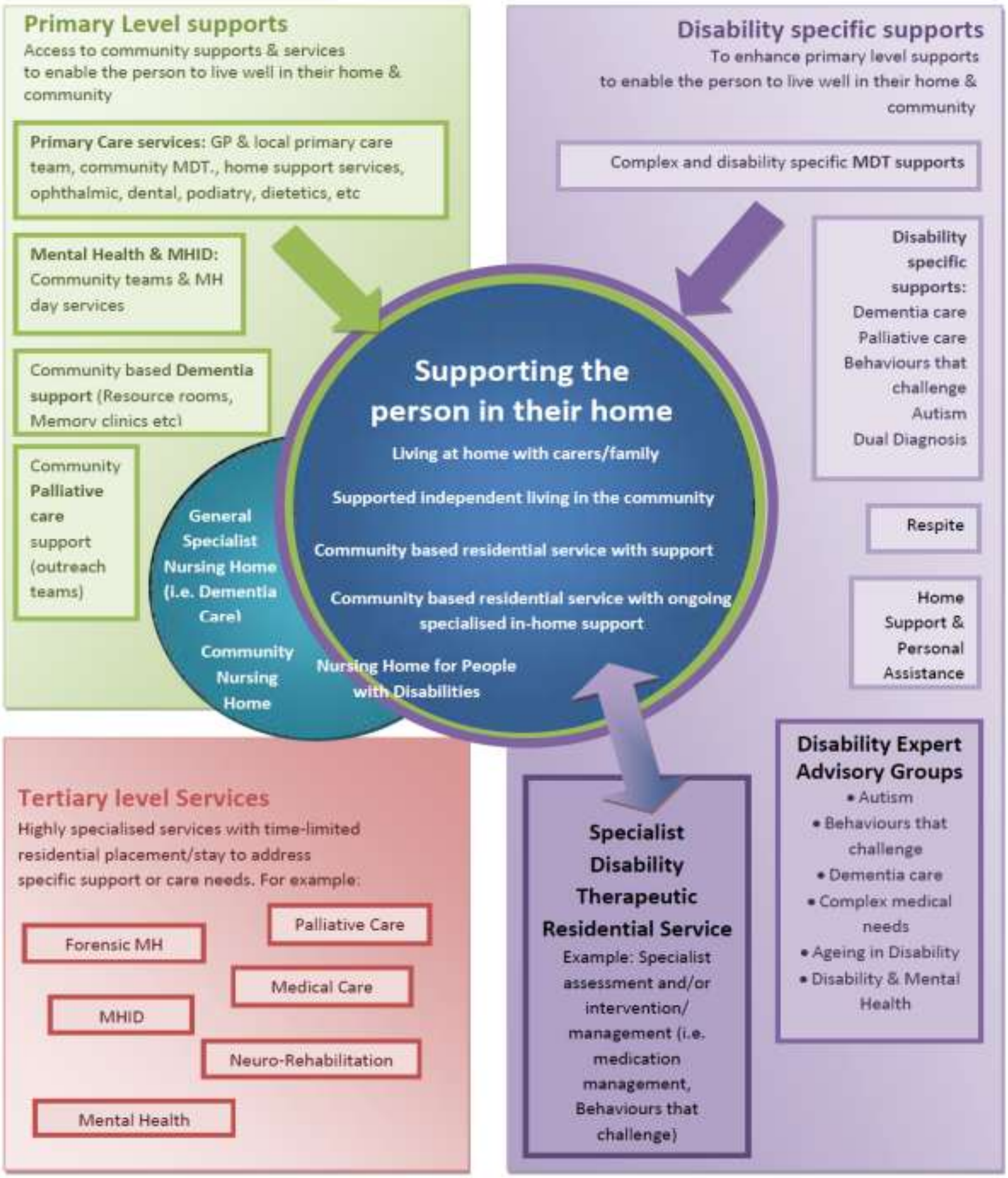
- Community inclusion intersectoral working
- Supporting new models of service innovation
- Developing alternative person-centred and family centred supports
- Implementing the Time to Move On Policy
- On-going Capital funding investment

Best Practice Model of Care

The report identified that there needs to be a focus on developing the model of care and continuum of services that is person centred and will respond to the needs of the individuals and their families. For each person the supports should be person centred and delivered at the lowest level, close to home and in their community. Each person should have access to the level of support needed irrespective of their residential status and should be able to access different levels of residential and community supports as determined by their support needs at that time.

The following diagrammatical model of care has been developed.

Model of Care for People with residential support needs



Recommendations

The recommendations in the report identify the actions needed to ensure that an appropriate and effective care pathway is developed for all people with significant support needs that will be needs based, person and family centred and enable individuals to enjoy equity of opportunity and participation.

Designing and delivering an appropriate care pathway that can respond to the needs of people with significant specialist support needs will require changes to the way current services are configured and delivered. In addition to this, resources will be needed to build capacity along the model of care to ensure that the service responses to individual need are appropriate both in terms of the level of support and timing.

The recommendations are set out under three delivery strands which are set out to ensure that where possible actions can be progressed towards the development of a best practice model of care. This approach recognises that there are resources required and other conditions to be met, including external stakeholder support in order to progress other recommendations.

Three Delivery Strands		
Review current provision and align service elements to best practice model of care	**Build capacity along best practice care pathway**	**Enhance the current disability policy framework to inform and support the delivery of specialist residential services**
Priority Action 1.1 Map current model of care and the capacity of services on a geographical basis	**Priority Action 2.1** Continue to support innovative practice and alternative models of care	**Priority Action 3.1** Review of Disability Policy Framework to ensure all necessary guidance is in place to support service planning and delivery
Priority Action 1.2 Review Existing Specialist Services on a case by case basis and align to best practice model of care	**Priority Action 2.2** Develop Expert Advisory Groups to deliver and support capacity building	**Priority Action 3.2:** Develop and implement a policy that supports best practice in the area of "Ageing with a Disability"
Priority Action 1.3 Examine non-disability specific specialist services and align to best practice model of service	**Priority Action 2.3** Develop cross care group referral processes to support best practice model of care and care pathways	
Priority Action 1.4 Identifying unmet need on the best practice model of care		

Conclusion

On-going work is needed to continue the move away from the traditional model of residential service provision in order to develop the range of supports that will enable all people with disabilities to live well in the community and to enjoy equity of opportunity and participation. Key to this is building the capacity of the individuals, their carers', support staff, as well as that of the community services, disability services and other specialist services.

The recommendations set out the necessary steps to ensure that going forward services are planned, developed, configured and delivered in keeping with the guiding principles identified in the literature review and the views expressed by of families, experts, service providers and leaders working in the disability field.

Continuing to support the capacity and capability of the service providers is a priority. Strong leadership, joint working and a shared vision with a focus on the individual, with services delivered as close to home as possible, with access to any additional supports when required. Increasing service capacity to meet these needs will support the development of an appropriate model of care and care pathways for all people with disabilities and meet people's needs at the lowest level of complexity.

3. Introduction

In 2017 a work stream was established under the Time to Move on Subgroup to undertake a review of residential locations and examine best practice solutions for individuals with a disability and significant specialist residential support needs.

Term of Reference (TOR):

To identify appropriate best practice models to meet the residential support needs of individuals with a disability and significant specialist support needs. The following actions were proposed to deliver on this:

- Examine current literature and research to identify current models of best practice in relation to residential supports for those with significant support needs.
- Gather examples of current good practice within community based residential services in Ireland.
- Identify individuals in residential settings whose support needs may require a specialist solution.
- Examine application of best practice approaches to meeting residential support needs of individuals identified as requiring specialist supports.
- Recommend on the appropriate approach to meeting the residential support needs of individuals identified as requiring specialist supports in line with current best practice

Methodology

To complete the review in line with the Terms of Reference and a comprehensive work plan was followed that included a range of consultations and engagements, literature reviews, research on best practice internationally, gathering case studies and site visits. The individual chapters in the report set out the work covered by the review Group.

Scope of the Review

This review was undertaken to examine the specialist residential support needs of people currently living in the congregated settings. However, there are people with disabilities currently in the community who at various times in their lives may develop significant specialist residential support needs. In this context, this review has sought to reflect and inform the provision of services for all people with disabilities and significant specialist residential support needs.

4. Disability Policy: Background & Context

Transforming Lives Programme

The Transforming Lives Programme was established in 2014, to drive the implementation of the recommendations of the Department of Health's 2012 *Value for Money and Policy Review* report. Under the Programme six working groups were established to examine and progress specific areas of reform. Working Group 2 of the Transforming Lives Programme is concerned with *Person Centred Model of Service & Support – Implementation, Oversight & Support.*

This includes the implementation of the *Time to Move on from Congregated Settings* Report for residential services, the *New Directions* report on adult day services and the *National Programme on Progressing Disability Services for Children and Young People (0 to 18 years)*.

NATIONAL IMPLEMENTATION FRAMEWORK
VALUE FOR MONEY & POLICY REVIEW OF DISABILITY SERVICES IN IRELAND

Subgroup 1 under Working Group 2 is the *Time to Move on* Subgroup with responsibility for:

> *Implementing the initiatives which underpin and enable a new model for residential support in the mainstream community, where people with disabilities are supported to live ordinary lives in ordinary places.*

This multi-stakeholder, cross–departmental group drives the implementation of the policy and provides support and oversight at a national level.

Time to Move on From Congregated Settings: A Strategy for Community Inclusion

The Expert Working Group report *Time to Move on from Congregated Settings: A Strategy for Community Inclusion* was published in 2011 and adopted as policy in 2012. The report defined congregated settings as,

> ***"where ten or more people reside in a single living unit or are campus based".***

The report found that notwithstanding the commitment and initiative of dedicated staff and management, there were a significant number of people still experiencing institutional living conditions where they lacked basic privacy and dignity, and lived their lives apart from any community and family.

Time to Move on from Congregated Settings
A Strategy for Community Inclusion

The report recommended a seven year timeframe for the implementation of the policy and made 31 recommendations covering a wide range of issues and identifying a diverse group of stakeholders and responsible bodies. It was envisaged that delivering on the recommended actions could bring about the necessary wide reaching changes to enable individuals in congregated settings to transition to homes in the community and live meaningful lives of their choice. The recommendations fall into a number of broad categories:

- Development of national policies and strategies to support implementation
- Leadership & Implementation structures
- Key principles to be adopted
- Funding streams and mechanisms
- Managing the reconfiguration of existing services
- Supporting individuals to have a life of their choice and a meaningful day
- Assessing and evaluating change and sharing the learning

There is no reference in the recommendations to the need for a different approach to be taken when supporting individuals with significant specialist residential support needs. The relevant recommendations advise:

- Recommendation 7: The new model of support should be based on the principles of person-centeredness; it should enable people with disabilities to live in dispersed housing, with supports tailored to their individual need.

- Recommendation 8: All those moving from congregated settings should be provided with dispersed housing in the community, where they may:
    - Choose to live on their own
    - Share with others who do not have a disability
    - Share their home with other people with a disability
    - Live with their own family or opt for long-term placement with another family

- Recommendation 11: People with disabilities living in dispersed accommodation in community settings will need a range of support programmes to help them to plan for their lives, and take up valued social roles.

- Recommendation 12: Action is required by HSE to strengthen the capacity of community health services to deliver supports to people with disabilities.

- Recommendation 15: The individualised supports for people with disabilities should be delivered through a coordinating local structure based on defined HSE catchment areas, within which the full range of supports is available.

- Recommendation 19: There will be instances where purpose built new housing in the community to meet particular individual needs will need to be built, or purchased and made accessible.

A Quality Framework: supporting persons with disabilities to achieve personal outcomes

The focus on personal outcomes is an essential part of the recommended service delivery framework under the Transforming Lives Programme. Following research and consultation by the National Disability Authority, including literature on outcome measurement and experiences from other jurisdictions, the Department of Health and the HSE have approved nine outcome domains for Irish disability services for adults. These reflect widely recognised aspects of life that are important to all people as follows:

Nine Quality of Life Domains:

1. Are living in their own home in the community
2. Are exercising choice and control in their everyday life
3. Are participating in social and civic life
4. Have meaningful personal relationships
5. Have opportunities for personal development and fulfilment of aspirations
6. Have a job or other social valued roles
7. Are enjoying a good quality of life and wellbeing
8. Are achieving best possible health
9. Are safe, secure and free from abuse

Working Group 4, under the Transforming Lives Programme has developed the Quality *Framework: Supporting persons with disabilities to achieve personal outcomes* document. This identifies the outcome predictors for the individual and organisation that can support the measurement and evaluation of activities and practice that are known to support positive quality of life outcomes under the nine domains. The outcome predictors are themed at the individual level and at the organisational level.

The Framework does not reference specialist residential services per se but promotes a person-centred model. The outcome predictors at the individual level refer to having access to supports and opportunities that enable a person 'in ***line with my needs and wishes'***. This is to reflect that the persons who use services and supports are diverse, and that services and supports should be person-centred and individualised. The Framework gives examples of what this might look like for example:

- **Under Theme 1: Individualised and Effective Services and Supports** confirms that
  - *I have access to person-centred home and community-based supports that promote my autonomy and self-determination and my participation in community activities, in line with my needs and wishes.*
  - *I have meaningful choice over where to live, and who to live with, in line with my needs and wishes. This includes access to small, community-based living arrangements or living on my own.*

- **Under Theme 3: Health**
    - *I have access to supports and opportunities to make informed decisions and choices about my health and wellbeing and to manage any long-term conditions that I have, in line with my needs and wishes*.

Transforming Lives Report on the Future Needs for Disability Services Working Group 1 April 2018

This report produced by a subgroup of the Transforming Lives Programme under Working Group 1, estimates the demand for HSE-funded disability services up to 2026, by examining both current levels of unmet need, and the impact of demographic change.

The report identifies the key demands and pressures in the area of residential services, children's and adult therapy services, and the need to increase day service places each year to meet school-leaver demand. The current demographic pressures are also considered in the report.

In relation to residential and specialist service provision some of the key findings of the paper include:

- Gross spending on disability services fell by 7% between 2009 and 2016, at a time when the population requiring services grew. The numbers registered on the National Intellectual Disability Database increased by 8.4% over the same period. As a result there have been significant areas of unmet need, spanning residential, respite, therapy and other services.
- Expenditure on elements like assistive technology, respite care, personal assistants, and community support services from specialist and peer-led disability organisations, while forming a relatively small section of total spending, may be critical in sustaining people to live at home and avoid more expensive forms of support.
- While the total number of adults receiving intellectual disability services has remained fairly stable in the last dozen years, an increasing number are aged over 50, at a period when they are more likely to require residential care rather than day support. The number of over-50s has increased from 3,900 in 2003 to 5,200 in 2012 and 5,700 in 2015.
- Demographic change alone could increase the number of residential intellectual disability places required, relative to 2015, by 400-500 additional places by 2020 and by 700-800 by 2025.
- Around 15% of over-60s with intellectual disabilities live with family members, usually with siblings or parents. Given the ages of those involved, most of these arrangements will not be sustainable.
- The proportion of under-45s with ID getting residential care has fallen by about 10 percentage points from that of the pre-recession era (2007). This deferred demand has fed into rising numbers presenting for residential care as emergency placements. A return to the

2007 residential care rates would require around 1,200 additional residential places in both 2020 and 2025, over and above those due to demographic pressures.

- Based on unmet need recorded on the disability databases, provision of adult therapy services would need to double from its 2016 level. The number of staff currently providing such services is not known with service providers suggesting that that the expansion to date of children's therapy services has been achieved partly through cutting services for adults. Extrapolating ratios from children's services on staff numbers per service user would suggest that 480 additional staff are required now, and a further 100 staff by 2026.
- Ireland's disability services evolved from a medical model, and the skill mix is still characterised by a high proportion of staff with nursing qualifications. In cost terms, however, nursing staff and social care workers earn equivalent amounts. In considering the skill mix the services of the future require, it would be important to develop an overall competency framework for disability services, informed by the suite of nine quality of life outcomes.

Shaping the Future of Intellectual Disability Nursing in Ireland

Supporting people with an intellectual disability to live ordinary lives in ordinary places

The 2018 report *Shaping the Future of Intellectual Disability Nursing in Ireland – Supporting people with an intellectual disability to live ordinary lives in ordinary places*, sets out a clear direction for the future role of intellectual disability nursing in Ireland to deliver on a key priority for the HSE; ensuring the best possible health and social care is delivered to individuals with an intellectual disability.

Shaping the Future
of Intellectual Disability
Nursing in Ireland

The findings confirm that the changing landscape of service provision does, and will continue to present new challenges for stakeholders and service providers alike.

> "Key *policy documents guiding change within disability services highlight the need for greater integration with general population health and community services as well as interventions to address specific health and social care issues of individuals with an intellectual disability.*
> *....All of these have implications for the development of professional skills to meet the care and support requirements of people with intellectual disability and of their families."*

The report suggests these changes offer new opportunities for a reconfiguration of service provision offering a new context within which the unique skills of the Registered Nurse Intellectual Disability (RNID) can be embraced and enhanced.

The findings of this project are structured into the following four themes, each of which is discussed in the report in the context of relevant policy, legislation and evidence.

1. Person-Centredness and Person-Centred Planning
2. Supporting Individuals with an Intellectual Disability with their Health, Well-being & Social Care
3. Developing Nursing Capacity, Capability and Professional Leadership
4. Improving the Experience & Outcomes for individuals with an Intellectual Disability

It is notable that under Theme 1: **Person-Centredness and Person-Centred Planning**, particular attention is given to the potential expansion of the role of the RNID to support person centred service provision that meets the specialist support needs of people with an intellectual disability . This is represented diagrammatically in the report as shown in Figure 2 below and it can be noted that the areas identified include significant support needs such as complex needs, end-of-life and palliative care, and dementia care.

Figure 1: Expansion Areas of person-centred service provision

The Report also recognises the potential for Future Areas for Specialist and Advanced Practice to support people with ID, as noted in Figure 2 below. The report notes that " *many participants indicated that they saw nurse specialists …operating in a fluid way…(such that) nurses could be located between Intellectual Disability services and generic health facilities providing interventions liaising with others, educating family and professionals and promoting health"*.

Figure 2: Future Areas for Specialist and Advanced Practice

5. Other Relevant National Policies

A number of other national policies, strategies and reports were found to be relevant to this review:

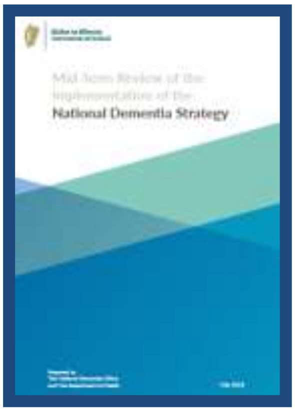
- National Dementia Strategy
- Palliative Care Services Three Year Development Framework (2017 – 2019)
- Vision for Change Report of the Expert Group on Mental Health Policy
- Autism
    - National Review of Autism Services Past, Present and Way Forward 2012
    - Estimating prevalence of Autism Spectrum Disorder (ASD) in the Irish Population: A review of data sources and epidemiological studies
    - Review of the Irish Health Services for Individuals with Autism Spectrum Disorders 2018
- National Strategy & Policy for the Provision of Neuro Rehabilitation Services: From Theory to Action Implementation Framework 2019-2021
- Housing Options for Our Ageing Population: Policy Statement

An overview of each of these is given below, with particular note made as to how the support needs of people with disabilities are included or referenced in each policy.

National Dementia Strategy

The National Dementia Strategy was launched in 2014. The Strategy identifies 14 Priority Actions and 21 Additional Actions, which are grouped under the following headings:

1. Better Awareness and Understanding
2. Timely Diagnosis and Intervention
3. Integrated services, supports and care for people with dementia and their carers
4. Training and Education
5. Research and Information Systems
6. Leadership


National Dementia Strategy

An Implementation Plan for the Strategy was developed in 2015 identifying key deliverables and indicative timelines which included the establishment of a National Dementia Office (NDO). A mid-term review of the implementation of the Strategy, published in May 2018, provides an overview of work completed to date and the on-going work under each of the priority and additional actions identified.

Within the National Dementia Strategy the following actions are identified as relevant to people with disabilities:

Priority Action 3.14

The Health Service Executive will examine a range of appropriate long-term care options to accommodate the diverse needs of people with dementia, including those with behaviours that challenge. In planning future long-term residential care, the Health Service Executive will take appropriate account of the potential of new residential models, including housing with care, for people with dementia.

Priority Action 3.1

The Health Service Executive will critically review health and personal social services for people with dementia to:-

- identify gaps in existing provision, and
- prioritise areas for action in accordance with resource availability, with priority being given to the most urgent deficits that can be addressed either within or by reconfiguring existing resources.

Priority Action 2.5

The Health Service Executive will review existing service arrangements to maximise the access that GPs and acute hospital clinicians have to specialist assessment and diagnosis of dementia, including Old Age Psychiatry, intellectual disability services, geriatric medicine, neurology services and memory clinics.

Considerations from a Disability perspective:

- Ensure the needs of people with disabilities are being addressed and in particular that the residential requirements of people with disabilities are fully represented in discussions regarding models of service.

- Ensure the mapping of existing service provision includes services provided by disability providers.

- Ensure planning reflects the needs of people with a disability with a diagnosis of dementia.

- Ensure the pathway to services and access to these, is equitable for people with disabilities and dementia.

http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf

The Review Group have engaged with the NDO to ensure the needs of people with disabilities are included and considered under the actions. Details of this engagement are included in Section 7 Consultation and Engagement.

Palliative Care

Palliative Care Services Three Year Development Framework (2017 – 2019)

Palliative Care Services

THREE YEAR DEVELOPMENT FRAMEWORK

2017 - 2019

The Palliative Care Services Development Framework informs and directs the development of adult palliative care services in Ireland. The Framework builds on existing policy and development documents, remaining true to the principles and vision described in the 2001 National Advisory Committee on Palliative Care (NACPC) Report which was adopted as government policy, and directs national palliative care strategic development. A review of the current Framework indicates that a number of actions are relevant to people with disabilities. These are as follows:

Recommendation 2:

It is recommended that a properly resourced palliative care corporate function be re-established to coordinate, monitor and develop palliative care services in emerging healthcare structures.

Action Point: Services need to consider how best to extend care to vulnerable populations, such as those with intellectual disabilities, (2.4)

Action Point: New specialist palliative care inpatient units and existing local community specialist palliative care services should formally engage to develop shared governance structures, to ensure integrated care of patients and families, to meet the requirements of regulatory compliance, and to prepare for a commissioning funding model**.** (2.7)

Action Point: The HSE's Palliative Care Provider Network should prepare recommendations on how the commissioning model of funding might work best for all stakeholders (2.14)

Recommendation 8:

...the following Action Points should be addressed as part of the revision of the NACPC Report and in the development of the Strategic Plan in 2019:

Action point: Considering how best to extend care to vulnerable populations, such as those with intellectual disabilities, those with psychiatric illness, homeless people, the travelling community, ethnic minorities, and prisoners;

Recommendation 4:

The National Clinical Programme for Palliative Care should be properly resourced, supported and sustained to continue its work in integrating palliative care across the HSE's Divisions, pursuing the quality agenda and ensuring the best use of resources.

Adult Palliative Care Services Model of Care for Ireland

In April 2019 the National Clinical Programme for Palliative Care launched A Model of Care bringing together regulatory, organisational, financial, and clinical aspects of service provision to outline best practice in patient care delivery.

The aim of the Palliative Care Model of Care is that:

> *'Every person with a life-limiting or life-threatening condition can easily access a level of palliative care appropriate to their needs regardless of care setting or diagnosis in order to optimise quality of life'*

To realise this aim and deliver palliative care according to the Model of Care, the following eight foundations are identified:

Eight Foundations of the Palliative Care Model of Care:

1. People with life-limiting or life-threatening illness receive regular, standardised assessment of palliative care need and individualised care plans are co-developed to meet identified need, with the aim of optimising quality of life.
2. Family and carer needs are assessed so that they receive practical, emotional, psychosocial and spiritual support, including into bereavement.
3. An enabling environment is created where hospital, community and primary health care providers are supported to provide a palliative care approach as part of their normal service provision.
4. Access to specialist palliative care is provided for those patients with complex needs and the capability of services is developed.
5. Hospital, community, primary care and specialist palliative care providers are supported to work together to provide an integrated model of care provision.
6. Effective and timely flow of information between hospitals, community, primary health care and specialist palliative care providers is in place. Communication is inclusive of patients and carers, where appropriate.
7. A culture of quality improvement is embedded in palliative care provision.
8. A research and innovation agenda that improves the quality and value of palliative care is supported.

The Model of Care provides guidance on palliative care needs assessment; national clinical guidelines, quality improvement measures, developing and supporting staff, metrics, funding and improvement models and also outlines an initial implementation plan.

The full report is available at https://www.hse.ie/eng/about/who/cspd/ncps/palliative-care/moc/ncp-palliative-care-model-of-care-24-04-0219.pdf

Considerations from a Disability perspective:

- There needs to be engagement with the Palliative Care Steering Group to promote the inclusion and representation of Disability Service Providers on committees as service providers who have experience of and are delivering palliative care to people with disabilities
- The HSE Palliative Care Provider Network forum for voluntary and statutory service providers should be extended to include relevant disability service providers
- That there is engagement with the Irish Hospice to adapt /develop resources to reflect an intellectual disability perspective.

The Review Group have engaged with the National Palliative Care lead to ensure the needs of people with disabilities are included and considered under the actions. Details of this engagement are included in Section 7 Consultation and Engagement.

A Vision for Change: Report of the Expert Group on Mental Health Policy

The Vision for Change report details a comprehensive model of mental health service provision for Ireland. It describes a framework for building and fostering positive mental health across the entire community and for providing accessible, community-based, specialist services for people with mental illness:

It proposes a person-centred treatment approach which addresses each of these elements through an integrated care plan, reflecting best practice, and evolved and agreed with service users and their carers. Key recommendations include:

- Specialist expertise should be provided by community mental health teams (CMHTs)
- Teams should serve defined populations and age groups and operate from community-based mental health centres in specific sectors throughout re-configured mental health catchments areas
- Some of these CMHTs should be established on a regional or national basis to address the complex mental health needs of specific categories of people who are few in number but who require particular expertise.

This policy envisions an active, flexible and community based mental health service where the need for hospital admission will be greatly reduced. The report considers best practice in the provision of mental health services for people with an intellectual disability and states that:

“The service principles are the same as those for all the mental health services proposed in this policy: citizenship, inclusion, access and community-based services. The specific resonance for people with

intellectual disability is that the rights of an individual with an intellectual disability are the same as those of any other member of society. A service that is based on these principles should be respectful of, and sensitive to, the unique needs of each individual."

The Report makes the following recommendations:

1. The process of service delivery of mental health services to people with intellectual disability should be similar to that for every other citizen.
2. Detailed information on the mental health of people with intellectual disability should be collected by the NIDD based on a standardised measure. Data should also be gathered by mental health services for those with intellectual disability as part of national mental health information gathering.
3. A national prevalence study of mental health problems including challenging behaviour in the Irish population with intellectual disability should be carried out to assist in service planning.
4. The promotion and maintenance of mental well-being should be an integral part of service provision within intellectual disability services.
5. All people with an intellectual disability should be registered with a GP and both intellectual disability services and MHID teams should liaise with GPs regarding mental health care.
6. Mental health services for people with intellectual disability should be provided by a specialist mental health of intellectual disability (MHID) team that is catchment area-based… distinct and separate from, but closely linked to, the multidisciplinary teams in intellectual disability services who provide a health and social care service for people with intellectual disability.
7. The multidisciplinary MHID teams should be provided on the basis of two per 300,000 population for adults with intellectual disability.
8. One MHID team per 300,000 population should be provided for children and adolescents with intellectual disability.
9. A spectrum of facilities should be in place to provide a flexible continuum of care based on need. This should include day hospital places, respite places, and acute, assessment and rehabilitation beds/places. A range of interventions and therapies should be available within these settings.
10. In order to ensure close integration, referral policies should reflect the needs of individuals with intellectual disability living at home with their family, GPs, the generic intellectual disability service providers, the MHID team and other mental health teams such as adult and child and adolescent mental health teams.
11. A national forensic unit should be provided for specialist residential care for low mild and moderate range of intellectual disability. This unit should have ten beds and be staffed by a multidisciplinary MHID team.

A review of Vision for Change is planned and an evidence review has been prepared and published. The Review Group engaged with the Mental Health of Intellectual Disability Lead to ensure the needs of people with disabilities are included and considered under the actions. Details of this engagement are included in Section 7 Consultation and Engagement.

Autism

Three reports that examine the support needs of people with Autism are considered below.

National Review of Autism Services Past, Present and Way Forward 2012

This national review outlined the historical background, the current models, the gaps in service provision and the need for a consistent clear pathway for individuals to access services in the least restrictive way. The report noted the need for a clear focus on the individual and their family in ensuring that the needs of the individual remain at the centre of service provision.

The review noted that service provision varied significantly in different geographical areas. Future provision of services for children and adults with ASD must be in line with the Government's commitment to mainstreaming where people with a disability have access to the same services as the general population, and in addition receive the appropriate support and intervention to address individual needs.

The authors of the review found

> "*that the future range of service provision for adults should continue to be provided by an appropriate mix of agencies and that greater co-operation and collaboration should take place across all sectors to ensure that adults can access all appropriate mainstream services as required*".

However, the report also found that it would be necessary to:

- Look at new models of service provision and to reconfigure services as appropriate to ensure that they are person-centred and responsive to need.
- Create an environment of equity and quality by developing a standardised approach to elements of service provision.
- Provide appropriate autism-specific training/information/awareness to ensure that staff involved in the delivery of services have the necessary skills and expertise to meet the needs of individuals and their families.
- Work collaboratively with individuals, families, carers and other government departments to ensure an integrated, co-ordinated and seamless approach to service provision.

In particular the report identifies a number of service provision elements as key for development and improvement including:

- Appropriate care pathways for adults including access to Mental Health Services.
- Appropriate range of residential options tailored to meet the differing needs of adults on the autism spectrum.
- On-going education/training and support for families, service providers and professionals working with adults with ASD.

The review outlined the range of existing residential options currently available for adults with autism and noted that:

> *"Services in the main are provided by autism-specific and intellectual disability providers but increasingly there are also a number of private, for profit agencies involved in service provision. There are also a large number of adults within intellectual disability services who have a dual diagnosis of autism and intellectual disability*".

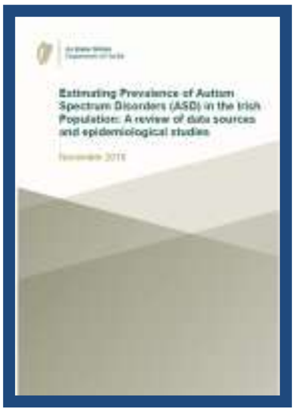
The review went on to note that:

> "(the) *number of new residential placements developed for adults with autism in recent years has been small in comparison to the number of places developed for adults with learning disabilities and has not kept pace with the emerging needs for this client group*". It further stated that "*The future development of residential services for adults on the autistic spectrum must take cognisance of the (Time to Move On from) Congregated Settings Report 2012."*

🖱 https://www.hse.ie/eng/services/publications/disability/autismservices.html

Estimating prevalence of Autism Spectrum Disorder (ASD) in the Irish Population: A review of data sources and epidemiological studies

In December 2018, the Department of Health published the research report *"Estimating prevalence of Autism Spectrum Disorder (ASD) in the Irish Population: A review of data sources and epidemiological studies*". The report found the prevalence of autism has increased in the last twenty years, but concludes that uncertainty remains about the true prevalence of autism globally. Drawing on a variety of sources, the paper concludes that there is a robust case for estimating a prevalence rate of autism in children of 1-1.5% for the purposes of planning policy and developing services in Ireland. This is similar to prevalence rates recently reported in other countries.



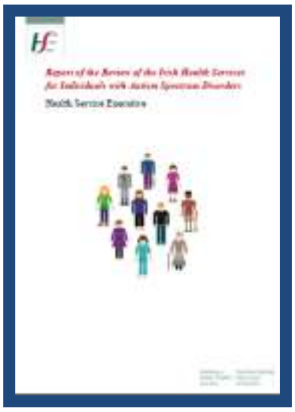
Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies

🖱 https://health.gov.ie/wp-content/uploads/2018/12/ASD-Report-Final-19112018-For-publication.pdf

Review of the Irish Health Services for Individuals with Autism Spectrum Disorders

This review undertaken by the HSE examines the operational effectiveness of the current services in addressing the particular needs of those with autism spectrum disorder (ASD) and seeks to identify models of good practice. The review gathered information on current service provision from service users, families, partner agencies and HSE staff and extracted key themes for consideration.

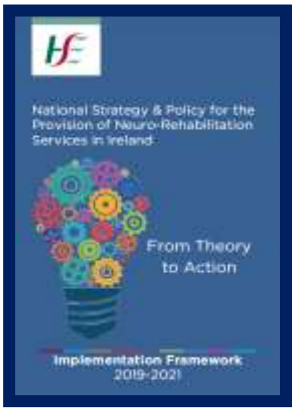
The Report makes 10 key recommendations with further sub-recommendations. The key recommendations and the sub-recommendations relevant to this review are noted below:



1. Engagement and collaborative working where all services work together with service users to meet their needs:
   1.4 Service users need easy access to various services where they can move in and out depending on their needs... Primary care services and more specialist services should provide shared care/services dependent on the unique needs of the service user.
2. Clear and functioning pathways to services
3. Tiered approach to assessment
4. Effective performance management / governance structures
5. Development of Adult services:
   5.2 Adults with ASD should be able to access the full range of health services available to all. Access to counselling and mental health services in particular need consideration.
6. ASD Specific Training
7. Communication, Information, and Awareness
8. Evidence-based interventions
9. Supporting service users / families
10. Research programme
    10.2 … *Research the outcomes of particular service provision models for individuals with ASD.*

https://health.gov.ie/wp-content/uploads/2018/12/HSE-Report-of-the-Review-of-the-Irish-Health-Services-for-Individuals-with-Autism-Spectrum-Disorders-07.02.18-DG-Ref-449142.pdf

Neuro-Rehabilitation Strategy and Policy From Theory to Action



National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland

From Theory to Action

Implementation Framework 2019-2021

The National Strategy & Policy for the Provision of Neuro-Rehabilitation Services was launched in 2011. This strategy noted that neuro-rehabilitation services are underdeveloped and those that exist have been developed in an ad hoc manner, primarily by the voluntary sector. Where services have been developed by the statutory health system, the focus of provision has been on medical rehabilitation, which, while most important, is not comprehensive and many of the existing services and service structures are condition-specific with access to some also determined by reference to age.

In 2019 the *National Strategy & Policy for the Provision of Neuro-Rehabilitation Services: From Theory to Action Implementation Framework 2019-2021* was published. The focus of the neuro-rehabilitation strategy is on achieving best outcomes for people, by providing safe, high quality, person -centred care at the lowest appropriate level of complexity. This must be integrated across the care pathway, and provided as close to home as possible and only in specialist centres where necessary.

A National Steering Group (NSG) is in place and an implementation framework has been developed which is being led jointly by the HSE through the Disabilities Strategy and Planning Team and the Clinical Programme & Strategy Division.

The NSG have adopted the 10-step framework as prescribed by the HSE's Integrated Care Programme for Older People. This is a scientific data based approach which includes a population needs assessment and an analysis of gaps in current services in line with benchmarked best practice. It will also support the development of acute, inpatient and specialist community services through:

- The development of local implementation teams,
- The development/enhancement of neuro-rehab services at each level of the network,
- The configuration of services into a Managed Clinical Rehabilitation Network Model (MCRN),
- Governance structures including overall leadership and accountability,
- Involvement of all stakeholders on the local implementation teams and in the implementation process, including service users.

The main premise underpinning all rehabilitation service delivery in the Model of Care is:

- Person centred approach to patient care,
- Development of appropriately resourced interdisciplinary inpatient, outpatient and community based specialist rehabilitation teams across Ireland supported by education and training,
- Case management of patients,
- Managed Clinical Rehabilitation Networks (MCRN).

The MCRN is a new concept within the Irish healthcare system and in order to assess the feasibility of such a model, the NSG made the decision to pursue a demonstration project in specific CHO Areas so that the learning from introducing such a system could be applied nationally. The demonstration project will see the development of inpatient and community based neuro-rehabilitation services across CHO 6 & 7.

It is recognised that continued investment in and development of neuro-rehabilitation services will need to be prioritised in order to address the significant lack of capacity within existing services.

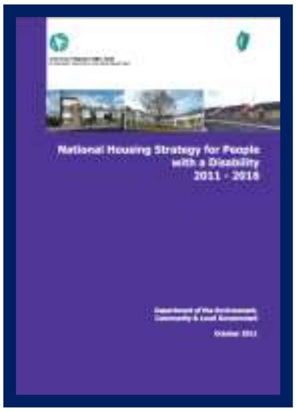
http://health.gov.ie/wp-content/uploads/2014/03/NeuroRehab_Services1.pdf

National Housing Strategy for People with a Disability

The Government's National Housing Strategy for People with a Disability was published in October 2011 by the Department of the Environment, Community & Local Government and the Department of Health. The vision set out in the National Housing Strategy for People with Disability 2011 – 2016 is to:

> *facilitate access, for people with disabilities, to the appropriate range of housing and related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living*

The Strategy was re-affirmed in the Action Plan for Housing and has been extended to 2020 in order to support on-going deliver on its aims.



Housing Options for Our Ageing Population: Policy Statement

Developed jointly by the Department of Housing, Planning and Local Government and the Department of Health this policy statement acknowledges that Ireland's population is living longer than ever before, that the r older population is consistently growing in size and that as people age, their housing needs are likely to change.

A key principle underpinning the Government policy is:

> *"To support older people to live in their own home with dignity and independence for as long as possible. The aim is to ensure that older people will have greater choice by developing a range of housing options that are suited to their needs, so they can plan ahead and, insofar as possible, choose the right home for them"*

And

> *"Varying levels of support will be needed to enable older people to continue living in their own homes and communities, including meeting health & social care needs where appropriate. Older people are not a homogenous group and this policy statement recognises the diversity and uniqueness of individuals."*

The policy statement identifies a framework for Government to facilitate a variety of housing options including housing with care /supported housing for older people.

There are six principles outlined to inform strategic thinking and practical planning in housing options:

1. Ageing in Place
2. Supporting Urban Renewal
3. Promoting Sustainable Lifetime Housing
4. Using Assistive Technology
5. Staying Socially Connected
6. Working Together

The policy statement identifies a number of strategic actions aligned to the six principles with solutions that will be delivered by a range of stakeholders. The suite of actions will require significant inter-departmental and agency working and collaboration.

6. Literature Review

A literature review was conducted to gather evidence on best practice in the provision of support for people with disabilities that have significant specialist residential support needs. The review sought evidence on the challenges, outcomes, benefits and recommendations in relation to different models and approaches taken to meet specialised support needs.

This review was undertaken from May to October 2018 and in the main included material available from 2015. In order to capture literature on the different support needs that may require specialist residential support a series of searches were conducted using key words : ageing; dementia; autism; behaviours that challenge; complex medical needs: medical frailty; mental health; palliative care and forensic care. The searches focussed on material that discussed residential provision for people with an intellectual disability /learning disability/ disability and the general population, service user and family engagement, staff management and capacity building. Searches were conducted using Google, Google Scholar, Lenus and Open Athens.

In total over 70 reports, published research papers, articles, grey literature and policy documents from Ireland and other jurisdictions were reviewed. A separate Literature Review report has been drafted which highlights the most relevant articles found and includes a full reference list.

This literature review was not exhaustive and was conducted specifically to support and inform this Review. While the material reviewed is evidentiary, it is not intended to reflect disability policy or the views or opinions of the Group members.

Key Themes from Literature Review

In reviewing all the literature seven key themes emerged which have been captured as the Guiding Principles to underpin the development of services and models of support. It is noteworthy that these themes are equally applicable as principles for the wider disability services as well as those that are focused on supporting people with significant and complex needs.

The themes focus on a person-centred approach, the importance of capacity building, cross sectoral engagement, the need for care pathways and the inclusion of people with disability in national policy developments. These themes underpin the final recommendations of this report.

Key Themes from the Literature Review

Person Centred Care and Engagement: People with disabilities and their carers must be involved and consulted in all decision-making processes related to the provision of, and access to support. Where possible, people should be enabled to "co-produce" plans.

Inclusive National Policies: All policies, plans and strategies that inform how health and social care services are to be delivered must take account of and include services for people with disabilities. Statistical data on the population collected to support planning must include information on people with disabilities. Public consultations undertaken in the development of policies, plans and strategies must be inclusive of people with disabilities.

Provision of and access to community based and mainstream services: People with disabilities should be able to access the support they need on an equal basis to others within their community. To achieve this, community services and supports including primary care services need to be appropriately configured and enhanced to ensure there is sufficient service capacity and expertise to enable people with disabilities to have equitable access on a geographical basis.

Collaborative cross-care group working: Collaborative working across health and social care services must be undertaken to support service development and to improve information sharing and learning. At an operational level, there needs to be collaboration to ensure the interface between different services/teams effectively support people with disabilities regardless of the initial point of contact.

Developing individual support capacity: Enhancing skills & capacity building: Targeted skills training and capacity building is needed to effectively support families, carers and staff. This includes education programmes and /or training in specialist areas such as dementia care and palliative care that is tailored to the individual based on their role and relationship (family member, carer or paid support staff) to the person being supported. There may also be a need to support and build the personal capacity of the person with a disability who has changing needs and/or is sharing their home with someone else whose needs are also changing.

Specialist residential services: Where specialist services are required in a residential setting to meet specific needs, they should be available and accessible. The provision of services at this level should be no longer in duration than is necessary to enable the person to access the specific specialist assessment and/or therapeutic support required in line with their person centred care plan.

Research and new models of service: Flexibility in supports and services is essential. Different models of support need to be tested and there should be piloting of specific projects. Services must be designed to reflect the preferences of people rather than the providers of care.

7. Research Projects

Research Projects

A number of research projects that focus on models of best practice in disability residential services were underway in Ireland whilst this Review was being undertaken. The progress, findings and recommendations of these projects, as noted below has been taken into consideration to inform the recommendation of this review.

IDS – TILDA Wave 3

2017

Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland

IDS-TILDA is a longitudinal study researching ageing in Ireland among people with an intellectual disability aged 40 and over. This study is the first of its kind in Europe, and the only study able to directly compare the ageing of people with intellectual disability with the general ageing population.

The Wave 3 summary report focusses on the main challenges facing an ageing population in Ireland, and where possible, compares the findings of the intellectual disability population to the general population. Some of the findings include:

- *Overall there was an incidence of 4.7% of dementia between Waves 2 and 3 in the total population. Of the people who received a new diagnosis of dementia between Waves 2 and 3, 74% had Down syndrome.*
- *In Wave 3, 35.55% of people with Down syndrome had a doctor's diagnosis of dementia, which rose from 15.6% in Wave 1, and there was further incidence of 22.5% between Waves 2 and 3.*
- *Dementia screening within the last two years rose from 14.5% in Wave 1 to 30.5% in Wave 3 overall and from 13.9% in Wave 1 to 61.4% on people with Down syndrome.*
- *Of those with a diagnosis of dementia in Wave 3 ADL functions declined over the three waves for activities such as dressing, bathing, eating, getting in and out of bed and toileting.*
- *For people with Down syndrome the average age of diagnosis of dementia was 52.3 years compared to 65.5 for those with intellectual disability from other aetiologies.*
- *An approximate incidence rate of 7.5% per year was found for people with Down syndrome compared to an estimated incidence of dementia of 2% for these 60 years and older*
- *For those with Down syndrome, prevalence of epilepsy without dementia was low at 14.5%; however among people with Down syndrome with dementia, the prevalence of epilepsy rose to 54.8%*
- *As expected with an ageing cohort, there was increased health service use since previous waves with increases in particular in emergency department admissions, GP use, outpatient appointments and hospital admissions.*

From institutions to community living for persons with disabilities Fundamental Rights Agency

All personal, civil, political, economic and social rights enjoyed by people within the EU are contained in the Charter of Fundamental Rights of the European Union. The Charter became legally binding across the EU with the entry into force of the Treaty of Lisbon in December 2009. It applies to everyone living in the EU.

The Fundamental Rights Agency (FRA) is the agency is the mandated to deal with the full spectrum of fundamental rights as enshrined in the Charter. It provides comparable data on an important number of fundamental rights issues across Member States.

In June 2014 the FRA commenced a project to look at the right of people with disabilities to live independently and to be included in the community as set out in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Focusing on the process of deinstitutionalisation the objective of the project is to provide evidence-based assistance and expertise to EU institutions and Member States on how to fulfil this right.

The report ‘From institutions to community living for persons with disabilities: perspectives from the ground’ brings together findings from FRA’s fieldwork in Bulgaria, Finland, Ireland, Italy and Slovakia. The three part report published in October 2017 provides insights that can support efforts to make independent living a reality for persons with disabilities. The first and second report highlight the obligations the EU and its Member States have committed to fulfil, and look at how funding and budgeting structures can turn these commitments into reality. The third report assesses to what extent Member States have implemented the right to independent living, focusing on the effect commitments and funds are having on persons with disabilities’ daily lives. Taken together, the reports provide important insights that can support on-going processes of change.

National reports also capture the results from fieldwork countries including Ireland. In relation to aging in particular the Irish Case Study noted that:

“*There is an unresolved policy question around older people with disabilities. Given that Ireland is currently embracing a largely nursing home model of care for older people, that question becomes whether persons with disabilities will be accommodated in mainstream nursing homes, or accommodated in specialised nursing homes for people with disabilities. This is an issue because, as one participant pointed out, people with intellectual disabilities often develop dementia earlier than the general population. This means that people with intellectual disabilities risk being put into nursing homes at a much younger age than is the norm, effectively being ‘re-institutionalised’.*[1]”

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[1] From institutions to community living: drivers and barriers of deinstitutionalisation Case study report: Ireland 2018 FRA European Union Agency for Fundamental Rights

Quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability. An evidence review.

In September 2018 the HRB published, "*Quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability An evidence review*". The purpose of this review was to systematically evaluate the evidence on quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability. The review aimed to answer three research questions:

1. What is the evidence on how deinstitutionalisation for adults with intellectual disability affects quality of life?
2. What is the evidence on how deinstitutionalisation for adults with intellectual disability affects costs?
3. Of the evidence for Questions 1 and 2, what is the evidence on deinstitutionalisation specifically for people who have highly specialised support requirements: people with severe physical and intellectual disability who have complex medical needs (such as people who use ventilators), people who are a forensic risk or who are ex-prisoners, people with dementia, and people with very challenging behaviours?

This review found that there were few studies worthy of inclusion in the systematic review. However the report did conclude:

> *Nevertheless, this evidence review does offer some support for the hypothesis that moving from an institutional residential setting to a community residential setting is associated with improved quality of life for adults with intellectual disability. There is no clear evidence on the cost-effects of residential moves, and few conclusions can be drawn for people who have highly specialised support needs.*

Notably, the review found no studies that explicitly examined people with very complex medical needs (e.g. ventilation requirement), people with dementia, or people who present a forensic risk.

The report recommended that longitudinal studies with "agreed standardised variable and measures" be undertaken with pre-move data and to include "health-related, community participation, and life satisfaction variables". Two studies on costs were included but due to the fact that "very limited information was provided on both the people moving and the size and the environment of their post -move residences". This precluded any "substantive policy recommendations" being made. The report concluded that:

> *Comparison of cost-effects requires measurement from the broadest possible perspective, incorporating both formal (residential, health and social care, out-of-pocket costs) and informal (unpaid carer) cost domains in ways that illuminate the relationships between specific types of residential settings and associated utilisation*.

A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome

A longitudinal study undertaken by Trinity College Dublin *"A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome*" on dementia in adults with Down syndrome in Ireland has found very high prevalence rates, significantly earlier onset than in the general population and high risk rates for dementia for people with Down syndrome.

The study followed 77 women with Down syndrome over the age of 35 years who were enrolled and screened in 1996 and then assessed for symptoms of dementia on an annual basis until death.

It found that 97.4% of the women assessed developed dementia over the 20-year period. In the general population, the estimated prevalence rates are 5-7% in people aged 65 years and over. It also found that the risk of developing dementia in people with Down syndrome is 23.4% at age 50, 45% by age 55 and 88% by the age of 65 - significantly higher than in the general population, which is between 4.3% and 8.6% in people aged 65 years and older. The study found the average length of survival after developing dementia was 7 years, with some people living with dementia for 20 years. It was previously thought that people with Down syndrome lived between 3-5 years.

"Moving In" Study

Commissioned under the Transforming Lives Programme the National Disability Authority is co-ordinating a large scale study which is exploring the quality of life outcomes and costs associated with the move to models of service that are community based and person centred, called the "Moving In" Study. As part of this study around 150 people, living in congregated settings are being interviewed before and (6-9 months) after they move to the community.

The commentary below has been provided by the National Disability Authority in relation to the progress and findings of the study to date:

While the progress of the decongregation process has been slower than anticipated, a number of moves have taken place, and post-transition interviewing is underway. These interviews have provided some very interesting information, and while we can't yet assume that these findings will hold true for everyone who moves out of congregated settings to the community, for the most part the outcomes have been positive. Many participants have significant communication and/or cognitive deficits and so interviews were conducted with the support of staff or by proxy.

The majority of those who have transitioned to the community so far have high support needs. Most of the participants lived in congregated settings for many years before their move to the community-

many for decades and several for over 50 years. Two of those included in our post-transition interviews were aged 78 and several others were in their 70s.

The post-transition interviews conducted to date provide evidence of significant and at times transformative changes in quality of life following the move to the community. Community integration has greatly increased, family contact is being promoted, and challenging behaviours have reduced with a resultant reduction in medication for some participants.

Many of the staff members we encountered on our visits commented on the ease of the transition process. In one residence we were told that before the move staff in the congregated setting commonly expressed the view that the transition would fail and that the residents would return within a week. In fact, staff reported that to their surprise the residents settled in their new home from the first day and the positive changes in their behaviour have exceeded all expectations. A staff member in one house noted that a psychiatrist described the changes in behaviour of one individual as so fundamental that it was like treating two different people. In another house the example of a resident going to a shop and picking a pair of shoes for himself was given to illustrate the improvement in this man's behaviour- previously staff would have considered it unsafe to bring this man shopping.

The participants now live in environments which are quieter, calmer and safer than before. Many have transitioned from locked units and some from dormitory style accommodation. The noise level is lower because there are fewer people and because in many cases challenging behaviours have reduced. They now have their own bedrooms and live in a home with usually 3 other persons. Bedrooms provide residents with privacy - a space of their own where they can rest, display family photographs and other personal mementoes.

Although some of those who have moved to the community are physically frail many are robust and healthy. These participants now have more opportunities to engage in physical exercise. We heard accounts of a range of physical activities such as hill walking, horse-riding, long walks on beaches and swimming. Staff attributes better sleep patterns and reduced restlessness and challenging behaviours to the increased physical activity.

Since their move to the community some participants continue to attend day centres within the campus where they previously lived. Others only return to the campus on rare occasions or not at all. The move to the community has promoted social integration as participants now access community based services and activities to a far greater extent than in the past. The community activities reported include going to local pubs and coffee shops, attending GAA matches, hill-walking with a local group, as well as sporting activities such as swimming and horse-riding.

In many instances staff report increased family contact since the moves have taken place. Families find it easier to visit in the less crowded, quieter, more homely surroundings. Staff have actively sought to strengthen family bonds. This can be especially difficult when people have spent decades in institutional care and when parents are deceased, but in one case the occasion of the participant's

60th birthday was used to re-establish contact with family members and has resulted in now on-going contact with siblings. This type of reconnection has been seen in a number of cases in the study.

Overall, the results to date indicate very positive improvements in quality of life for those who have made the move to the community. The results indicate that on-going study of outcomes for those who transition from congregated settings is merited.

The situation of younger people with disabilities living in nursing homes in Ireland - phase 1


The situation of younger people with disabilities living in nursing homes in Ireland - phase 1

DCU

The Time to Move on from Congregated Settings: A Strategy for Community Inclusion report recommended that further work was required to review the placement of people with disabilities in nursing homes. The report specifically recommended that a review should be undertaken to identify actions needed to ensure that residents with disabilities can access the same levels of community-based support and inclusion that were proposed by the Working Group for residents of congregated settings.

Following a review of placements in the Bray area the Disability Federation of Ireland commissioned further national research on this matter. This study sought to focus on the placement of younger people with disabilities (aged between 18 and 65) in nursing homes which are generally considered as places for the care of older people, noting that "*close to 1,500 younger people with disabilities are currently residing in nursing homes in Ireland in part because community supports are not sufficient*."

The research was limited as access to the relevant data on all people with a disability in nursing homes was not possible feasible due to resource constraints. On this basis the study progressed with a review of 48 Common Summary Assessment Reports (CSAR) in one geographical area. The CSAR is the standardised national medical assessment form for the Nursing Home Support Scheme (NHSS).

The report noted that "*A range of factors are contributing to the placement of younger people with disabilities into nursing homes*". The report found that many of the younger people have high and complex care needs with some needing 24 hour care and supervision. Other factors noted included "*high levels of co-morbidity… high levels of polypharmacy… high risk of pressure ulcers, falls, malnutrition and risk of wandering* " *and* "*seven younger people …had severe and enduring mental health problems*" In discussing the findings the report draws on literature to explore the factors contributing to the referral of younger people into nursing homes. The authors note that "*this review of CSAR forms shows little evidence from the assessment process is underpinned by an independent living/person-centred perspective. The structure of the CSAR form does little to facilitate such an approach*"

The report in its conclusions notes that based on the small sample the "*results cannot be generalised beyond the specific population from which the sample was drawn*" and notes that the information collected in completing the CSAR forms "*embody a rehabilitative / medical perspective".*

The report makes a number of recommendations on policy, practice and research which include:

> *The Government should support efforts to reduce the number of younger people placed in nursing homes, including through the development of alternative models of care, such as the provision of a range of purpose built residential services, providing high quality and individually tailored person-centred care and support; and revision of the funding arrangements so that funding follows the person and not the place.*
>
> *There is an urgent need to move towards a person-centred approach to assessment and care planning, whereby younger people with disabilities are given every opportunity to explore their skills and strengths and have an opportunity to contribute in a meaningful way to decisions about their goals and aspirations and where they wish to live.*
>
> *Where the person has stated a clear preference for care in the community, there should be a commitment by all staff involved in this person's care to exhaust all possibilities before nursing home care is considered.*

A second phase of this study is scheduled to explore the experiences of younger people with disabilities with regard to their transfer to nursing homes as well as the experiences of staff involved in making and reviewing the referrals.

8. Consultation and Engagement

To support and inform the work of the review a series of meetings and consultations were organised. These included meetings with families, leaders and experts in the provision of specialist services, national policy leaders, service providers, CHO Disability Service teams and a number of site visits.

Family Focus Groups

Inclusion Ireland through the Connect Family Network are committed to supporting local family support groups to engage with the HSE and service providers in the planning, design and review of disability policy or programmes. The Connect Family Network gives local support groups a voice into policy and legislative formation at national level through discussion and consultation.

Two Connect Family Network focus groups were arranged to give family members an opportunity to engage in this review. The groups were facilitated by Inclusion Ireland and a semi-structured approach was taken with five set questions posed to the groups.

The participant's views were sought on the provision of services and their lived experience in relation to residential supports for family members with complex and significant support needs. Participants were also invited to give their views on this review process to ensure it was fully inclusive. A report and summary findings were produced following both meetings.

The main points raised at the consultations were:

- The key to the success and effectiveness of a community residential service is good leadership and a consequent good culture in the service, a top down quality service
- Generic medical or therapy services in the community, in the experience of family members, can meet complex and significant needs but other community/generic services (e.g. nursing homes) lack the resources, skills and experience to address the needs of individuals with disability with complex and significant support needs.
- Family members believe that community based residential services can succeed with sufficient and skilled staff. Such services need to be specifically disability services, with the skill mix and resources that entails, rather than generic or mainstream services, in order to meet the needs of those with complex and significant needs.
- Access to community and specialist supports and properly planned funding should be informed by continuing individual assessment and effective long-term planning for the person with significant and complex needs

The full Focus Group Reports are available in Appendix 1.

Engagement with Experts

The review group engaged with a number of leaders and experts working in specialist disability services field in Ireland, to gather their views and opinions. Through a series of meetings and site visits, members of the group met with representatives from:

- IDS-TILDA team ,Trinity College Dublin (TCD)
- Chair of Ageing and Intellectual Disability ,TCD
- Laura Lynn Foundation
- COPE Foundation
- Daughters of Charity Services , Dublin
- Positive Futures
- Gheel Autism Services

In addition to this the opportunity was also taken to gather the views of the leaders and the transition teams working in congregated settings sites. This was possible through the on-going schedule of site visits, Service Reform Fund project meetings and other collaborative work on-going during the course of this review. The services involved in this included:

- Brothers of Charity, Galway
- Daughters of Charity Limerick & Roscrea
- HSE Cork Kerry, Cluan Fhionnain
- HSE Cork Kerry, St Raphaels Centre
- HSE Cork Kerry, Youghal & West Waterford Community
- HSE Mayo, Aras Attracta
- HSE Sligo, Cregg and Cloonamahon
- HSE Wexford, Residential IDS
- Muiriosa Foundation
- St John of God Service, Drumcar
- St Patricks Centre, Kilkenny
- St Margaret's Centre

It was found that the view of the experts and other stakeholders consulted were in keeping with the Guiding Principles developed from the Literature Review.

However the engagements also highlighted that opinions differ amongst the experts, leaders and managers in terms of when a specialist residential service is appropriate. The review group concluded that these differences of opinion arise as each person's view is uniquely informed by their work experience; training and professional background as well as being influenced by organisational culture and ethos.

Engagement with HSE CHO Disability Teams /Service Providers

The review group met and engaged with HSE Disability Service Teams and service providers as part of the consultation process. Due to time constraints this consultation process was limited. There was direct engagement with three Areas where there service configurations are substantially different, in order to capture different perspectives. The engagements included a combination of face-to-face meetings, telephone calls and written submissions.

Consultation meetings were arranged through the General Managers for Disabilities, who identified and invited the key stakeholders in their CHO Area. The meetings were semi-structured with a number of set questions posed in order to capture the views of the group on particular issues. The meetings provided the opportunity for the service providers and HSE teams to engage and discuss current and future policy implementation, in relation to the provision of residential services and support for people with disabilities who have specialist support needs.

The discussions examined the current practice in each of the Areas and identified the challenges, opportunities, advantages and difficulties with the current model of service delivery. The engagements focussed on what is working well, service gaps and what the CHO teams and service providers believe is needed to support people with significant specialist support needs.

There were a number of common points and concerns that emerged from the engagements, as follows:

- There needs to be access to ‘generic’ community services particularly for people with an intellectual disability – a shared care approach is required between disability services, older persons and primary care
- There is a lack of availability of funding to develop multi-disciplinary therapeutic supports to support people in the community
- There is a lack of services for people who require psychiatric inputs and access to inpatient psychiatric services
- There needs to be a recognised pathway to support ageing in place / positive ageing strategies for people with an intellectual disability
- There is an unmet requirement for residential supports for people with an intellectual disability
- The appropriateness/suitability and availability of housing are all impacting on the delivery of services
- The current approach is inequitable. As services are not demand-led and are limited by budgets, with no capped ‘cost of care’ or ‘cost-band’ approach, high cost placements can be a significant draw on limited resources.

Full details of the meetings and discussions undertaken, the structured questions and the submissions made to the Review Group are included in Appendix 2.

Summary of the viewpoints gathered from the engagement with families, service providers, CHO teams and experts

Strategy to Drive Change (Decongregation): It is necessary to strategically plan and drive the move to community based services

- Supporting the development of individualised packages that enable individuals to remain within their communities, either in the family home or a person's own home.
- Move away from specialist or condition-specific residential services in favour of individual support packages and models of service that can fully support a person centred approach.

Develop Supports in the Community: There needs to be a focus on developing service responses and interventions to support people and their carers to enable them to remain in their community

- Adopt a model of care that supports families and the children (and young adults) with life limiting conditions to live at home or within their community with support
- Provision of palliative care and support for those with life-limiting conditions and their families and carers

Addressing Challenges: There are challenges to designing and delivering person centred supports for individuals and their families

A number of real-life challenges that influence best practice in supporting people with significant residential support needs were highlighted as follows:

- Staff pressures: developing and maintaining specialist skill sets amongst staff
- Family and stakeholder expectations
- Competing and conflicting demands: supporting aging in place versus impact on others in a house
- Accessing diagnostic services to enable early intervention, planning and supports for changing needs
- Current accommodation and access to housing
- Access to other relevant non-disability support services to enable a person to live well in the community
- Lack of multi-annual funding: on-going revenue and capital resources to build capacity
- De-bundling of financial supports for individuals and funding for changing needs
- Safeguarding priorities

Planning for Changing Need: There is a need to plan for and support those with changing needs.

There are different views /options as to how this should be achieved:

- Need to identify and develop emerging models of service to meet changing needs
- The need to plan for changing needs to facilitate people to "move back" to a higher support model of care engagement with those leading out on the implementation of relevant national policies

A series of meetings and engagements took place with the teams leading out on the implementation of a number of relevant key national policies. The purpose of these engagements was to: gather information on any work being advanced that is relevant to people with disabilities; to raise awareness of the support needs of people with disabilities to ensure they are recognised equitably under the other strategies; to drive collaboration and ensure that disability strategy is not working at cross purposes with other strategies.

Meetings were held with:

- National Dementia Office team
- Lead for Palliative Care
- Lead for Neuro Rehabilitation Strategy in disabilities
- Mental Health of Intellectual Disability team

Synopsis of the outcome of the engagements

The engagements confirmed that work is on-going in policy implementation elsewhere in the healthcare system to develop service models in response to specific support needs. The engagements highlighted that there are common challenges around resourcing programmes and implementing large scale change projects, with the result that progress is slow. In general, addressing the support needs of people with disabilities had not featured highly on the agenda for the teams when we initially contacted them. However, from the engagement process, there was a clear willingness to engage with the disability sector and ensure this population are appropriately and equitable supported and that there is an alignment of policy and inclusive models of service.

These engagements highlighted that whilst this review is focussed on driving best practice for the people moving from congregated settings, there is also a need for on-going collaboration that considers the implications of these policies across the wider disability population including the people who are engaged with disability service providers and those who are living at home with no disability-specific supports.

The engagement papers and outcome of the engagement are detailed in Appendix 3.

Site Visits

A number of visits took place to residential services that are currently supporting people with significant specialist needs. The range of settings visited included both congregated and non-congregated locations. Some of the congregated settings visited were actively decongregating, whilst others were not engaging in the process. All the non-congregated locations visited are supporting people that have moved from congregated settings, some who moved many years ago and others who transitioned quite recently.

The purpose of these visits was to engage with the providers to understand in detail the model of service in place, to gather their views on the appropriateness and sustainability of the current services and/or proposed model of services, to identify the specific challenges faced and/or overcome in delivering supports. Information was also gathered about the plan for these services going forward in light of current disability policy and the demand for support. The sites visited included:

Congregated settings:

- HSE Cregg House, Dementia Specific Unit
- Ashville, COPE Foundation (unit for those with ID and medically complex needs)
- Knockmann and other units on St Ita's campus, Portrane (MHID services)
- Laura Lynn, Sandyford (units for those with life limiting conditions and medically complex needs)
- Shalom, Carriglea Cairdre Services, Waterford (unit for those with ID & Challenging Behaviour/Complex needs)
- St Brid's, Peamount Healthcare (neurological unit)
- St Joseph's Centre, Daughters of Charity, Dublin (ID & Dementia Care specific units)
- St Vincent's Centre, Daughters of Charity, Dublin (units for those with ID & medically complex needs)
- The Cottages, Cork Association for Autism (ID & Autism specific service)

Non-congregated settings:

Visits also took place to a number of community based homes where people with challenging behaviour, complex medical needs and significant physical and intellectual disabilities are now living.

Summary of the key findings from the site visits

Access Criteria & Admissions Policies

- Access to high quality specialist residential support services has to be equitable and needs-driven. To enable this, services need to be identified and/or developed to facilitate equitable access on a geographical catchment area basis.
- Where a location/ home is purposefully designed and resourced to meet the needs of those with significant specialist support needs, this needs to be identified in the Statement of Purpose and supported by a robust admission policy.
- The policies in place must support best practice, so that every admission to a home providing specialist support is needs- based and clearly aligned to the person's PCP.

Home Design & Location

- A well-designed home can maximise a person's ability to carry out activities and live well at home. There are examples of homes/units that have been adapted/designed to support the changing needs of people.
- A particular issue that can arise is how the equipment and specialised furniture required for a resident can be accommodated, whilst endeavouring to maintain an "ordinary home" environment.

Outreach Supports & Respite

- Meeting the needs of those with significant specialist support needs /life limiting conditions in the community can be achieved through a model of support that includes respite, outreach and therapeutic support, palliative/medical care.
- Consideration needs to be given to enhancing the provision of outreach support and respite services to ensure there is adequate support available
- Access to respite, outreach and therapeutic support, palliative/medical care should be allocated on the basis of a standard assessment of need.

Quality of Life

- There is evidence of improvements in the quality of life for people with significant needs who move to community. There are many factors impacting this but consistently benefits arise from:
  - A staff to resident ratio that enables people to participate in activities of their choice,
  - A better living environment and
  - An increase in family engagement and time spent with friends.
- A person centred approach delivered in a smaller setting ensures and supports that
  - Individual preferences and support needs are more visible and can therefore be addressed. This leads to positive quality of life outcomes for individual residents.
  - There is a reduction in incompatibility issues.

Person-Centredness & Personal Outcomes

- Services face very significant challenges when trying to support people to "age in place" in accommodation that is shared and /or no longer meeting the person's individual needs.
- At times there can be a conflict of interest when individuals are living together in a residential service and one person's needs change. This can impact on the others living in the home either because of the nature of the changing needs (behaviours that challenge etc.) or because this leads to of changes in the service response (i.e. increased /changing staff supports)

Impact of setting location on community inclusion

- Residential services that are purposefully developed to support individuals with significant specialist support needs should ideally be in locations that enable all existing community inclusion and connectivity with personal networks to be maintained as well as providing new opportunities for community inclusion.
- In a number of exceptional cases, where a unit in the congregated setting is so well positioned and suitably configured, it is feasible to create a sustainable stand-alone home in that location that will support meaningful community integration, whilst the closure of the setting/campus is still progressed.
- The change in setting is often a significant factor that leads to greater involvement of family and friends. Visitors feel more at ease calling to a person in their own home.
- For some residents, there is little evidence to date that the move to community has offered them any greater or more meaningful community inclusion. Where a person has significant specialist support needs the capacity for the person to get involved or engage with community can be limited.
- The harsh reality has been that some neighbours and local community or resident groups do not always welcome people with disabilities moving into the area.

Staffing and Governance

- Maintaining a team of skilled staff in dispersed community services can be challenging. This requires on-going role negotiation, flexibility, strong leadership and support.
- Robust governance structures are needed when services are community based to ensure and safeguard that the needs of people with significant specialist support needs are being appropriately met.
- Consideration needs to be given to the skill mix of staff and the up skilling, training and on-going capacity building of support staff, carers and service users to enable the best outcomes for the person with a disability who has significant specialist support needs.

Sustainability & Affordability

- Services are demonstrating that they can meet the significant specialist support needs of people with disabilities in the community and that services can respond to changing needs in place.
- The smaller settings delivering person centred models of care potentially offer greater stability for individual residents as they reduce the likelihood of incompatibility and safeguarding issues that can arise in larger settings.
- Smaller settings may not deliver the “economy of scale” savings seen in larger settings. However working in smaller settings is more person-centred and enables the support needs of each person to be more easily identified and addressed, which can prevent the need for an escalation in the level of support.
- There is capital funding required to fund equipment to support the cost of developing, adapting and maintaining appropriate quality dispersed housing. This is a particular challenge in the current housing environment when there is a lack of suitable housing. At the same time it is acknowledged that upgrade works to congregated settings in order to achieve regulatory compliance represents poor value for money

9. Examples of current good practice within community based residential services

There are over 80 agencies providing residential services, all with their own unique identity, culture and ethos, many of which operate in specific geographical areas only. As a result practice on the ground varies. Below an overview of current practice and a number of case studies are featured that demonstrate good practice approaches in supporting people with disabilities with significant residential support needs.

Current Practice: Changing needs & Dementia care

Overall disability service providers are striving to support "ageing in place" within community settings, whether that is within a person's own or family home or in a community based residential service. However, across the services and disability teams, there are differing opinions on the most appropriate pathway and model of care to meet the changing needs of people with disabilities. On the ground, the pathway and model of service are dependent on funding, resource allocation approaches, service configuration etc.

Some providers take a "cradle to grave" approach, so that when a person's needs change over time, they strive to continue to provide the support needed. This may be an "ageing in place" approach or a person may be accommodated in another part of the service , through internal transfer to "older persons" unit or units for individuals specifically developed to meet dementia care needs, medical needs etc. Other providers support residents to access generic older persons services such as nursing homes, once a person's age-related needs overtake their disability support needs.

In summary, the provision of residential support for people with changing needs tends to fall into the following groupings:

- The person is supported to remain in their current residential home with the supports required
- Individuals are supported and facilitated to move to an alternate home in the community once their needs change and can no longer be met in their current arrangement
- Individuals are supported and facilitated to move to a disability specialist residential service once their needs change and can no longer be met in their current arrangement. This may be on a campus or in larger unit settings
- Individuals are supported and facilitated to move to generic older persons residential service once their needs change and can no longer be met in their current arrangement.

Case Study: Dementia Care

Born in 1969 into a loving family, Mary was diagnosed with Downs's Syndrome. Her parents and family were very proactive in ensuring that Mary was encouraged to do as much for herself and was very active within her local community. She attended a day service 5 days per week and was bubbly, energetic and her mischievous smile endeared her to all.

In 2010 Mary's life changed. Her elderly widowed mother was no longer able to care for her due to failing health. Mary moved in to a community home, which she shared with four other residents. Her mother passed away shortly after her admission, followed by the death of her brother in 2013. Mary transferred to her new home in 2014, a four bedded bungalow, where she continues to happily share with three other people. Her home is situated within very close proximity to her childhood home.

Mary had been offered baseline dementia screening prior to her admission. During routine follow up assessment in 2014 some changes in her behaviour and a decline in test scores was noted. Mary was supported with a robust review of her behaviour and a behaviour support plan was developed. She was referred to her G.P for a physical work up, in addition to completing assessments of vision and hearing.

Recognising the losses in Mary's life she was offered a mental health review and was subsequently diagnosed with mild depressive episode and unresolved grief. She availed of support from a member of our pastoral care team and commenced on an anti-depressant. Parallel to this support Mary's family were encouraged to engage with her and maintain family links and ties. Staff supported her to develop her life story, which provided an insight into the life that she had lived before entering residential care, which highlighted the importance of being continually included in the decisions concerning her life.

After completing a rigorous differential diagnosis process, Mary was diagnosed with Alzheimer's type dementia following a dementia consensus meeting in 2016. She was informed of her dementia diagnosis and commenced a cholinesterase inhibitor. In the months following her diagnosis, Mary's mood and demeanour changed, she experienced a range of medical conditions, which were treated, was assessed by members of the local MDT and a range of programmes, plans and support were put in place. Over time and after careful consideration and review of her wishes, she was supported to retire from her day service in 2016.

Nearly three years on from diagnosis Mary is thriving and is happy again. Her dementia progression has meant that she now requires more staff support during the day and at night; the additional support ensures that she has flexibility in her routine if/when she requires it. The staff team is consistent, educated in dementia care and experienced in anticipating and addressing her needs. They plan everything with Mary and include her in all the goals and decisions that concern her. When last reviewed by our CNS Dementia, she was bubbly, energetic and her mischievous smile shone brightly. As she recently declared in her own words 'I'm living my best life'.

Note – The names of the people in our case studies are not their real names

Current Practice: Palliative Care

In most cases people with disabilities in a residential setting that require palliative care are supported in place by the disability service provider in their existing residential placement who may also be supported by the specialist palliative care services. There was good evidence gathered during the review of effective collaborative working between the disability services and palliative care teams to support people in their homes. There were a small number of people admitted from community residential services to congregated settings for active end of life care and due to their support needs it is likely that these individuals would have eventually been transferred to a palliative care unit if a placement in the disability service was not available.

Case Study: Palliative Care

Pat transitioned to our community house in the spring of 2017. He had a diagnosis of Dementia and was presenting as being in mid stage of the disease. As Pat had a right to be respected and treated throughout the trajectory of the disease as appropriate, not just when it is obvious the end is near and in line with our views and practice that Dementia is a life limiting disease, we made a referral via his GP for Specialist Palliative Care.

In December 2017, Pat began experiencing seizure activity, a new event secondary to Dementia, and he was prescribed anti epilepsy medication by his GP. By January 2018 the impact of his seizure activity on his mobility resulted in him requiring a hoist for transfers, and, a second waking staff member was secured for the house at night. During February 2018, mindful of guidance (Medical Council, HIQA) recommending that End of Life planning should commence if death in 12 months would not be unexpected, in conjunction with Pat, his family and the wider MDT; and in consultation with Specialist Palliative Care staff, an End of Life plan for Pat was developed and agreed.

Throughout this time the nursing team in the house carried out palliative care needs assessments, managed symptoms and all of these tasks were managed independently, with advice if needed from Specialist Palliative Care who called depending on Pat's condition, including increasing rescue medication. Pat died peacefully at home in March 2019 (RIP).

While supporting Pat staff identified subtle changes in the presentation of one of his housemates, Mike who was subsequently diagnosed with a complex brain tumour. Conservation treatment and pain management was the agreed and appropriate plan of care; Mike also had additional medical requirements in situ and required exceptional daily assessments of need. Mike predeceased Pat and passed away at home in February 2019 (RIP).

In response to changing needs of the resident group in the house, and to support them to age in place, additional staffing was required. The service supported staff to build capacities and upskilled by undertakiung palliative care trianing. The collaboration between the disability service and specialist palliative care nurses clearly represents best practice.

Note – The names of the people in our case studies are not their real names

The review group noted that some of the residents living in the congregated settings are not being actively supported to transition to community as their age related care needs are changing and the services are anticipating they will soon require palliative/end of life care . Once these residents pass away, there will be no further admissions or backfilling of vacancies and these services will continue the process of decongregating these settings. There needs to be on-going collaboration to ensure the future requirement for palliative care services of those that have moved from the congregated settings, those already living in community residences and those who are still living at home will be met.

Case Study : Ageing with a disability and high support needs

Anne was born in a Gaeltacht and lived there with mother, father and uncle for almost thirty five years. Anne never left home during the time she lived in her family home – she did not attend school, never went outside the house, and her first and only language was Irish. Sadly, Anne's mother passed away in 1994. Shortly after this, Anne's father was admitted to a Nursing Home. Anne was admitted to a Campus based Service to an over-crowded bungalow living with nine other individuals with I.D. and high support needs.

The staff team in the campus based service began to reconnect Anne with family and friends in the Gaeltacht. In 2007, an opportunity arose for Anne to move back to the Gaeltacht. This was supported by the team in both service areas as Anne's father had transferred to a nursing home near to her new residential home. Anne's circle of support had begun to develop and grow.

She settled in very well to her new surroundings. Staff could immediately see the changes in her, the fun-loving person who loved the Irish Language and Irish songs showed signs of being much happier. It was so unfortunate for Anne that bowel cancer then developed. The mainly non-nursing staff team all wanted to help her and were up-skilled to support her with a colostomy as there was only one staff nurse in the geographical area. All of this was done in a very person centred manner with the acute service and community services coming together to support Anne.

Before Anne turned 50 she was diagnosed with dementia. The condition resulted in Anne becoming immobile and staff requiring new skills to support her remain at home. This included training on epilepsy awareness, safe administration of medication and peg care. Catheter care was provided by nurses in the service. The individual support package developed and delivered to Anne was of the highest standard.

Towards the end of Anne's life in 2017, the local GP, PHN, and palliative care team from the hospice all worked collaboratively with the service to ensure the most dignified death at home. Anne's funeral was attended by a wide circle of family and friends who had been able to reconnect with her in the last 10 years of life.

Note – The names of the people in our case studies are not their real names

Current Practice: Medically complex individuals with intellectual disabilities

It is recognised that every person with complex medical needs and intellectual disabilities can be supported effectively in the community setting once the appropriate supports are in place. The challenge in this regard can be the need for: the up-skilling of care staff; the requirement for nursing interventions or a different staff skill mix; the provision of specialised equipment; medication management and administration practices; increased levels of support; and access to additional or enhanced therapies to maintain wellbeing. Several service support people with complex medical needs and/ or an intellectual disability to be supported effectively in small-scale residential services in the community. More recently, several providers have supported a number of people with complex medical needs and an intellectual disability to transition from congregated settings to new community based arrangements.

These arrangements can be viewed as high cost and high support, but it is important to note that regardless of the setting, the level of support to meet the needs will be significant. Where these services have been developed in the community, facilitating residents with different support needs to live together, can be an effective way to ensure staff resources and space are used effectively within the home, once the individuals are compatible. The greatest challenge for many of the services seeking to support people with complex needs in the community is addressing the equipment and accommodation needs in the home initially. Once this has been addressed, the longer term challenge can be around enabling community inclusion.

Case Study : Younger Adult with medical and palliative support needs

Denis is a 22 year old male with a diagnosis of Cerebral Palsy, Spastic Quadriplegia, Severe Scoliosis, epilepsy and is under the care of the Palliative team. He lived at home until he was 12 years old, he them moved into a congregated setting following a hospital admission and due to complex medical needs and requiring nursing care.

In March 2018 Denis moved from the congregated setting to a new purpose built bungalow in the local community. Prior to the move and with input from Occupational Therapist it was established that some adaptions would be required to meet his needs. This included a profiling bed, oxygen condensers, a wheelchair bus (for the house) and a tracking hoist system. Denis was registered with a local GP in close proximity to his new home and he continued to access the same pharmacy service. Due to his complex medical needs and the needs of the other people in the home there is 24 hour nursing support, and support from care assistant and student nurses.

In the first 6 months in his new home Denis social life increased to include attending football matches, to cinema and family fun days in local community. Denis who hadn't been on a home visit for 1 ½ years due to health reason is now able to go home for visits more frequently. His overall health has improved and family visits to the house increased. He goes to the GP practice as needed, palliative care team and other disciplines visit the house to review him.

Note – The names of the people in our case studies are not their real names

Case Study : Adult with disabilities and medical support needs

Nora is 34 years of age and she has lived in a large congregated setting for 26 years. She goes home every weekend and has a very supportive family. Nora has complex needs, she has an intellectual and physical disability, does not use verbal language to communicate and she experiences epileptic seizures on a daily basis. Nora has lots of equipment to support her, in her everyday life and she requires nursing support.

Nora moved to a community house, with three other ladies in December 2017. This house identified for her, has a large living space, quiet and peaceful location and compatibility with other housemates. The house is fully wheelchair accessible throughout, offering level access to the outside terrain and has a large garden. Nora has her own key to her own front door. She has a full and active day, focusing on activities that are meaningful to her and she continues to go home for two nights each week to her family.

All restrictive practices have been reviewed and discontinued, wherever possible. Nora's overall health has improved; she has a risk feeding care plan in place as adequate hydration and nutrition have been on-going issues for her. Her BMI is now within a healthy range and has a significant reduction in medications and hydration interventions. (None since after 6 weeks of her community move)

Supporting Nora to achieve nutrition and hydration goals, has been in the most part, due to the staff team's responsiveness to Nora's needs. Daily, she has a choice of fresh, home cooked meals which she participates in preparing. Staff ensure she has had adequate rest period before offering her meals, to ensure she is in the best of form. Nora's meal-times are completely aligned to her needs and the necessary time is spent with her, to support her with her meals. Nora continues to have oral nutrition supplements; these were also reviewed with the dietician, taking into consideration her choice and preferences.

Staff report the move to the community has enabled Nora to be given more time and the team have been able to focus on the quality of life outcomes that have the most positive impact for her. Due to the improvements in her overall health her wellbeing and stamina continue to increase. Nora is now better placed to experience new opportunities and discover what are her preferences and interests. She was recently supported to attend a musical theatre show in Dublin and really enjoyed this experience.

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Current Practice: Autism Specific

Currently people with Autism with significant specialist residential support needs may be living in a range of disability and or autism specific services that are congregated and non-congregated. The awareness, understanding, diagnosis and management of the support needs of people with Autism has improved significantly over time which has resulted in the disability sector developing and adapting existing services or creating new services in response to presenting need. A key driver in this has been the recognition that people with autism are not a homogenous group and their individual support needs can be driven by a range of co-morbidities, such as mental health issues, levels of intellectual and/or physical disabilities. On this basis, many residential services for people with Autism are now underpinned by a person centred and individualised model of care. However, there is also a prevalence of cluster-type arrangements for people with Autism that has arisen as families and providers have sought to duplicate and grow model of services and achieve some economies of scale and access to particular specialist supports.

Case studies Impact of Community Living

Tom is 44 years of age and he has lived in a large congregated setting for 32 years. He has an intellectual disability and he finds unpredictable and changing situations extremely difficult to cope with. Tom lived alongside 12 others, many of whom presented with unpredictable behaviours. His campus home was noisy and busy. Up until time of transition, he did not leave his campus setting home for approx. 5 years, unless his mother (who is 86 years old) collected him.

MDT supports recommended a low arousal house for Tom. In the planning stages of his transition, his housemates were identified in terms of compatibility. With much support, Tom moved but for the first five months, he again refused to leave his community home unless his mother collected him. Everything had to be provided to Tom in his home and he did not get exposure to community options.

Under the guidance of the MDT team, the staff supporting Tom, implemented 'trauma informed' support guidelines and started to offer him choices every day. Sometimes he would respond and other times he might not. After thirteen months staff again asked Tom would he like to go out for dinner and he decided to get his jacket and proceeded to leave the house and entered the car. Staff immediately responded and supported Tom to a local restaurant, whereupon he had his dinner and favourite dessert. This was a huge step for him and an indication that the continuity and intentionality of staff to assist him to feel safe and secure enabled him to take the 'risk' of going out.

Since then, Tom goes out every Sunday for his lunch and he has also started to go food and clothing shopping with familiar staff. The staff continue to provide very structured and predictable supports to ensure Tom maintains his sense of safety and security and thus enabling him to experience community life and explore new opportunities.

Tom is also showing enhanced competencies with many tasks. He now collects his own pyjamas when he wishes to go to bed, butters his own toast, chooses his meals etc. Tom is also starting to take an interest in what his housemates are doing and is following their actions with interest. Tom is in good health and has lost a significant amount of weight, since moving to his new home. His mobility has increased and staff have reported that they feel his mental health and wellbeing has improved. His mother is very relieved that he is engaging and willing to go out into the community with the staff as this offers him so many more opportunities.

Note – The names of the people in our case studies are not their real names

Current Practice: Behaviours that Challenge

There are some people with disabilities that exhibit behaviours that challenge. Currently, there is significant expertise within the services to positively support behaviour that challenge, manage and reduce the risks associated with behaviours and reduce the frequency and/or severity of incidents as can be seen in the following case study.

Complex Needs /Challenging Behaviour / Autism

A significant challenge to the disability operational system is in managing and responding to the support needs of people with disabilities that have complex and multifaceted support needs, which may include behaviours that challenge, mental health, autism and intellectual disability. With no new development funding since 2008, the capacity of the existing disability residential services to respond to the support needs of people with complex needs has been eroded.

Disability service providers have continued to respond to the changing needs of those people already in residential services, as demonstrated in earlier case studies. At times this is very challenging, requiring services to divert and reconfigure resources and alter accommodation. However, due to the specificity of the support needs of individuals, service providers do not always have an existing residential vacancy and resources appropriate to the person's support need. As a result, there has been a steady rise in the number of one- off arrangements developed on an emergency basis to support those with significant specialist support needs. The provision of specialist residential services to meet the needs of these individuals requires service providers and teams from different care groups, to work together.

Work is currently underway through the Placement Improvement Programme, to review the current high cost and complex care placements put in place in disability and mental health services over the last number of years. The output of this programme will be used to inform the model of care and pathway that needs to be developed and the level of capacity required to respond appropriately to complex support needs on a demographic basis. This in turn will ensure that services for those with complex support needs are person centred, outcome focussed, time-sensitive and cost effective.

Case Study: Disability and Behaviours that Challenge

Joe is a 59 year old gentleman with a diagnosis of Autism, Intellectual Disability and associated behaviours of concern. He entered full time residential care in an institutional type setting aged 7, where he lived for 51 years. Joe has swallowing difficulties and requires a modified diet, he has a long well documented history of poor coping skills in relation to changes within his home, types of food and clothing, collecting papers and magazines feature strongly in his life. Traditionally, all services were provided to him on the campus, services such as Doctor, Dentist and health screening were all provided with no community input.

Two years ago Joe transitioned to his new home in the community. Initially his family were very anxious about a move to the community and there were many practical concerns around how Joe would sleep at night in a new building/bedroom, safety concerns within a community setting and how would he be regarded within a community setting. In short, how could Joe be supported to overcome the raft of changes that we had (most probably) been helping him avoid for years?

Despite family member concerns they fully engaged with the transition process and their involvement proved key to his successful transition, for example they supported him choose the décor for his bedroom and liaised with a contractor to install sensory mood lighting in his bedroom. Joe visited the house a number of times, together with his housemates, as part of a phased transition, spending increasing amounts of time in the house and engaging in activities with the support of familiar staff who would be transitioning with him. The staff team and the four gentlemen were familiar and accepting of each other, and one staff member had good local connections which sped up linking. Small practical things like kitchen equipment to modify food consistencies were as important as ensuring the provision of house transport. Specific staff training in Positive Behaviour Support and managing swallowing disorders proved of vital importance in building conditions to support success, while keeping Joe's needs foremost e.g. awareness of his particular behaviours and traits, and the importance of allowing Joe enough time to process and manage change.

Since Joe moved there has been an obvious, if difficult to measure, increase in the quality of the life he is leading, which will only increase with time, experience and success. There has been a measurable reduction in behaviours of concern, his family contact has increased and he is becoming a recognisable and accepted member of his local community, greeted by his first name in the local shop and pharmacy. He actively participates in purchasing personal items, weekly groceries and browsing the magazine aisle. Joe has benefitted significantly from a reduction the number of people he lives with and has found the space to better communicate his needs, which has (in turn) resulted in reduced episodes of frustration.

We underestimated Joe's capacity and ability to tolerate and cope with change. We are learning to push boundaries (his and/or ours), take positive risks and support Joe in social situations that had not previously been explored. We are refocused on promoting independence, supporting Joeatrick develop new skills and explore new experiences.

Note – The names of the people in our case studies are not their real names

10. Data

A number of recent reports and data sources provide information on the demand for disability health services and disability health service spending. These reports provide information on current services and future demographic requirements. The reports highlight the impact arising from population changes and existing gaps in provision that need to inform the planning of services.

'Planning for Health - Trends and Priorities to inform Health Service Planning 2017' (HSE)

Planning for Health provides a population-based focus and analysis of the current and future demands on health services. It aims to provide a comprehensive overview of the imminent demographic pressures due to arise in the next five years up to 2022. The report noted that:

- Currently there are 5,576 older people (over 50 years) with an intellectual disability recorded on the NIDD (NIDD, 2014).
- The population with intellectual disability like the general population is not evenly distributed across CHOs, with the greatest proportion living in CHOs 4 & 7 (13.8% and 14.6% respectively) and the lowest proportion living in CHO 6 (4.6%).

The report recommends the:

- Development of an indicator (index) to describe activity and complexity of care provision in residential facilities both for older persons and persons with disabilities is required. A costing model should be developed in parallel.
- Development of an indicator (index) to describe complexity of care needs among people with a disability, based on a standardised assessment tool is needed. The data generated to be web-enabled and available in a timely manner to inform service planning and development.

Report on Future Needs for Disability Services

This project drew on a number of different data sources including the Census and the HRB's disability databases. A number of specific analyses were undertaken to inform the forecasts for future requirements including residential services. Key Findings included:

- Demographic change alone could increase the number of residential intellectual disability places required, relative to 2015, by about 400-500 by 2020 and by 700- 800 by 2025
- In addition, there is a backlog of unmet need for residential care, including an emergency waiting list of over 800 at end 2017
- Around 15% of over-60s with intellectual disabilities live with family members, usually with siblings or parents. Given the ages of those involved, most of these arrangements will not be sustainable. It is suggested residential use rates need to rise to 95% in this age group. That would add additional 200 or so places by 2020, and about 370 extra places by 2025, over the extra places needed for demographic change

- The proportion of under-45s with ID getting residential care has fallen by about 10 percentage points from that of the pre-recession era (2007). This deferred demand has fed into rising numbers presenting for residential care as emergency placements. A return to the 2007 residential care rates would require an extra 1,200 or so residential places in both 2020 and 2025, over and above those due to demographic pressures.

Disability Databases

National Intellectual Disability Database (NIDD) & National Physical and Sensory Disability Database (NPSDD)

The National Intellectual Disability Database (NIDD) was established in 1995, and the National Physical and Sensory Disability Database (NPSDD) were established in 2002. The Health Research Board had a team in place to manage these databases on behalf of the Department of Health.

These databases were stood down in 2017 and are currently being replaced by the National Ability Support System (NASS). Up to 2017 the databases recorded information on the demographics, current service provision and future specialised health and personal social services for people with intellectual, physical, sensory, neurological or speech or language disabilities.

Annual Reports were produced that profiled and identified key trends in service provision and unmet need. The NIDD 2017 Report (published July 2018) does however highlight the following trends, which will impact on future service provision:[2]

- There were almost 50,000 people registered on both databases (28,388 NIDD and 20,676 NPSDD)
- Of the 28,388 on the NIDD: 32% (9,151) mild ID; 42%(11,787) moderate ID; 17% (4,846) severe/profound
- 27% (7,530 of people registered on the NIDD lived in full-time residential services).
- Almost one third (2,579, 31.6%) of people aged 35 years or over with moderate, severe or profound intellectual disability lived at home in 2017.
- Life expectancy for adults with moderate/severe/profound intellectual disability has improved with 49% aged 35 years or older in 2017

In terms of Future Service Requirements the NIDD report notes that:

- 2,267 people in full-time residential places require a change or upgrading of their current service in the next five years 2018-2022.
    - Of this group, 1,318 (58.1%) require a move to an alternative residential service including 806 (35.6%) who require a move to a community group home and 413 (18.2%) to an intensive placement, for either challenging behaviour or multiple disabilities.

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[2] As the current and unmet need for the NPSDD was based on the 5,654 people (27.3% of total registered) whose NPSDD records were either registered or reviewed in 2017 so has not been included as a data source.

  - A further 949 (41.9%) people require an upgrade of their existing residential service type. The majority of this group (2,040, 90%) had moderate, severe or profound intellectual disability, and 1,996 (88%) were aged 35 years or older.
- 1,461 people require changes or enhancements to their residential support places. Most of this need was for more frequent centre-based crisis or planned respite breaks for people already availing of this service (982, 67.2%).
- Unmet need residential - The majority (84%) of full-time residential services required were for placements in community group homes
- Sixty-nine per cent of those registered on the NIDD (19,589 people) require a new and/or enhanced multidisciplinary support service in the period 2018–2022. The main therapeutic services required are psychology, occupational and speech and language therapies

With regard to the NPSDD the 2017 Report notes that while it is recommended that a full review of each NPSDD record takes place on an annual basis, the "*rates of review are lower than anticipated and some of the data have not been updated annually. Of the 20,676 registrations, 9,956 (48.2%) records were registered or reviewed in the five year period 2013-2017. The numbers of registrations and reviews carried out are influenced by staffing levels within each area."*

While there is no future residential requirement indicated for individuals registered on the NPSDD it must be noted that the report on *current service use and future service requirements* is only based on the 5,654 (27.3%) people who were either registered or reviewed in 2017.

Congregated Settings Master Data Set

The *Time to Move On from Congregated Settings* report published in 2012 identified "*over 4,000 people with disabilities in Ireland live in congregated settings*". In 2013 a dataset was introduced to collect detailed data on this population to enable and track policy implementation. At the end of 2018 the dataset showed 2,136 people were still resident[3] in congregated settings.

The dataset is designed to capture key information in relation to each person who is or has been a resident in a congregated setting at any point since the policy was implemented in 2012 and provides robust and detailed information that is used to generate the Annual Progress Report and can be used to provide useful statistical information on a geographical basis, by Community Health Organisation and by individual agency.

The Master Data set captures information on the type and degree of disability and allows for additional information on medical and support needs to be identified, although this is not always available. A review of the 2016 data identified the prevalence of the following additional needs amongst the congregated setting population at that time, as follows:

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[3] Time to Move on from Congregated Settings Annual Progress Report 2018

Description of additional support needs *	Percentage prevalence
Challenging Behaviours	28.5%
Not identified	23%
Epilepsy	19.5%
Autism	11%
Mental Health	8%
Physical Needs	8%
Fraility, Palliative, ABI, Complex	4.5%
Cerebral Palsy	4%
Down Syndrome	3%
Dementia	2%

** Please note that these figures are not mutually exclusive and no additional information was available on 598 records.*

Sláintecare

Under the Programme for a Partnership Government, an All-Party Oireachtais Committee on the Future of Healthcare was established in June 2016 to create a cross-party vision for the future of our health and social care services. The Committee sat for almost a year, engaging with stakeholders across the system and published the Sláintecare Report in May 2017. Built on consensus Sláintecare is a ten-year programme to transform our health and social care services. Over the next ten years, Sláintecare will:

- Promote the health of our population to prevent illness
- Provide the majority of care at or closer to home
- Create a system where care is provided on the basis of need not ability to pay
- Move our system from long waiting times to a timely service – especially for those who need it most
- Create an integrated system of care, with healthcare professionals working closely together

The Sláintecare report acknowledged that it had not done any detailed analysis of needs in the disability area, but recommended earmarking €290 million over ten years for expansion of these services. With regard to Intellectual Disability Mental Health Services the report also recommended *"120 additional staff - €8.5 million to be delivered by year 5."*

The Report notes that, *"While many people with disabilities live at home, some remain in residential care due to the absence of appropriate accommodation and supports in the community. This has a negative impact on the wellbeing of people with disability and militates against independent living."* The lack of integration between residential care and primary and acute care was also noted by disability groups.

11. Discussion

There is a broad consensus on the direction that our approach to supporting people with disabilities needs to take. This includes enabling people to stay at home and in their own communities for as long as possible, meeting people's needs at the lowest appropriate level of complexity and when required, providing specialist supports that may in some cases include a residential component.

The implementation of the *Time to Move on* policy is driving the development of community-based residential placements where people with disabilities are enabled to exercise their will and preference over the way they are supported and care is provided. The *Time to Move on* policy recognises and identifies that in order to support people to live well in their own homes the capacity of a wide range of community-based services must be developed to respond appropriately. This includes primary health care and social care supports as well as local amenities such as housing, transport services, community groups, education, business and leisure facilities.

Community Inclusion Intersectoral Working

The ratification of the United Nations Convention on the Rights of Persons with Disabilities by Ireland and the development of the National Disability Inclusion Strategy recognise the government commitment to supporting people with disabilities in their communities. However there is much that has to be achieved before we can be confident in saying that sufficient supports are in place to enable all people with disability to live well within their local community.

For people with disabilities and significant specialist support needs, the under-development of appropriate community-based supports and services can have a particularly negative impact, eroding the opportunity for them to remain in their own or family home or in a community residential setting.

Currently there are limited opportunities for people with disabilities, even for those with less complex support needs, to access mainstream and community based supports. This compounds the challenge faced by disability service providers that are striving to respond to the demand for services from a population whose needs range from mild/moderate levels of disability through to significant specialist and complex support needs.

A recent report by The Netherlands Institute for Social Research[4] provides insights into how appropriate care can be developed for people with mild and borderline intellectual disabilities, considering the development of demand and its causes for consideration. The report notes that:

"*due to the lack of appropriate support, people with borderline or mild ID may end up in other, more expensive, types of care such as psychiatric or forensic care, or be homeless*" and that "*there are*

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[4] An International comparison of care for people with Intellectual Disabilities An Exploration The Netherlands Institute for Social Research, SCP, The Hague 2018

indications that providing guidance early in life…helps prevent significant behavioural problems later on".

Supporting New Models of Service Innovation

Working within existing budgets and defined activity parameters, there is limited scope for disability providers to develop and implement new models of support and grow the capacity of a service to provide a safe and appropriate alternative response to a residential placement. The result is that the demand for full time residential places is perpetuated and the provision of alternative responses remains under-developed. To overcome this, work is required to secure a commitment and the resources needed to develop safe and trusted alternative responses and to increase the capacity of mainstream primary care and community based disability services that can support and complement this work. This will require support at all levels: government, inter-departmental, HSE national and across care group and disciplines with health and social care.

Developing alternative Person-centred and family centred supports

The introduction of alternative day supports, home supports and respite options can be of benefit to people with disabilities and their families. Once supports are person and family centred and meet the support needs sufficiently, they will enable people to live well and remain at home for longer, delaying or reducing the need for centre based respite and/or long term residential care.

Data from the Health Research Board show that around 1,600 additional people with an intellectual disability will require a respite service by 2021[5]. If families are not adequately supported to care for those with complex disabilities with respite breaks, family care is vulnerable to breaking down altogether, leading to earlier admission to full-time residential care, at a much higher cost than the provision of regular respite support.

Models of respite support are changing. In addition to the demand for centre-based respite, the HRB have also estimated there will be additional demand for other forms of respite: – holiday residential placements; occasional respite with a host family; and overnight respite in the home. The Transforming Lives *Report on the Future Needs for Disability Services* document identifies 1,461 people require changes or enhancements to their residential support places, but notes that most of this need is for more frequent centre-based crisis or planned respite breaks for people already availing of this service (982, 67.2%).

There are currently a number of projects supported through the Service Reform Fund (SRF) focused on developing alternative respite and day supports. Investment and support for projects of this nature needs to continue beyond the end of the current SRF programme in order that alternative appropriate responses continue to be developed to address local demand.

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[5] Table 4.4 National Intellectual Disability Database Annual Report 2016

Implementing the Time to Move on Policy

The consultation process that informed this review has shown that providers and disability operation teams for the most part fully support the *Time to Move on* policy but are constrained in terms of what they can achieve within current resources. Service providers are encountering many challenges in implementing this policy for those with significant support needs including: adequate revenue funding to support places; access to adequate community based supports; developing and maintaining skilled teams; access to therapies; adequate governance and support structures; achieving meaningful community inclusion and access to non-disability specialist services. It is important to note that all of these difficulties are a result of service configuration and funding issues that will need to be managed over time.

To ensure people with specialist residential support needs can be supported well in the community, funding is required for an enhanced level of community based services, the provision of other specialist supports (MHID, Dementia services etc.) with on-going investment in disability awareness training, community inclusion supports and the up skilling and capacity building of disability services.

Resourcing and developing greater and more responsive capacity across services will take time but in the intervening period we must still promote the implementation of the *Time to Move on* policy and advocate for and support the development of appropriate residential services which deliver the key quality of life outcomes for all those currently in congregated settings.

Capital Funding

A key issue that arose in discussions with stakeholders during the review was the frustration with both slow rate of change achieved in congregated settings deemed no longer fit for purpose and with the on-going investment into these services to achieve regulatory compliance when they are neither fit for purpose in the mid to long term or compliant within policy.

The current HSE Disability Capital programme is a multi-annual capital plan focussed on the delivery of homes for those in a defined list of congregated settings known as the priority sites. The capital investment in the priority sites will ensure there is housing available to support their closure, but further funding is needed to extend the capital programme out to enable other sites to progress towards full decongregation. Currently under this programme, homes are being acquired for those moving from the congregated settings. To date the cost of homes provided for those with significant support needs has been higher than the cost of an ordinary home whilst the cost of housing for those with less complex needs has been in line with market norms. An analysis of the homes being developed through the Disability Capital programme shows that the capital cost of individual projects does vary and that in some cases a higher capital investment is appropriate to ensure that a property is well located and equipped to minimalize the long term running costs.

This investment enables the State to provide some homes for people with disabilities who historically had no choice other than living in a congregated setting. In line with the UNCRPD, people are being enabled to have a home and return to their community as equal citizens in our society.

This investment helps to ensure that good quality housing is being developed that will support the population of people with disabilities for generations to come.

Elsewhere under the National Housing Strategy for People with Disabilities and Rebuilding Ireland 2020, the Department of Housing Planning and Local Government had provided funding through the Capital Assistance Scheme to support the development of housing through mainstream housing mechanisms.

12. Recommended Next Steps

This report has sought to make evidence-based best practice recommendations for the disability services supporting people with disabilities and significant specialist residential support needs in the context of the *Time to Move on* policy. Whilst this review is specifically focussed on addressing the challenges around appropriately responding to the specialist residential support needs of those living in the congregated settings, it cannot be completed without reference to the broader disability sector.

There is an on-going demand and pressure on residential services for additional placements to address the unmet need in the population. On this basis, when considering the appropriate model of service for the people with disabilities and specialist residential support needs currently living in congregated settings, cognisance must be taken of the current and future demand for specialist support from those currently living in the community.

It is the view of the Review Group that to appropriately support individuals with significant residential support needs, services should be configured developed and delivered in keeping with the Guiding Principles that were developed from the literature review:

- Person Centred Care and Engagement
- Inclusive National Policies
- Provision of and access to community based and mainstream services
- Collaborative cross-care group working
- Enhancing Skills & Capacity Building
- Specialist residential
- Research and New models of service

These principles are in line with the views that emerged from the consultation process with families, experts, provider and leaders working in the disability field.

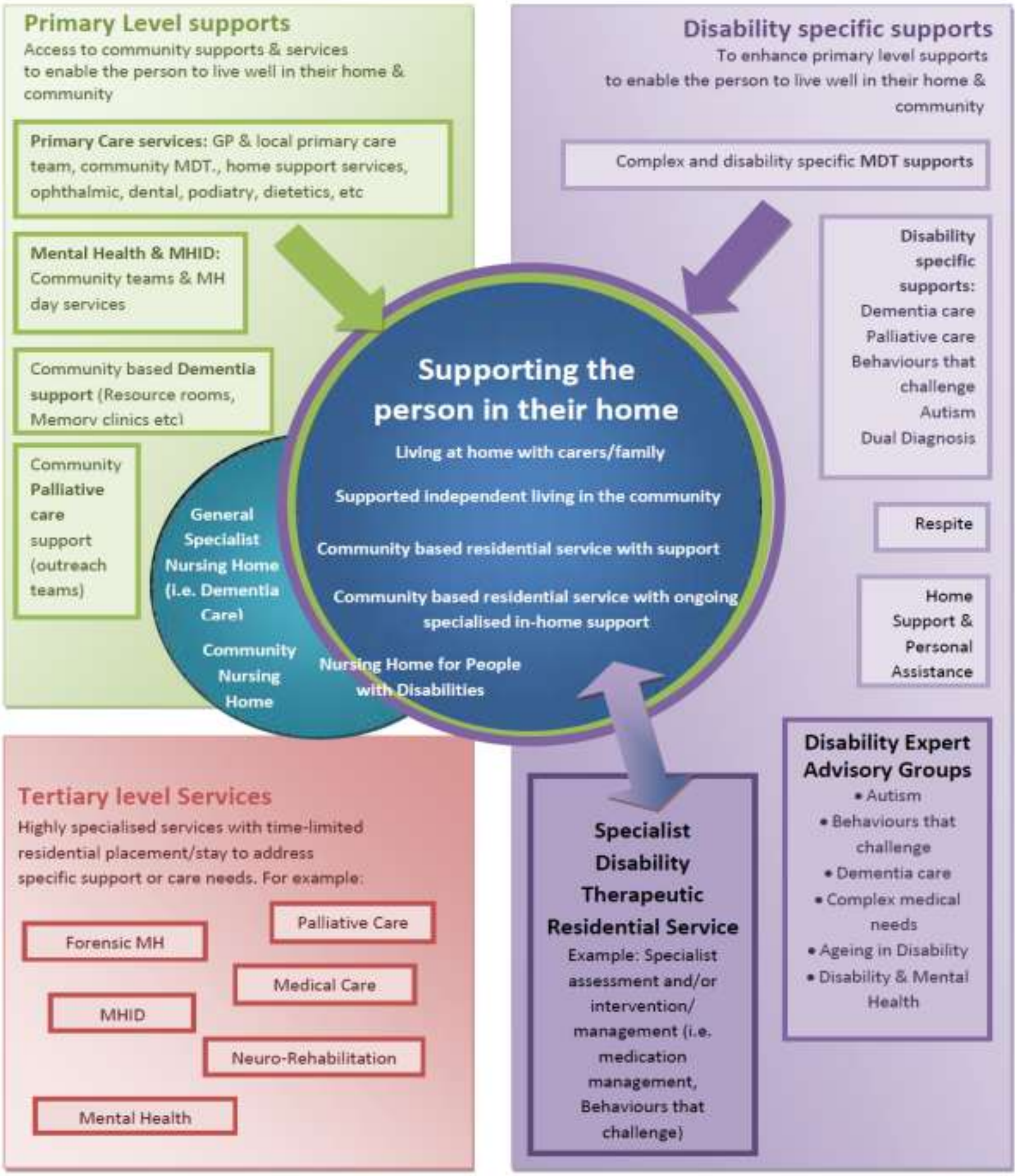
Best Practice Model of Care

There now needs to be a focus on developing the model of care and continuum of services that is person centred and will respond to the needs of the individuals and their families. On-going work is needed to continue the move away from the traditional model of residential service provision in order to develop the range of supports that will enable all people with disabilities to live well in the community and to enjoy equity of opportunity and participation. Key to this is building the capacity of the individuals, their carers’, support staff, as well as that of the community services, disability services and other specialist services.

In order to capture the model of best practice for those with significant residential support needs, the following diagrammatical model of care has been developed.

This aims to demonstrate clearly that for each person the supports should be person centred and delivered at the lowest level, close to home and in their community. Each person should have access to the level of support needed irrespective of their residential status and should be able to access different levels of residential and community supports as determined by their support needs at that
time.

Model of Care for People with residential support needs



Recommendations

The following recommendations identify the actions needed to ensure that an appropriate and effective care pathway is developed for all people with significant support needs that will be needs based, person and family centred and enable individuals to enjoy equity of opportunity and participation.

Designing and delivering an appropriate care pathway that can respond to the needs of people with significant specialist support needs will require changes to the way current services are configured and delivered. In addition to this, resources will be needed to build capacity along the model of care to ensure that the service responses to individual need are appropriate both in terms of the level of support and timing.

The recommendations are set out under three delivery strands. These delivery strands are set out to ensure that where possible actions can be progressed towards the development of a best practice model of care. This approach recognises that there are resources required and other conditions to be met, including external stakeholder support in order to progress other recommendations.

Three Delivery Strands		
Review current provision and align service elements to best practice model of care	**Build capacity along best practice care pathway**	**Enhance the current disability policy framework to inform and support the delivery of specialist residential services**
Priority Action 1.1 Map current model of care and the capacity of services on a geographical basis	**Priority Action 2.1** Continue to support innovative practice and alternative models of care	**Priority Action 3.1** Review of Disability Policy Framework to ensure all necessary guidance is in place to support service planning and delivery
Priority Action 1.2 Review Existing Specialist Services on a case by case basis and align to best practice model of care	**Priority Action 2.2** Develop Expert Advisory Groups to deliver and support capacity building	**Priority Action 3.2:** Develop and implement a policy that supports best practice in the area of "Ageing with a Disability"
Priority Action 1.3 Examine non-disability specific specialist services and align to best practice model of service	**Priority Action 2.3** Develop cross care group referral processes to support best practice model of care and care pathways	
Priority Action 1.4 Identifying unmet need mapped on the best practice model of care		

RECOMMENDATION 1: REVIEW CURRENT PROVISION AND ALIGN SERVICE ELEMENTS TO BEST PRACTICE MODEL OF CARE

Priority Action 1.1: Map current model of care and the capacity of services on a geographical basis

In order to plan for the delivery of services based on need, a mapping exercise needs to be undertaken to identify how people with significant residential support needs services are currently being supported in each Area. This exercise will quantify the number of people currently receiving support, the type and quantum of support provided and the pathways to services in a geographical CHO Area (or equivalent structure). The findings of this exercise will highlight the strengths and deficits in the current model of care in each geographical CHO area, which in turn will inform the need for reconfiguration of the current provision and pathways.

Priority Action 1.2: Review Existing Specialist Services on a case by case basis and align to best practice model of care

There are a number of disability residential services that are identified as supporting people with significant specialist support needs, both in congregated and non-congregated settings. For the most part it is expected that these services sit at the “far-end” of the continuum of support, designed and developed to meet the most significant specialist support needs in a residential setting.

It is recommended that each CHO carefully review the practice in every setting that is identified as providing a specialist service and as part of the mapping exercise. Led by the CHO team with the support of the National Disability team this review should identify how each service can or should be aligned to support the wider disability service in that area as part of a continuum of support in the model of care in line with the guiding principles . The CHO should ensure that there is appropriate and defined allocation of the placements, a clear and adequately resourced pathway to and from these services to prevent premature or inappropriate admissions, delayed discharges or the ineffective use of specialist resources.

In some cases these services may need to be reconfigured to deliver best practice for the population. This will inform and enable each CHO Area to develop a plan as to how the disability services in their Area can be configured to meet the specialist residential support needs of people with disabilities on a geographical basis, in line with national policy.

Priority Action 1.3: Examine non-disability specific specialist services and align to best practice model of service

In some areas people with disabilities with significant specialist residential support needs are supported in non-disability residential settings. These individuals may be placed in these services doe to support needs dementia, medically complex needs, palliative care, mental health or behaviours that challenge. All of these settings should be reviewed and captured similar to the previous recommendation.

There needs to be engagement at Area level with the service providers and the CHO or other geographical structures that are meeting these needs in the general population, such as the dementia services etc., to ensure that service provision for people with disabilities is aligned to best practise and disability policy at a local as well as national level.

Priority Action 1.4: Identifying Unmet Need on best practice model of care

Sufficient capacity will be needed along the model of care to ensure that people with disabilities can be supported at an appropriate point in time and level that is in line with their needs and wishes. Developing the capacity along the care pathways in the model will enable services to respond to emerging and changing needs incrementally and reduce the demand for the most specialised residential places.

In order to determine and plan where service capacity need to be reconfigured or enhanced in order to provide adequate support, it is recommended that an exercise is undertaken to estimate the current level of unmet need and the future demand for support on a geographical basis. This data can then be mapped against the current quantum of service that has been aligned to the best practice model of care, in order to identify where they are deficits and strengths in terms of unmet and future needs.

The planning for each geographical area needs to be informed by the individuals with highest support needs in that area, their capabilities and preferences and their social and community support needs. The strategic plan for services in each area needs to be able to support these capabilities and social and community connections as well as meeting immediate care needs.

Outcomes:

- Current services and pathways to the model of care will be mapped
- All non-disability specific supports and pathways to the model of care will be mapped
- Unmet need and gaps in model of care will be identified

RECOMMENDATION 2: BUILD CAPACITY ALONG BEST PRACTICE CARE PATHWAY

Priority Action 2.1: Continue to support innovative practice and alternative models of care

There are currently a number of initiatives, reviews and service developments underway that will support the development of models of care that are in line with best practice including:

- Personalised Budget Demonstration projects
- Service Reform Fund projects
- Placement Improvement Programme

The outcomes and learning from these projects should be used to inform service planning on an on-going basis.

In addition to projects currently underway opportunities need to be taken to ensure that service models continue to evolve with new projects identified and developed to respond effectively to changes in presenting needs and support a learning culture across services.
In particular there needs to be a focus on:

- Developing and piloting innovative models of support and presenting needs, that are specific to the Irish context
- Comparative studies on different models of support to inform future service planning
- Identifying and sharing costed case studies on innovative practice and approaches to care that are supporting people with significant specialist support needs to live well in the community.

Priority Action 2.2: Develop Expert Advisory Groups to deliver and support capacity building

There are over 80 voluntary providers delivering services, many covering a defined geographical area. It is not feasible that every provider will have experience and sufficient in-house expertise to respond to the specialist support needs of every person in their area. As a result, at times supporting a person with a disability and complex needs can be a challenge for individual service providers.

In order to support services effectively, to share learning and to build and sustain capacity, it is recommended that consideration is given to developing structures and resources that will support and build expertise in specialist areas and provide training and support across disciplines and for frontline staff teams. An example would be the development of an **Expert Advisory Group** who can work across services to support best practice and up skill teams at a local level. An Expert Advisory Group would be comprised of health and social care professionals who work or have expertise in a speciality. These individuals may be working in different settings and locations, but will collectively form an Expert Advisory Group that can support the practice in other locations. The Expert Advisory Groups are identified in the model of care as a key support and resource within the disability sector.

Shared learning events and collaboration across services are common features in the disability voluntary sector, but it is recommended that this is developed into a more formal structured approach to ensure capacity building is supported across all the services, both statutory and voluntary.

Priority Action 2.3: Develop cross care group referral processes to support best practice model of care and care pathways

A shared understanding needs to be established and agreed regarding what supports and services should be delivered by mainstream versus specialist services at primary and community care level and where and from whom a more specialised response is needed. This should reflect best practice rather than be predicated on what is available or historically in place. There should be a clear outline of what is envisaged for a local community level service, the role of the service provider and the supports that should be delivered by a specialist/ tertiary service.

- Cross care group work is needed to identify a clear pathway to appropriate assessment and support services for people with disabilities that is supported by policy and service planning in all care groups. For those assessed as having specialist support needs there should then be an appropriate referral pathway into other specialist services to address any unmet support needs. Related to this is the need to agree a standard assessment tool and to develop and test new and improved diagnostic tools for people with disabilities.
- Agree pathways and cross care group protocols to provide a seamless service that supports people with complex or changing needs. This is particularly important when support needs can change over time or fluctuate, for example for those who have episodic mental health needs and when support is needed at particular transition periods, for example, a move from child to adult services.

Outcomes:

- Learning to inform model of care and care pathways will be systematically shared
- Expert Advisory Groups to support model of care will be mapped
- Access pathways and eligibility criteria to the different service levels will be clarified and agreed to facilitate a person moving between services across the model of care.

RECOMMENDATION 3: ENHANCE THE CURRENT DISABILITY POLICY FRAMEWORK TO INFORM AND SUPPORT THE DELIVERY OF SPECIALIST RESIDENTIAL SERVICES

Priority Action 3.1: Review of Disability Policy Framework to ensure all necessary guidance is in place to support service planning and delivery

Service planning and delivery needs to be supported and underpinned by clear policy and best practice guidelines. The current suite of policies underpinning the delivery and development of disability services is incomplete. Currently there is no disability policy or nationally agreed guidelines on the development or delivery of multi-disciplinary supports for adults or how to support people with a disability who are ageing. Work is ongoing in relation to the development of a respite policy and on the development of a statutory scheme and regulation for the home support services across social care for adults, but this does not include personal assistance support or home support for children.

There is also a challenge where disability policy is at odds with the practice in other areas, such as the drive to decongregate the institutions and support all people with disabilities to live in dispersed housing in the community whilst in the older persons services, the movement of older people from home into congregated settings is facilitated under the nursing home support scheme.

It is recommended that the HSE, voluntary service providers and other key stakeholders under the direction of the Department of Health work collaboratively to enhance and strengthen the disability policy and best practice guideline framework.

Collaboratively these stakeholders need to work to address the gaps in policy or guidance material that are needed to effectively drive and underpin service planning and enable service development both at a national and the local level. Working together, these stakeholders can develop the policy framework and specific guidelines that will inform practice and ensure new service developments will be fully aligned to the wider legislative and policy landscape, such as HIQA regulation, the National Disability Inclusion Strategy, Assisted Decision Making legislation, the United Nations Convention on the Rights of People with Disabilities.

Priority Action 3.2: Develop and implement a policy that supports best practice in the area of "Ageing with a Disability"

It is recommended that as a priority a policy should be developed to provide clear direction on the appropriate model of support and the care pathways for people with a disability who are ageing, as the demographic data and evidence from services indicates there is rising pressure for provision in this area and concerns exist around the appropriate best practice model of care.

There are a number of disability service locations that support older persons with disabilities in a nursing home style residential setting. It is also acknowledged that some older people with disabilities are living in nursing homes. This presents a particular challenge to the disability sector when the nursing home standards, regulation and funding model for older person's services are distinctly separate to those governing the disability residential services.

Alongside the work to develop a national policy on " People with Disability who are Ageing" , work will need to be undertaken at a national level in collaboration with the regulator and the Department of Health to examine and address the disparity between the model of residential service for people with a disability who are ageing and the service provision for older persons in the general population, to ensure that the implementation of a policy and best practice is supported by the legislative framework and regulation of the residential care services that ensures services are equitable and person centred.

Outcomes:

- Plan to address gaps in the Disability Policy framework and best practice guidelines will be developed and agreed
- National Policy on *Supporting People with Disability who are Ageing* will be developed

13. Conclusion

This review found that for of the people with disabilities that we support, there is no evidence that the delivery of specialist residential support services in a congregated setting, (where ten or more people are living together in a single unit or on a campus) is more appropriate or supports best practice better.

The negative outcomes for people living in congregated settings are well documented and the services who have supported individuals to transition are reporting good outcomes. Whilst changes or improvements in the quality of life for a person with significant support needs may appear less dramatic, it is essential to recognise that small changes for a person with a disability can be very significant for them in their life. The findings of the National Disability Authority led “Moving In” study will inform this further in due course.

During the engagements undertaken as part of this review and as outlined in the case studies, many teams and individuals have demonstrated their commitment and capacity to support people with disabilities who have or develop significant support needs in line with best practice. These services provide evidence to show that strong leadership, joint working and a shared vision will support the development of person-centred services with a focus on the individual, where services are delivered cost effectively as close to home as possible and with access to any additional supports when required.

The recommendations and priority actions set out in this review identify the steps that need to be taken to enable the capacity and capability of the disability and wider health and social care sector to deliver person-centred services in this manner, that will support the development of an appropriate model of care and care pathways for all people with disabilities and meet their needs at the lowest level of complexity.

APPENDICES

Appendix I: Members of Working Group

Suzanne Moloney, Health Service Executive, Chair

David O’Connor, Department of Health

Teresa Mallon, St. John of God Services

Sr. Marion Harte, Daughters of Charity

Sean Abbott, COPE Foundation

Mary Lee, Inclusion Ireland

Aisling Hunt, Health Service Executive (left group Oct 2017)

Caroline O’Nolan, National Disability Authority (joined group Jan 2018)

Anna Cunniffe National Disability Authority (left group Oct 2017)

Máiread Lyons, Head of Social Care, HSE (joined group Sept 2018)

Norma Murphy, Health Service Executive, Project Support

Appendix II: Focus Group Meetings

Inclusion Ireland through the Connect Family Network facilitated a number of focus group meetings during 2018. The purpose of the focus groups was to give family members an opportunity to engage in, review the process and share their lived experience in relation to residential supports for family members with complex and significant support need. All of the participants were parents of teenagers or young adults with complex and significant needs. Two meetings were held in March and October and the following questions formed the basis for the conversation.

Question 1: What is your impression of this list, is it complete, would you change or remove any items?

Question 2: Do you have experience of successful community residential or support services that are being delivered in a community setting to people with significant support needs. What makes these services successful? What are the limitations or disadvantages?

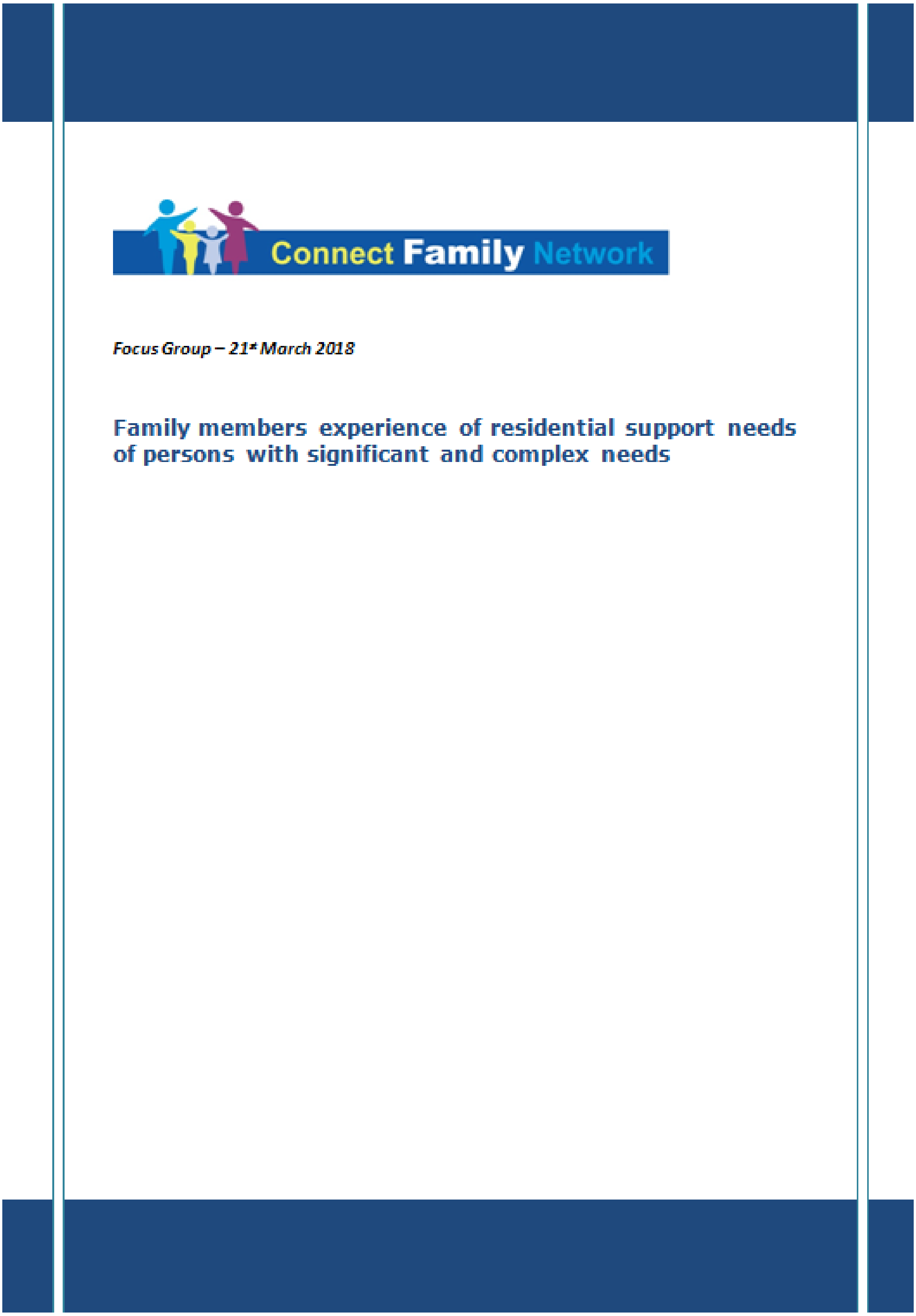
Question 3: Do you have experience of a small scale disability specialist care unit?
What advantages are there to such a service? What disadvantages are there to such a service?

Question 4: What is your experience of people with significant support needs accessing generic / community specialist services? What has worked? What has not worked?

Question 5: Suggestions as to experts who could be consulted and research or literature on positive service options being delivered here or elsewhere

The Reports on the findings are included below.

Appendix II-i: Focus Group Meeting 21/03/2018



Connect Family Network

Focus Group – 21st March 2018

Family members experience of residential support needs of persons with significant and complex needs

Connect Family Network

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Focus Group 1 21st March 2018

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Connect Family Network

Reasons for Focus Group

As part of our advocacy on community living and decongregating Inclusion Ireland is represented on the HSE “Location Review Group”. The “Location Review Group” is a subcommittee of the Department of Health “Time to Move On from Congregated Settings Working Group”.

As part of its remit the “Location Review Group” is considering the housing and support needs of residents with significant and complex needs.

As outlined in its terms of reference the “Location Review Group” will identify appropriate best practice models to meet the residential support needs of individuals with significant specialist support needs. The “Location Review Group” will

- Examine current literature and research to identify current models of best practice…
- Gather examples of current good practice within community based residential services in Ireland
- Examine applications of best practice approaches to meeting residential support needs of individuals identified as requiring specialist supports and
- Recommend on the appropriate approach to meeting residential support needs of individuals identified as requiring specialist supports, in line with current best practice.

All “Location Review Group” members apart from Inclusion Ireland represent a service provider or service funder. Individuals with disability and family members of persons with disability are not directly represented.

Inclusion Ireland through the Connect Family Network has committed to supporting local family support groups engage with the HSE and service providers in the planning, design and review of disability policy or programmes and to giving local support groups a voice into policy and legislative formation at national level through discussion and consultation.

The purpose of this Connect Family Network focus group was to give family members an opportunity to engage in this examination of services, review the process and share their lived experience in relation to residential supports for family members with complex and significant support needs.

Focus Group participants

The focus group met on the 21st March 2018 and was attended by 5 family members (4 women and 1 man), all parents of teenagers or young adults with complex and significant needs. 2 of the parents attending also support a second family member with significant disability. The family members with disability and requiring support range in age from 8 years to 24 years. The experience for all is predominantly of life at home and accessing services in the community.

Connect **Family** Network

In introducing themselves to the group parents outlined the many difficulties they have dealt with in providing care and support for their family member. These difficulties dominated the conversation. Issues arising within their personal experience included:

- lack of suitable respite services as, when and where needed; A new respite centre is currently inaccessible to one family member with physical disability as the building is not wheelchair accessible
- failure to provide the support needed to sustain care at home
- Inappropriate and detrimental residential placement
- concerns around use of medication
- absence of future planning or preparation
- private medical services and clinics not available to persons with disability even where they have private health insurance
- ability to attend day service often impacted by ill health
- very little support from other family members
- Failure to feedback to parents following participation in HSE forums and a severe/profound research project
- Failure by the HSE and others to follow through on commitments to continued consultation and to progress the issues families highlighted, despite extensive participation by family members.
- Failure to provide or support school placement for a teenager with autism
- A parent obliged to become a fulltime-carer for young adult due to lack of appropriate home support or community based supported accommodation options

Areas of positive experience included:
- provision of an individualised budget to fund nurse led care at person’s own home in their own community
- good local day services and specialist day programme
- good local respite provision

Focus Group Questions
1. Scope of the “Location Review Group”

The Location Review Group identifies “Individuals that may require specialist support” under the following headings:
- *Changing needs, ageing and dementia*
- *High medical need/medical frailty*
- *Behaviours that challenge*
- *Palliative Care*
- *Autism*
- *Neuro-Rehab”*

Connect Family Network

Question 1: What is your impression of this list, is it complete, would you change or remove any items?

Discussion: The nature and scope of the list caused dismay across the group. The list suggested a review process that was focussed on a medical model of service and looking only at an aging population group. The meaning of the term “specialist support” needed to be more clearly set out. In addition to medical need the term “specialist support” could for example also mean” in need of more constant personal assistance” as in the case of a person who needs support to communicate and engage in daily activities.

The list is focussed on service options first and then where people will fit in. The services models listed are defined by the person’s difficulties or deficits and not by their capacity or choices. It does not suggest human rights based or a community inclusion based model of support. The list of service models was the wrong perspective from which to start the review and the planning of supports.
The group agreed that planning should be for the person, not for the service. Where a person has complex and significant support needs the process must start with life planning for the person and social/community supports. There should be community accommodation with real choice but with recognition that community services cannot meet the person’s needs without proper personal supports in place. The need for parents to sub vent staff in order that an adult can participate in day service activities was given as an example of how services are failing to recognise and meet the needs of those with significant and complex needs in a community setting. Proper and planned funding is an essential to meet an individual’s complex and significant needs. Use of personalised funding is enabling an individual to live at home but family members observed that personal budget management can be very difficult in a complex needs situation and the amount provided does not actually meet the needs.

2. Community based residential or support services

The Location Review Group reports that “Evidence is that service providers are striving to support living and ageing in place within community settings. Some advocate for all service to be community based, some for specialist residential services to be provided in campus or larger settings to meet changing needs.”

Question 2: Do you have experience of successful community residential or support services that are being delivered in a community setting to people with significant support needs. What makes these services successful? What are the limitations or disadvantages?
Discussion: The initial discussion focussed on the limitations. There were concerns that community living or supported self-directed living will not succeed in all cases. Family members said that the reality is that the service in the community is hit and miss and that service provision may not be sufficient to meet complex and significant needs. There was a particular concern that in a rural setting the needs of a person with complex medical needs could not be met due to the distance to hospital coupled with an inadequate ambulance service.

Connect Family Network

“It is a challenge to put C, who has complex medical needs, into a community setting and recruit nurses”

“What happens (at home) when there is snow?” (Re. recent difficulties during storm Emma getting nursing staff to hospitals)

“What happens when parents are not there to sub vent (staffing)?”

A further worry was that a person with complex needs in a house on their own may become lonely and isolated. It was suggested that within a smaller setting, in the community, a core group should be kept together.

However focus group members had experience and knowledge of community based accommodation that could meet the needs of a person with significant needs. The accommodation is an ordinary house, in a rural area, with several residents with mixed abilities sharing accommodation and with good support staff. With very dedicated staff it was envisaged that a person with complex needs could live and thrive in this setting. The key to the success and effectiveness of this accommodation was good leadership and a consequent good culture in the service, a top down quality service.
There was criticism of the HSE for failing to examine and address the matter of complex needs in policy and development. Family members said that there were no case studies on this matter and where people with complex needs have moved to community there were no follow up studies and a perceived silence about the outcomes for these individuals.

3. Disability Specialist Care Units

The “Location Review Group” described an example of a specialist care unit – advanced dementia care DoC Clonsilla, on campus, 2 x 6-8 bedded homes. The model of care would propose a strict admissions policy, respite availability to other community homes run by the same service provider, the possibility of specialist outreach teams capable of carrying out assessments and providing training/support to community based individuals with changing needs.

Question 3: Do you have experience of a small scale disability specialist care unit?
What advantages are there to such a service?
What disadvantages are there to such a service?

Discussion: As this service model is rare, family members did not have experience of a small scale disability specialist care unit. The concepts of small scale and community based were considered positively. It was felt that in a smaller setting that staff tended to be more content, there are fewer sick leaves, more continuity of staff, and more loyalty to the service. Communication (with family) should also be better. But there were concerns in relation to the example given. The language was of a medical model and family members felt such a service could be very homogenous and lacking in the variety and the company of an ordinary (non-specialist) supported community setting.

The conversation came back to the need for sufficient specialist staff with proper monitoring. It was generally believed that this depended not on location or scale but on proper and consistent funding, and good leadership and culture. It was important to have experienced management and continuity of service.

Several examples of services including day services, a respite service and a residential service were discussed where funding cuts or lack of dedicated funding or “for profit” motivation resulted in a community service that could not meet or started failing to meet the needs of those with complex or significant needs.

4. Generic or community specialist services vs. Disability specialist services

The “Location Review Group” considered that “Some advocate that people with disabilities should be supported to access other generic specialist services e.g. nursing homes, once their needs change.”

Question 4: What is your experience of people with significant support needs accessing generic /community specialist services? What has worked? What has not worked?

Discussion: It was generally agreed that medical or therapy based community specialist services could meet the needs of those availing but otherwise community or generic specialist services lacked the resources and experience to include people with complex and significant needs. This opinion was based not just on experience of accessing generic specialist services but also accessing the community in general.

“Generic and community specialist services cannot have the breadth and skills to meet the needs of those who are in particular non-verbal with intellectual disability”

“Nursing homes can be dreadful if just managing people’s needs, people deteriorate”

“We don’t see people with severe profound needs in community, they are not visible.”

Family members observed that for example a lack of Changing Places (fully accessible toilet facilities with hoist etc.) means that for many people all kinds of event and activities are not an option and that integrating a child with complex or significant needs in their community can be very difficult; more public education is needed. These are the difficulties that make concepts such as an intentional community and onsite provision of services attractive to families.

However parents said that they persist to support life in the community as their family member needs to engage and to socialise to have a quality of life. Family members believed that community homes for persons with mixed abilities could work with sufficient and skilled staff but such services need to be disability services rather than generic services to meet the needs of those with complex and significant needs. The group agreed that the number of people with complex and significant needs is a small proportion of the population and should be prioritised in service development and policy.

Family members see service providers as primarily focussed on and prioritising the needs of persons with mild or moderate disability in community based accommodation and services,

5. Consultation with experts
The "Location Review Group" proposes meeting and consulting with experts on the support needs of residents with significant and complex needs.

Question 5: Suggestions as to experts who could be consulted and research or literature on positive service options being delivered here or elsewhere

Response: Family members who attended the focus group are available to speak with the "Location Review Group" to share their experience.
Other suggestions included: Francis Coughlan, CEO SOS Kilkenny. Joe Mason, CEO WALK Walkinstown, Dublin 12.

Summary of findings

Question 1   Scope of the Location Review Group

Person first and life planning
Service planning should be individual/ person focussed rather than service model focussed. The process must start with life planning for the person and their social and community supports, it should be defined by the person's abilities and choices not their difficulties or deficits. Sufficient and planned funding is what is needed to meet the support requirements of a person with significant and complex needs

Connect Family Network

Question 2 Experience of Community based residential or support services, what makes community based services successful and what are the limitations or disadvantages?

Good leadership, a good culture and dedicated staff

The reality is that services in the community are hit and miss and may not be sufficient to meet the needs of the person with complex and significant needs. In the experience of family members, the key to the success and effectiveness of a community residential service is good leadership and a consequent good culture in the service, a top down quality service. The importance of dedicated staff was also stated.

Question 3 Experience of small scale disability specialist care units, the advantages, the disadvantages

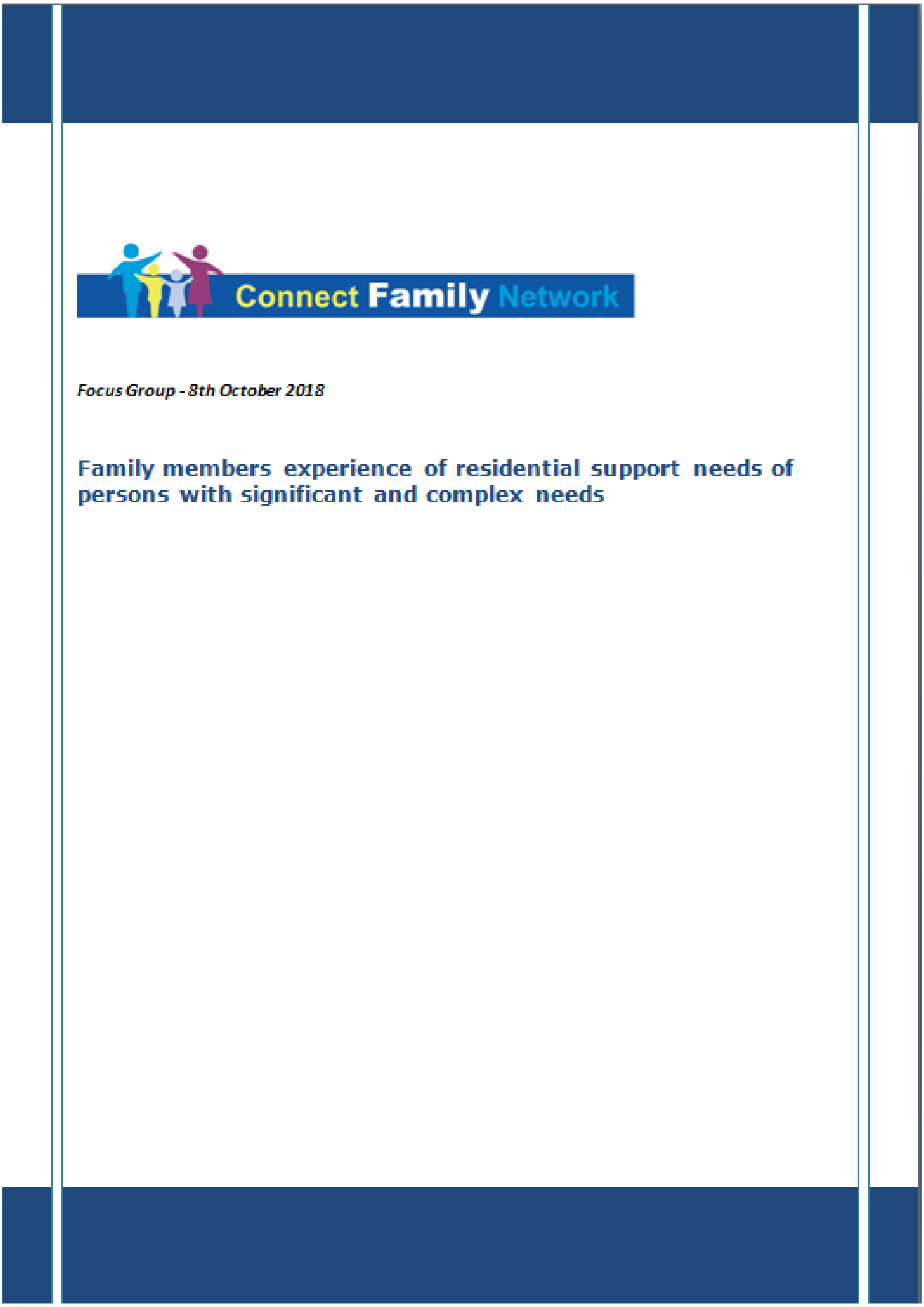
A medical model design that could lack the variety and interest of ordinary community living The concept of small and community based was positive but there were concerns about a medical model design creating a place to live that lacked the variety and interest of an ordinary life. A suitable service is not determined by scale, scope or location but proper and consistent funding and good leadership and culture. It is important to have experienced management and continuity of service from experienced staff.

Question 4 Experience of generic/community specialist services e.g. nursing homes

Residential services must have a disability focus and experience to meet complex needs

Medical services or therapy services in the community can meet complex and significant needs but otherwise community or generic specialist services lack the resources, skills and experience to include complex and significant needs. This lack of capacity and resources is mirrored within the general community resulting in daily access to community being limited. Family members believed that community homes for persons with mixed abilities could work with sufficient and skilled staff but such services need to be disability services rather than generic services to meet the needs of those with complex and significant needs.

Appendix II-ii: Focus Group Meeting 08/10/2018



Connect Family Network

Focus Group - 8th October 2018

Family members experience of residential support needs of persons with significant and complex needs

Connect Family Network

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Reasons for Focus Group

As part of our advocacy on community living and decongregating Inclusion Ireland is represented on the HSE "Location Review Group". The "Location Review Group" is a subcommittee of the Department of Health "Time to Move On from Congregated Settings Working Group".

As part of its remit the "Location Review Group" is considering the housing and support needs of residents with significant and complex needs.

As outlined in its terms of reference the "Location Review Group" will identify appropriate best practise models to meet the residential support needs of individuals with significant specialist support needs. The "Location Review Group" will

- Examine current literature and research to identify current models of best practice
- Gather examples of current good practice within community based residential services in Ireland
- Examine applications of best practice approaches to meeting residential support needs of individuals identified as requiring specialist supports and
- Recommend on the appropriate approach to meeting residential support needs of individuals identified as requiring specialist supports, in line with current best practice.

Many "Location Review Group" members represent a service provider or service funder. Individuals with disability and family members of persons with disability are not directly represented.

Inclusion Ireland through the Connect Family Network has committed to supporting local family support groups engage with the HSE and service providers in the planning, design and review of disability policy or programmes and to giving local support groups a voice into policy and legislative formation at national level through discussion and consultation.

The purpose of the Connect Family Network focus groups (21st March and 8th October 2018) was to give family members an opportunity to engage in this examination of services, review the process and share their lived experience in relation to residential supports for family members with complex and significant support needs.

Focus Group participants
Focus group 2 met on the 8th October 2018 and was attended by 5 family members (3 women and 2 men), parents of teenagers or adults with complex and/or significant needs. The experience for some is of life at home and accessing services in the community and for others is of life in a large residential setting with transition to community living.

Connect Family Network

After introductions group members shared experiences in relation to supporting a family member with disability and their advocacy roles to date. The meeting then progressed to the focus group questions.

Focus Group Questions

1. Scope of the "Location Review Group"

The Location Review Group identifies "Individuals that may require specialist support" under the following headings:

- *Changing needs, ageing and dementia*
- *High medical need/medical frailty*
- *Behaviours that challenge*
- *Palliative Care*
- *Autism*
- *Neuro-Rehab"*

Question 1: What is your impression of this list, is it complete, would you change or remove any items?

Discussion: This review of specialist service needs in community initially prompted general discussion on the move to community. The idea of moving to community was a challenge for some particularly where the person has lived for a long time in an institutional setting or where the individual finds socialisation and change difficult. It was felt that if socialising and managing change are a difficulty in the limited environs of a congregated setting they would remain a difficulty in the community setting. There was fear expressed that services would be diluted in the community setting. There was concern that it was not possible to meet very complex medical or rehabilitative needs in a smaller community setting. The meaning and scope of decongregating as set out in HSE policy was outlined by the chair as some participants were unclear on the matter. The role of HIQA in assuring standards of services in the community as well as the larger settings was also outlined.

An initial impression of the list was that specialist services in general should not be limited in scope to serving just one type of disability, that specialist services should generally be inclusive to avoid a situation where the needs of one disability were met at the expense of other disabilities. One participant felt that the list was not exhaustive enough; would there be a service to meet the needs of individuals with multiple diagnoses?

Connect Family Network

Participants asked if apart from the initial provision of specialist supports within the person's home would there be sufficient supports to meet their changing needs or the challenges of supporting life in the community and social inclusion. The reality of these concerns was highlighted by the personal stories of family members. One participant described a very difficult transition from a larger setting to community living. Another participant outlined the very specific and changing needs of their family member with autism and intellectual disability with the added and very individual complexities of medical and sensory issues.

Question 1- Specialist support options - continued:
The role of family support was seen as key for some individuals and it was proposed that the role of family should be included on the list as family can be the specialist support (or part of) that enables the individual to live in community.

"If the person is very socially isolated they could end up on the streets if not supported in the community."

"I would be afraid they would become isolated within the community setting."

"The difficulty getting what you feel is appropriate is unreal. Our family member was in residential (congregated) in their own little place. Now in the community it is a battle."

"S needs their own environment. They are very noise sensitive; their house at present is very sound proof. Early onset dementia with intellectual disability is also an issue. The place they move to would have to be very specific and sound proof."

"Families need to be more than just listened to but need support, where genuine issues are raised in support of their family member"

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2. Community based residential or support services
The Location Review Group reports that "Evidence is that service providers are striving to support living and ageing in place within community settings. Some advocate for all service to be community based, some for specialist residential services to be provided in campus or larger settings to meet changing needs."

Question 2: Do you have experience of successful community residential or support services that are being delivered in a community setting to people with significant support needs. What makes these services successful? What are the limitations or disadvantages?

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Discussion: Much of the conversation centred on a model of community living experienced by several participants where there is also access to a central hub providing specialised supports in times of crisis or specific illnesses. The model has developed out of a process of moving to community living with specialist supports provided as and when needed, separate to the community housing, but always with a view to recovery and return to the home in the community.

The advantages of community living with attached specialist supports are that the specialist service is familiar to the individuals and there is a multidisciplinary team available to provide the supports required. The disadvantages in this case arose from the fact that the specialist services were developed out of an older model of institutional care. The disadvantages include under resourcing, poor infrastructure and larger numbers of people living together (congregated) while availing of the hub based specialist care.

There was openness to the move to community from congregated settings but worry that despite much research and planning the individual's needs might not be met. There were concerns that the move to community would result in additional pressures on family members. Concern was expressed that the work of the Location Review Group, in proposing future models of support in the community, would result in recently developed smaller scale specialist services on campuses being dismantled, without being replaced in the community and a battle to obtain community based services. Family members asked that existing services remain available until the new services were in place.

The cost of moving to community living and the need for proper long term planning was discussed. There was concern that poor advance planning and crises situations result in community placements that are very expensive and may draw resources, and therefore services, away from other placements. There was agreement on the importance of on-going individual assessments and effective future planning for the individual.

Question 2 – community based services - continued:

"But take a step down, look at the transition projects. You have to look and see, will this be the best thing for the individual. We have had difficulties (with the move to community) we are looking to see if this can be successful. I believe that some cannot move to community but know others who have successfully and say it can work."

"They should stop closing things until they have the new models operational. Why close what is working before new models are in place?
"Services should be provided on the individual needs assessment and planned."
"Individual assessment is the key. If individuals were assessed at the start (from childhood and continuing, Individual Education Plans etc.) it would be better. These expensive options (community living crises

placements) arise because of no forward planning, a last effort after years of not planning. We can't have utopia all the time (limited budgets etc.) but with proper planning a lot can be done. Whatever specialised setting is provided it should be based on individual assessment and future planning.

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3. Disability Specialist Care Units

The "Location Review Group" described an example of a specialist care unit – advanced dementia care DoC Clonsilla, on campus, 2 x 6-8 bedded homes. The model of care would propose a strict admissions policy, respite availability to other community homes run by the same service provider, the possibility of specialist outreach teams capable of carrying out assessments and providing training/support to community based individuals with changing needs.

Question 3: Do you have experience of a small scale disability specialist care unit?
What advantages are there to such a service?
What disadvantages are there to such a service?

Discussion: As per question2 family members were familiar with specialist care units; in their situation specialist care units which are used in conjunction with community living, as and when needed. According to family members the advantages are that such specialist care units give a sense of safety and belonging as the specialist service has a connection to the community living service and is familiar to residents.

The view was expressed that some individuals require a full time specialist service as their support needs are such that they could not be accommodated in a community setting without the required level of specialist support. A family member said that they could not see any disadvantages to community specialised care units but the number of residents should be capped (as in other community residential settings). They suggested a limit of perhaps 6 persons per specialist accommodation.

See discussion in **Question 2** (above) for additional thoughts on specialist care units.

4. Generic or community specialist services vs. Disability specialist services

The "Location Review Group" considered that "Some advocate that people with disabilities should be supported to access other generic specialist services e.g. nursing homes, once their needs change."

Question 4: What is your experience of people with significant support needs accessing generic /community specialist services? What has worked? What has not worked?

Discussion: there was general agreement that generic or community services do not have the capacity to meet the needs of individuals with an intellectual disability who require additional or specialist supports. A range of typical community services were discussed and the difficulties experienced highlighted.

Connect Family Network

Family members said that schools did not have the capability to support all and often will not admit the person. One focus group member referred to a nursing home that a person with challenging behaviours cannot access and several family members asked would their family member get the right supports in a generic nursing home. Attending a medical or dental clinic or hospital also posed difficulties. The benefit of having specialist information or liaison staff in generic settings was discussed.

Group members also spoke positively about specialist outreach services supporting a person living in the community but highlighted the need for better awareness and education of the wider community so that neighbours and friends etc. supporting a person informally in the community would know who to contact if specialist supports were needed.

"Our family member has medical issues and needs bloods taken. This causes a lot of distress. We have asked for sedation but in a generic setting they cannot do it (sedation), their protocols don't cover it."

"Unless you know the dentist and they have acquired experience (of the person from childhood) to deal with the situation it will not work. If (our) dentist was not there you would have some job!"

"There was a guy at X hospital given the job to be a liaison. You could call him and let him know you were on your way and he would organise things. That service has fallen by the by."

"A neighbour has a support visitor for behavioural matters. The community needs to be aware (of these services) and where to access these services."

5. Consultation with experts

The "Location Review Group" proposes meeting and consulting with experts on the support needs of residents with significant and complex needs.

Question 5: Suggestions regarding experts to be consulted and research or literature on positive service options being delivered here or elsewhere

Response: Family members who attended the focus group suggested contacting family and friends associations for their input. The associations could represent views while giving anonymity to individual family members.

Other suggestions included:

- Muiriosa Services, found to be very progressive.
- Monaghan Parents and Friends MH Association, building community housing on an on-going basis
- St. Raphael's Parents and Friends Association, Celbridge

Appendix II-iii: Summary of Findings from Focus Group Meetings

Connect Family Network

Summary of findings

Question 1 Scope of the Location Review Group

Fear of change, the importance of individual specific and adapting supports when living in the community
Overall the discussion did not focus on the possible service options but on the current and future support needs of individuals. Will the significant and changing support needs of the person be met, in or through their community based residence? Will the person be supported and included in the wider community? Family was also seen as a specialist support, a means of community living and inclusion and, where appropriate, should be included as such.

Question 2 Experience of Community based residential or support services, what makes community based services successful and what are the limitations or disadvantages?

Community living **with** access to specialist services as needed, future planning based on individual assessment is fundamental.

Family members had experience of community living with access to specialist supports (a specialist hub) as needed and were in favour of such a service model. In their experience poor advance planning results in crises placements that are expensive. Access to community and specialist services should be informed by continuing individual assessment and effective long term planning for the person with significant and complex needs.

Question 3 Experience of small scale disability specialist care units, the advantages, the disadvantages

Specialist Care Units – an essential resource to support community living, as and when needed.
It was felt that the support needs of some individuals were such that they would require a full time specialist service in the community but that for many, living in the community could work with access to specialist support (residential and outreach) as and when needed. As with other community living options the number of persons living in a single special care unit should be capped.

Question 4 Experience of generic/community specialist services e.g. nursing homes

Specialist outreach support and dedicated trained staff are required to enable community or generic services meet the needs of individuals with significant and complex needs.
General family experience was that generic services did not have the capacity to meet the needs of individuals with intellectual disability requiring specialist supports. However access to experienced and dedicated staff or the provision of specialist outreach services and the availability of information or liaison staff resulted in generic or community services that were accessible and capable.

Appendix III: Engagement with Experts

Stakeholder Consultation Questionnaire

1. Scope of the "Location Review Group"

> *The Location Review Group identifies "Individuals that may require specialist support" under the following headings:*
> - *Changing needs, ageing and dementia*
> - *High medical need/medical frailty*
> - *Behaviours that challenge*
> - *Palliative Care*
> - *Autism*
> - *Neuro-Rehab*

What is your impression of this list, is it complete, would you change or remove any items?

2. Community based residential or support services

Do you have experience of successful community residential or support services that are being delivered in a community setting to people with significant support needs. What makes these services successful? What are the limitations or disadvantages?

3. Disability Specialist Care Units

Do you have experience of a small scale disability specialist care unit?
What advantages are there to such a service?
What disadvantages are there to such a service?

4. Generic or community specialist services vs. Disability specialist services

What is your experience of people with significant support needs accessing generic /community specialist services? What has worked? What has not worked?

5. Consultation with experts

Do you have any suggestions as to experts who could be consulted and research or literature on positive service options being delivered here or elsewhere?

Appendix III-i: Note of Engagement with Disability Staff and Services

Southeast Community Healthcare

A meeting was held with members of the Disability Service Team. Disability services across Southeast Community Care are delivered across a large group of small voluntary service providers and HSE run facilities that operate in local catchment areas and support a small number of people supported. There are two Section 38 agencies that provide some residential services. There is a concentration of intentional communities in the South East area. The key issues raised at the meeting included:

- There is a need for an access policy for Disability Services
- Ageing in place is recognised as the ideal model, but many social houses supported by disability services are struggling to meet changing and increasing need. This can also impact of other service users who may share a home.
- There is a need for a national pathway for person with ID accessing additional supports such as therapeutic interventions. Adult MDT's to include OT, Physio, SLT, behaviour support, Pharmacist and Psychiatry ID increasing as with need.
- Difficulties in accessing diagnostic tests are leading to behaviours being an indicator of changing need which are not clinically diagnosed. There is a need for specialist geriatrician for people with ID to ensure that clinical needs are diagnosis effectively and treated.
- There is a need for transition plan pathway or specific local intellectual disability dementia units to support people to remain in their own community with staff who know them best. The Area queried could this be registered under NTPF so that NHSS can be applied for and then under nursing home status for HIQA.
- There is inequitable access to supports between people with ID and people living in community who are ageing e.g. option for social housing v nursing home, which could be viewed as a reverse inequity. When the general population age and can no longer remain at home they have apply for NHSS and are financially assessed under the scheme. However, as an older person with ID ages they are financially supported to age in place without any additional financial assessment.
- There is a need for shared care approach between disability services, older persons and primary care
- There is a need for a recognised residential disability funding stream for service to ensure fairness and equity of provision
- There is inequity when many younger people with a disability are now in nursing homes awaiting placement in a community home whilst other people with extensive needs are being supported in social care houses in placements are beyond the remit of the design and purpose of the house and the people who live there.
- There is recognition that the voluntary disability agencies in the Area are doing their best to meet the needs of the ageing profile within the social housing model, but that this is not sustainable in the long term.
- The demographical profile of the local population indicates that many more people with disabilities will require a residential service going forward. An ageing Carer population (parents

and siblings), a slow turnover in residential places, as people with disabilities are living longer means that there is a need for more proactive approach to managing this issue.

Meeting with Cork Kerry Community Healthcare Residential Placement Committee

A meeting was held with members of the Cork Kerry Community Healthcare Residential Placement Committee and the Disability Services Team. Disability services in Cork Kerry Community Healthcare are in the main provided by approximately 10 voluntary service providers and dispersed geographically across the region. The largest provides residential services to over 400 people. The HSE has two services, both of whom have made significant progress in transitioning people to community homes in the last number of years.

The Time to Move On Project Lead met with the group and outlined her role as Lead for the Time to Move On policy and updated the group on progress to date of the policy implementation and spoke about the establishment of the Location Review group.

Feedback on the day

- There is a lack of access to generic primary care services for people with ID who live in the community
- There is a lack of access to multi-disciplinary supports for adults. Additionally in many cases when children with a disability who had been receiving support, transition to the adults service the level of support decreases significantly or ceases completely,.
- The long lead in time for CAS Housing (Capital Assistance Scheme under the Department of Housing) with the requirement to confirm the funding to meet the support needs for those accessing CAS funded homes is also problematic.
- The high cost of emergency care and the lack of residential services for people outside of congregated settings are a challenge. In this Area a proposal is being developed to look at developing a service and/or a response that will provide capacity to support individuals who are currently in private service provision. Not sure what this means Out of area?
- There is a lack of services for people who require psychiatric inputs despite the service model for MHID in the Vision for Change policy.
- The Area has found that implementing the Time to Move on policy is not cost neutral which is putting additional financial burden on existing services.

Appendix III-ii: Submission from Kerry Parents and Friends Association

Kerry Parents and Friends Association,
Old Monastery,
Port Road,
Killarney,
Co. Kerry
(064) 663 2742

Submission from Kerry Parents and Friends Association,, Killarney , Co. Kerry.

Kerry Parents & Friends Association supports the proposal for specialist residential models of service for older adults with intellectual disability. We are basing our support for this proposal on the following:

- A recently completed service based study (Dukes & Coughlan 2019) carried out by our department of psychology in conjunction with the University of Limerick found that the ageing experience of people with lifelong intellectual disability differs from that of the general population. The study focussed on psychosocial health and showed that areas such as self-determination, safety, loss, social engagement and coping patterns require specialised supports and these supports are at variance from that required by the general ageing population.

- Figures published by the Centre for Ageing Research and Development in Ireland (CARDI) in 2015 demonstrate the growth in numbers in people ageing with an intellectual disability in the last decades. Their figures show that in 1974 only 29% of people with an intellectual disability were aged 35 or over. By 2013 this figure had risen to 49 %. CARDI also draw attention to the projected growth in numbers in people ageing with intellectual disability in the next two decades as in 2013 the most populous age group was in the 35 to 54 range. This trend is reflected in figures available from the National Intellectual Disability Database (Kelly and O'Donoghue, 2014). A review of our figures in terms of age profile of the people supported by Kerry Parents & Friends also shows a continuing trend towards older age with up to 38% of our service users in the older age category. As such, old age is now an important part of life for many more individuals. While this is very good news it poses challenges for health care providers and health care professionals and there is an immediate need to re-assess our models of service. In Kerry Parents & Friends we continue to support older people in mixed age settings alongside younger individuals with challenging and complex needs. Findings from our service based study (Dukes and Coughlan, 2019) show that older adults with intellectual disability feel unsafe in this type of environment. This is not acceptable to us and we are continuously striving to ensure that older service users can feel safe as they navigate later life. Older-age specific models of service are urgently needed.

- In Kerry Parents & Friends we are experiencing first-hand the impact of dementia on our Down syndrome population and the requirement for focussed and specific dementia care. While the prevalence of dementia in the general population in persons up to 85 years of age is 5% the comparable figure in those with Down syndrome is 50% (*https://www.nia.nih.gov/health/alzheimers).* There is a strong argument for a specialised service for our older adults with Down syndrome as not only are prevalence rates for dementia extremely high, the trajectory of the condition is also at variance with the experience of the general population. Specifically, we have observed over the last 10 years that the very late stage of the condition can be protracted and the care needs very specialised and intense.

As a service provider in the intellectual disability sector we strive for the best quality of life for the people we serve. At this time a main priority for us is to achieve a better match between the service we provide and the needs of our older adults. This requires creative thinking and the people we support have waited long enough. Specialised older age residential settings would ensure that people ageing with intellectual disability would receive timely and appropriate support commensurate with their very specific requirements and have a safe and fulfilling ageing experience.

Eileen Dukes, Clinical Psychologist.

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Appendix III-iii: Submission from St. John of God Services, Co. Kerry.

Transforming lives is not merely about the structure of residential services and congregated services it is far more reaching than this and involves a fundamental transformation of how people with disabilities are supported through the country's health and social care services. Transformation can only be achieved through real and meaningful engagement with service users. A rights based approach to service delivery across all government departments is a critical element of this transformation e.g. Housing, Transport and health.

The HSE Transforming Lives supporting Person Centre Disability Services progress Report 2016
Outlines The Transforming Lives Programme vision as:

"To contribute to the realisation of a society where people with disabilities are supported;

(a) To participate to their full potential in economic and social life

(b) To have access to a range of quality personal social supports and services that enhances their quality of life and well-being."

The Department of Health and the Working Group have signed off on the 9 outcomes recommended by the National Disability Authority (NDA) research department. The 9 Quality Outcomes will now underpin the Development of a National Quality Framework for Disability Services.
The 9 Quality Outcomes are as follows:

- Are individuals living in their own homes in the community?
- Are individuals choosing and controlling their own lives?
- Are individuals participating in social and civic life?
- Have individual's personal relationships?
- Have individuals opportunities for personal development and fulfilment of aspirations?
- Have individuals a job or other valued social role?
- Are individuals enjoying a good quality of life?
- Are individuals achieving best possible health and wellbeing?
- Are individuals safe, secure and free from abuse?

These Quality Outcomes are measurable through the Council on Quality and Leadership CQL Personal Outcome measures which is a quality system used across many Service Providers in Ireland over the last two decades. The introduction of Health Act 2007 (Care and Support of

Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulation 2013 Regulation whilst hugely positive has meant for many services challenged with compliance that the focus has shifted away from the use of Personal Outcome Measures to using primarily compliance tools from the Regulator. The quality outcomes identified are in actual fact people's fundamental human rights and this should be the language used to describe them.

The impact of registration:

It is important to consider that not all compliant or registered services are delivering the 9 quality outcomes identified and in actual fact the variation in the attainment of these outcomes varies greatly for people. There can be an assumption that registered services are good services, however, this can only be measured through the person's quality of life. The men and women in larger settings do not experience the same quality of life as other people with similar needs do in community based services. Registration and compliance with regulation delivers the minimum that men and women are entitled to and aims to ensure services are safe and secure places to be.

Experts by Experience:
The experts on Disability Services are the persons with the disabilities. They live and have lived the experience. All others are stakeholders. It is critical that people with disabilities are fully consulted and heard in any process of transformation. The voice of people who communicate through different means e.g. non-verbal, behavioural, body language needs to be heard from in the first instance and based on this consultation, which can be intrinsic, should other stakeholders become involved. Individuals with complex needs and fragility also need to be supported in having their voices heard in a manner which supports their human rights and avoid the risk of being over supported away from society.

Family can be bedrock of support and advocacy for people with disabilities and they should play a key and central role in the transformation of services. They too are experts on how services impact on them, their family life and their family member. In the case of residential services this should not be confused with the "expert by experience" as it is the individual service users who lives in the service and experiences what it is really like, all other stakeholders go home. Society can often have low expectations for people with disability and once these individuals are cared for in a setting society and the persons family can often feel their needs are met. Our expectations and standards for people with disability need to be the same as they are those we expect for ourselves. People have a fundamental right to an ordinary life where these fundamental rights are respected. The transforming lives initiative cannot be under estimated in its potential to deliver real change to the men women and children with disabilities in our society.

The HSE Adult Residential Forum:
The HSE residential forum requested feedback from Service Providers on transforming lives under the following headings:

What works well?
What does not work well?
Potential Solutions
Views on specialist services

Questions were circulated to managers within our Service for their perspectives and responses were then collated. The document was also were informed by data relating to the men and women who live in the Services which is escalated through various means e.g. risk, incidents, and staff. Our Service also runs a variety of residential services from small group homes, supported living apartments and campus based services.

Transforming Lives

What works well?

- Person Centred Planning process and use of data to support and determine residents lived experiences of the current service and to identify future goals.
- Very positive reaction from the service users who have had the chance to live in our house in community.
- Residents who sampled a community house option have, through their nonverbal reaction, been able to change the view of their family advocate who thought the campus setting was what their family member wanted and needed.
- Positive reactions from families of service users who now live in community houses.
- Staff learning and change in attitude towards community living once residents moved from campus setting.
- CAS funding is available from County Council. This could be utilised to develop a network of services based on moves from congregated settings and unmet need.
- HSE Estates Property Development and working jointly on the project.
- Developing links with other providers who have completed moves – lessons learned.
- The development of funding for a Community Transition Co-Ordinator and Project Manager Roles will develop and drive project goals, motivation for teams trying to progress resident's goals and problem solving.
- Positive examples to share with families.
- For the fortunate residents who have the opportunity to move to the community, it is life changing and this is well evidenced.
- Community supports and the willingness of communities to support.
- Project Manager post has driven de-congregation in other CHO areas, particularly helpful the fact the project person was a HSE employee.
- Development of joint Transforming Lives Committee with the HSE CHO area.
- There are some good examples of Primary Care Services working well with residential and day teams to support individuals e.g. SLT, OT, Public Health nurse, access to aids and appliances for medical card holders.
- The involvement of generic palliative care team in services as required.

What does not work well?

- There is an expectation that services identified as currently being under-funded will have the capacity to de-bundle resources in the initial phase of projects.
- There is inconsistency in relation to lease agreements from CHO areas.
- There is huge political pressure to resist any move from congregated settings in the local area despite the challenges that residents face.
- There is a lack of confidence among stakeholders that the individuals' medical, therapeutic and safety will be guaranteed in community settings.

- Discussing 'possibilities' with families without definitive timeframes, locations, revenue for build and staffing costs.
- The experience of some individuals being unable to access generic services, aids and appliances the same as any other medical card holder
- Access to mainstream psychiatric services and the availability of specialist behaviour supports in community teams.
- The focus of development is narrowed to decongregation as opposed to looking at the wider potential and unmet need for residential supports. Offering choice with whom I live is not choice if it is narrowed to the existing population in the congregated setting and leaves the unmet needs of people outside these settings unaddressed also.
- Co-ordinated approach across all Service Providers as opposed to working in isolation.
- Revenue and capital is channelled to services with closure orders and compliance issues. This is double edged as it leaves residents in registered services in congregated settings that do not deliver the 9 quality outcomes with no investment in improving their lives.
- Unable to apply for CAS without confirmation that all revenue funding is in place.
- Capacity issues for individuals to enter into tenancy agreements.
- The voice of the family can be louder than the voice of the resident who communicates using alternative means.
- The role of the independent advocate is not a reality on the ground for the men and women in services and trying to access services.
- Lack of meaningful engagement with service users and family members (reference https://www.hse.ie/eng/services/publications/effective-participation-in-decision-making-final.pdf)

Potential Solutions

- The strengthening of the Transforming Lives Leadership Committees for CHO areas and include cross-communication.
- A defined budget should be identified as part of each services de-congregation plan by the HSE for the first three years to support individuals who wish to move to the community
- Providers need to be advised what revenue will be made available for 3 year plan so all stakeholders can get involved.
- Availability of revenue- to allow movement to be finalised and clarity for families as to service provided as community client.
- Given the fact that Time to Move on from Congregated Settings is over 8 years old, the need to develop a realistic strategy on where the plan is at now and what the plan is for implementation over the next 3-5 years.
- Services need to project the population level in the settings that will facilitate the de-bundle of resources toward community living.
- Strategic plans reflect meaningful time lines and incorporate cross service working including local disability team.

- The access for medical card holders to services is progressed with primary care services and other health services for all individuals regardless of where they live. The issues for primary care and other services need to be identified and addressed as part of this process.
- Many congregated services are paying retainer fees to ensure men and women can access services whilst this cannot be undone without supporting services develop in a manner to meet the needs of people with disability and Intellectual disability it should remain the vision and be actively worked towards.
- Progress mental health teams for people with ID.
- Funding needs to be made available to all congregated settings not just those with closure orders as all services significantly impact on the persons quality of life.

Specialist services:

It is critical teams supporting specific needs require the skillset and training to deliver high standards of services to deliver on individual quality outcomes. Specialist services should not be translated to mean congregated services. Many individuals present with significant challenging behaviour, however, it is important to understand very minor issues can lead to extreme responses from individuals if not addressed. Everybody has the right to live in the community this is a fundamental human right, the challenge for us; the current architects of services, is to ensure the right supports and skill sets are in place not only in our residential services but in all aspects of health services that interact with people with disabilities and people with intellectual disability in the course of their lives.

Residents should be allowed age in place as is the case in the community. However, like all people in society the impact of aging in place has to be assessed based on the person’s wishes and the impact on the household. As with all individuals there may come a time when a specialist service is required and with this in mind these services should be available based on the population. To date, people with ID and disabilities do not have good outcomes when placed in generic elderly services. Given that these services themselves are primarily congregated settings this is not surprising. Coupled with the lack of expertise and experience teams in nursing homes have with supporting people with intellectual disability / Disability it is more appropriate to have smaller community services available where individuals can be supported to live with their changing needs e.g. dementia and not be prematurely progressed to elderly and end of life service.

- With respect to individuals with behaviours that challenge, these individuals should be living in a community setting with plenty of space in their environment and not in a congregated setting. The option of individuals living in small scale homes/apartments in the community interlinked to provide cross support is worth exploring
- Elder care- community based medium setting 8-12 persons cluster type accommodation with 3-4 individuals per residence with central attached hub to support community activity, to provide for staff support and peer to peer learning, risk prevention.
- With respect to specialist services such as dementia again a purpose built house in the community would be far better than a congregated setting.

- The clinical competence of staff declines if not utilized so it is important to consider some team members having opportunity to work across settings to maintain a strong clinical focus in their work.
- There are many people who may wish to remain in their family home, however, they find seeking residential support as the only option available. The need to assess and identify both individual and carers needs is important to progress a more structured response to PA services and home support services from providers.
- The need for these services to be supported through skilled community teams is essential and needs to be developed through progressing disability services.

There is no doubt every individual has the ability to communicate. The challenge for all of us as family members, providers and communities is to listen; and for those who hear, to advocate on the messages heard.

Information collated By: Ms Nora Brosnan, Saint John of God Services.

Appendix III-iv: Notes on the submissions from Rehabcare & the Cork Kerry Community Healthcare Area

The submission from Rehabcare raised 4 specific concerns

1) Adequate GP services - GP's are reluctant to take more individuals on who are medical card holders, particularly when there is a need for certain processes to adhere to HIQA requirements - evidently financially it can be difficult for them.
2) Specialist older persons services are limited i.e. either residential placements, or supports for people with older needs and an ID. Inappropriate placing in nursing homes can cause issues. Similarly for those requiring end of life care, residential homes may be too noisy and active, and yet there is little alternative for those with an ID. We have seen significant health issues with people who have decongregated, particularly those clients who are older.
3) Those individuals who challenged services have managed to move into the community. However, we have little flexibility of different housing needs. For example, there is little flexibility or alternatives where individuals have found community living difficult. This may have been resolved should there have been variations in accommodation - separate flats, small house for 1/2.
   The choice of accommodation type can ensure whether it is successful for those who require what was deemed a "specialist" provision in certain situations. The environment can be key, rather than just the supports.
4) Being able to respond to changing needs is challenging - how do we anticipate changes in health, age, relationships. These are normal processes and yet often there is little choice for movement.

The Disability Manager Cork-Kerry Community Healthcare also highlighted a number of issues as follows:

- Specialist Services for Individuals with dual diagnosis of ID, Autism and Mental Health – there is a required to plan for MHID services and what the profile of day places, residential places will look like. The Vision for change policy does not clearly articulate this.

- Specialist Services for Individuals with Autism and Challenging Behaviours – there is significant growth in the number of individuals presenting with Autism and challenging behaviours both in child and adult age group; they require significant levels of support and on individualised living arrangement. We need to be considering specialist Residential support services designed to accommodate single living arrangements but within a designated site to maximise staffing resources.

- Aging Profile of individuals with ID, Down Syndrome and the impacts of ageing in services. The impacts of ageing and dementia and Alzheimer's on services is going to pose significant challenges.

- Impact of community living on primary care is something that requires significant discussions around accessing mainstream services and services people with medical cards are entitled to.

Appendix III-v: Submission from CHO 3

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

CHO 3 Discussion Paper.

RESPONDING TO THE NEEDS OF OLDER PEOPLE WITH DISABILITIES

This document has been produced by the HSE in CHO 3 in collaboration with a number of residential service providers to highlight the need to develop and implement a model of care and support that can respond to the changing healthcare requirements of people with Intellectual, Physical and Sensory Disabilities as they grow older, in order to ensure that their specific needs are met in the most appropriate setting/service possible.

Background:

Globally, people are living longer. It is well documented and widely recognised that population ageing is one the greatest success stories of the modern world. In the Irish context, it is predicted that the population of older adults will rise significantly from 532,000 in 2011 to 1.4 million by 2046. The "very old" population is expected to increase even more dramatically from 128,000 in 2011 to 484,000 in 2046 (Central Statistics Office 2013).

Ageing is a relatively new phenomenon for people with disabilities. Findings from the 2016 Census indicate that the number of people with a disability increased by 47,796 between 2011 and 2016 and now accounts for 13.5% of the population. Up to one in ten persons below 45 years of age had a disability, rising to 20% by age 60. The number of people aged 35 years and over reporting a disability with moderate, severe and profound Intellectual Disability has increased from 28.5% in 1974 to 49.3% in 2016 (CSO, 2016). Furthermore, the National Intellectual Disability Database (NIDD) registrations have increased by over 2,000 to a current total of 28,275. (NIDD, 2016). Increased longevity for people with Disability is a triumph of modern times. However, the changing age profile of adults with Disability is having a significant effect on service delivery and quality of life.

People with disabilities live in a variety of residential situations. Some live at home, some live in community group homes, many live in congregated residential settings and a small number live independently or semi independently. There were 44,531 people with disabilities living in communal establishments in April 2016 (CSO, 2016).

The NSW Ministry of Health (2012) outlined that people with ID have poorer health outcomes and greater difficulty obtaining health services in comparison with the general population and have a high prevalence of significant medical problems. In addition, their health conditions are often unrecognised, misdiagnosed and poorly managed. Haveman, et al. 2011, report a greater variety of healthcare needs as compared to the general population. The IDS – TILDA (2011) study supports these findings and highlights concerns in areas such as cardiac issues and associated risk factors, epilepsy, constipation, arthritis, osteoporosis, urinary incontinence, falls, cancer and thyroid disease.

People with disabilities have the same needs and rights with regard to medical care, adequate nutrition, housing, social interaction, etc. as the general population. However, generally, they have a higher risk of developing chronic health conditions at younger ages than other adults due to the confluence of biological factors in relation to syndromes and associated disabilities. Many of the residential facilities in which services are currently provided are not suitable for people as they become more physically, mentally and medically dependent due to the ageing process.

Consideration needs to be afforded to the development and implementation of a model of care and support that can respond to the changing and complex needs of people with disabilities as they grow older.

Legislation and Policy:

The everyday life of older people with disabilities is different to others within society in many ways. For many years researchers have delineated the need for policy makers to recognise the changing support requirements of ageing people with ID (Hogg, Moss, & Cooke, 1988; Janicki &Wisniewski, 1985; Seltzer & Krauss, 1987; Sutton, Factor, Hawkins, Heller, & Seltzer, 1993 in Bigby 2010). In the Irish context, this view is supported in the IDS TILDA study (McCarron et al 2013).

In recent years, a number of key documents have been published that aim to support the lives of people in Ireland as they age. **The National Positive Ageing Strategy (DOH 2013)** identifies the future of Ireland in relation to meeting the needs of older people. The strategy aims to ensure all older people in Ireland live long and healthy lives, where social integration and family life are seen to be central to overall wellbeing. The National Positive Ageing Strategy (DOH 2013) has four national goals and an implementation plan. ***National Positive Ageing Strategy (DOH 2013)*** promotes ageing which enables and supports older people to enjoy optimum physical and mental health and wellbeing and to participate in economic, social, cultural, community and family life. It also highlights equality, independence, participation, care, self-fulfilment and dignity as key principles for older people in Ireland. In addition, the strategy makes reference to the dramatically changing Irish population from a young homogenous population to an ageing multi-cultural Ireland, thereby presenting new challenges for government, policy makers, healthcare providers and society as a whole. How we respond to these changes is pivotal in determining the health and wellbeing outcomes and quality of life of people as they age in Ireland ***(National Positive Ageing Strategy (2013).***

An ageing population has implications for policy, service delivery and long-term planning in areas such as health, housing and environment. One key area of concern when considering the ageing population is the provision of long-term care. There is no provision within this strategy specifically for ageing people with Disability.

The Irish National Dementia Strategy (DOH 2014) outlines the need to ensure that resources are available as efficiently and effectively as possible to all those with Dementia including people with ID. Incidence of Dementia is the same for people with ID as the general population with the exception of Down Syndrome where the incidence is much higher (McCarron et al 2010). Diagnosis of Dementia in people with ID is difficult and management of healthcare needs following diagnosis requires a different approach for people with ID to that of people without. People with ID who develop Dementia are a disadvantaged group within society and are at risk of being unnoticed within mainstream Dementia service providers (Cahill et al 2012). While The National Dementia Strategy does include people with ID and Dementia, it may not go far enough in considering the unique difficulties and specialist services required by the ID population who develop Dementia.

Future Health (DOH 2012) was published by the Department of Health in 2012. This document outlines the aim of the Government to reduce the need for long term residential care for ageing adults by providing home care supports. There is no provision within Future Health specifically for ageing adults with ID.

The ***HSE 2018, National Service Plan*** identifies the following priorities:
Corporate Plan Goal 2: Provide fair, equitable and timely access to quality, safe health services that people need: Progress implementation of the of the national policy for reform of the disability services *Transforming Lives* – the programme for implementing the *Value for Money and Policy Review of Disability Services in Ireland, 2012.*

> *"Develop a strategic five-year framework to support multi – annual planning for residential care services and community supports taking account of national database projections and the need to develop sustainable models of services which achieve HIQA compliance with approved timeframes (such as additional places and changing needs".*

The ***Healthy and Positive Ageing for All Research Strategy (2015-2019),*** Pillar 3, refers to *'Ageing in Place'* and states:

> *'As people age, they spend more time in their homes. The condition of the home environment and its appropriateness has an impact on their health, wellbeing and quality of life. 'Ageing in place' has positive benefits for people as they age, for example continued social contact and relationships, and control over their life and daily routines (Department of Health, 2015a). However, poor quality housing design can limit daily activities, thus causing deterioration in physical and mental health'.*

Demographics CHO 3:

In CHO 3, residential services for people with disabilities are provided by a number of voluntary and private organisations with funding from the HSE. Traditionally, residential services for people with ID have been provided from *"cradle to the grave".* The model of service delivery has been through *"Congregated Settings"* in the main, i.e., large institutional-type facilities. Developments in residential supports for people with Disabilities in Ireland today reflect international moves towards individualised supports and community inclusion. Reflecting these policies, providers over the past 20 years have recognised the importance of satisfactory living arrangements in the everyday lives of people with disabilities. Accordingly, they have developed smaller-scale and more ordinary residential supports, such as group homes in community houses, supported independent living in apartments and supported living within the person's home. These trends are evident in changing patterns of residential accommodation for Irish adults with intellectual disabilities (National Disability Authority, 2007). In addition, to those clients that are provided with residential services and community services, there are a number of people with Disability who are cared for in their own homes by parents and/or other family members, many with varying levels of support from the care services, e.g., day services. For those living at home with a Disability care givers are often older adults, themselves requiring support for their own ageing difficulties.

The table below outlines the age profile of people with Disability living in residential services in CHO 3.

Table 1. Age Profile of Residents, CHO 3(November, 2017)

	Age Profile of Residents (November, 2017)								
Designated Centre Name	**0-20 yrs**	**21-30 yrs**	**31-40 yrs**	**41-50yrs**	**51 - 60 yrs**	**61- 70yrs**	**71 - 80yrs**	**80+ yrs**	**Total**
Brothers of Charity Limerick	0	2	13	65	93	31	10	3	217
Brothers of Charity Clare	3	22	15	20	13	9	1	0	83
Daughters of Charity Limerick	2	9	42	64	52	25	15	2	211
Daughters of Charity - Roscrea	0	4	44	36	25	9	1	0	119
St. Josephs Foundation	1	16	8	13	17	4	0	0	59
Rehabcare	8	44	14	13	3	1			83
Camphill	1	4							5
Enable	53	2	4	0	1	0	0	0	60
Acquired Brain Injury Ireland	0	1	4	4	2	1	0	0	12
Cheshire	0	1	2	5	6	12	1	0	27
Moorehaven	0	1	0	2	0	0	0	0	3
TOTAL	**68**	**106**	**146**	**222**	**212**	**92**	**28**	**5**	**879**

The above table highlights a significant number of people in the over 50 years' age bracket. This poses a challenge for the provision of services for people with Disabilities and the associated challenges that ageing brings.

Responding to an Ageing Population:

While the increased life expectancy of people with Disability is to be welcomed, it does present challenges. In order to address this changing need, services must ensure improved access to generic older person's services as well as the development of a more active infrastructure of specialised expertise. It is essential that the infrastructure comprise professionals who are skilled and experienced in the provision of health care to people with Disability and that it can facilitate service delivery whether from generic service providers, such as GPs or from specialised service.

Consideration needs to be given to those individuals that moved to community settings as part of de congregation and are now unable to remain in such settings due to changing needs associated with ageing.

Physical Health of Adults with and Intellectual Disability Ageing in Ireland 2011.

Table 2. General and age specific prevalence rates of health problems:

Health Problems	**40 – 49 years (n = 274)**		**50 – 64 years (n = 344)**		**65 years + (n = 134)**	
	%	Frequency	%	Frequency	%	Frequency
Abnormal Heart Rhythm	4.4	12	2.9	10	3.7	5
Macular Degeneration	1.1	3	3.8	13	3.8	5
Angina	0.4	1	0.9	3	2.2	3
Angioplast/Stint	0.4	1	0.3	1	-	-
Arthritis	7.0	19	11.7	40	16.4	22
Asthma	3.6	10	5.2	18	7.5	10
Cancer	1.8	5	4.1	14	9.9	13
Cataracts	11.4	31	12.0	41	19.4	26
Cerebral Palsy	7.3	20	5.2	18	3.7	5
Chronic constipation	13.5	37	17.7	61	23.9	32
Chronic lung disease	4.1	11	1.5	5	8.2	11
Cirrhosis	0.7	2	0.6	2	-	-
Coeliac disease	2.2	6	2.3	8	1.5	2
Congestive Heart Failure	0.7	2	0.3	1	6.8	9
Diabetes	3.3	9	10.5	36	12.2	16
Epilepsy	32.7	89	30.7	105	26.1	35
Gastroesophageal reflux disease	5.8	16	7.8	27	11.9	16
Glaucoma	-	-	1.8	6	3.0	4
Heart Attack	0.4	1	0.9	3	3.0	4
Heart murmur	6.2	17	4.7	16	3.0	4
High Cholesterol	24.2	66	32.9	113	43.3	58

Hypertension	7.3	20	17.4	59	27.6	37
Multiple Sclerosis	0.4	1	0.3	1	-	-
Muscular dystrophy	0.4	1	0.3	1	-	-
Open heart surgery	0.7	2	0.6	2	-	-
Osteoporosis	2.9	8	9.0	31	16.4	22
Parkinson’s	-	-	-	-	5.3	7
PKU	1.6	5	1.5	5	-	-
Scoliosis	6.9	19	4.4	15	3.0	4
Spina bifida	1.1	3	0.3	1	0.7	1
Stomach ulcer	4.0	11	4.7	16	4.5	6
Stroke	0.7	2		3	3.0	4
Thyroid disease hyper/hypo	13.9	38		59	9.7	13
Transient Ischaemic Attack	0.7	2		6	7.5	10
Varicose ulcers	0.7	2		6	4.5	6

Growing Older with an Intellectual Disability in Ireland TILDA (2011)

Possible Solutions/Suggestions

a) Specialised Disability Health Service Staff working together as a multidisciplinary team providing coordinated and integrated services for a local community while also providing advice to general primary and secondary health services.

b) Centre of Excellence (Specialist Nursing Home-type accommodation) for older people with ID and Physical and Sensory Disability, with the provision of the necessary clinical skills on site. The development of a centre of excellence would also provide a focal point for improved clinical practice based on robust evidence through the development of clinical practice and clinical education programs.

c) Enhancing the capacity of existing services to meet their health needs by future proofing community residences now as they are developed to ensure that people, as they age, can continue to live in their current environments. Issues to be considered include single storey accommodation, access, etc.

d) Sheltered housing type accommodation models especially tailored towards people with Disabilities.

e) If a client is admitted to a nursing home due to increasing physical needs associated with the ageing process, consideration should be given to funding the disability service that have supported the person in a residential service up to that time to continue to provide day supports for the client.

f) Combinations of two or more of the above.

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Appendix IV: Engagement with other National Strategy & Policy Leads

Disability Strategy and Planning - Engagement with National Dementia Strategy

A meeting was held in November 2018 with staff from the National Dementia Office. An Engagement Paper was prepared and circulated in advance of a meeting to support and guide the discussion.

Engagement Paper

Time to Move On from Congregated Settings – a Strategy for Community Inclusion / Engagement with National Dementia Strategy

Background:

In June 2011 the Report Time to Move on from Congregated Settings – a Strategy for Community Inclusion was published. The report identified that in 2008 approximately 4,000 individuals with disabilities lived in congregated type settings, defined as

"where ten or more people reside in a single living unit or are campus based"

The report recommended a seven year timeframe for the implementation of the policy throughout disability services from 2012 -2019 and made 31 recommendations covering a wide range of issues and identifying a diverse group of stakeholders and responsible bodies.

The Time to Move on Subgroup under the Transforming Lives Programme is driving the implementation of the recommendations of the Department of Health's 2012 Value for Money and Policy Review report with responsibility for:

Implementing the initiatives which underpin and enable a new model for residential support in the mainstream community, where people with disabilities are supported to live ordinary lives in ordinary places.

As part of this work in 2017 a Workstream undertook to:
To identify appropriate best practice models to meet the residential support needs of individuals with significant specialist support needs.

To deliver on this the group agreed a number of actions:

- Examine current literature and research to identify current models of best practice in relation to residential supports for those with significant support needs.
- Gather examples of current good practice within community based residential services in Ireland.
- Identify individuals in residential settings whose support needs may require a specialist solution.
- Examine application of best practice approaches to meeting residential support needs of individuals identified as requiring specialist supports.
- Recommend on the appropriate approach to meeting the residential support needs of individuals identified as requiring specialist supports in line with current best practice.

Engagement with National Dementia Office

The NDO team outlined the work currently being undertaken through a number of programmes (resourced through the Dormant Accounts Fund), which will provide learning and support for people with dementia, their families and carers:

1. National Rollout of Dementia Training Programme for HSE Home Care staff.

2. Dementia Resource Centres and Outreach Project: A centre of excellence will be established in Dublin in 2019 and will have three outreach services. The services will provide community supports to people living with dementia and family carers and will work with and complement the post-diagnostic and diagnostic pathway projects. They will also link to the Memory Technology Resource Rooms which are being established.

3. A National Intellectual Disability Memory Service: Will provide dementia assessment and diagnosis for people with an intellectual disability (ID), particularly people with Down's syndrome who have an increased genetic risk for dementia. A central coordinating national memory clinic, based in a Dublin teaching hospital, with a number of satellite clinics will also offer training programmes to staff and family members supporting persons with ID with or at risk for dementia. A dementia assessment and comprehensive diagnostic work-up for dementia will be offered to persons with ID with suspected cognitive changes, arising from local dementia screening.

4. Guideline development group on prescribing psychotropic medication to people with dementia: While the work of this group has a broader remit than Intellectual Disability Services there is a sub-group considering the impact on people with an Intellectual Disability. The aim of the guideline is to work to reduce the overall prescribing of psychotropic medicines.

The NDO team will continue to engage with the National Disability Strategy and Planning Team to ensure that the needs of the ID population will be included in the planning and development of services for people with dementia.

Disability Strategy and Planning - Engagement with National Palliative Strategy

A meeting was held in January 2019 with the National Lead for Palliative Care. An Engagement Paper was prepared and circulated in advance of a meeting to support and guide the discussion.

Engagement Paper

In June 2011 the Report Time to Move on from Congregated Settings – a Strategy for Community Inclusion was published. The report identified that in 2008 approximately 4,000 individuals with disabilities lived in congregated type settings, defined as***"where ten or more people reside in a single living unit or are campus based"***

At a national level, the Time to Move on Subgroup under the Transforming Lives Programme is driving the implementation of policy and has responsibility for: *Implementing the initiatives which underpin and enable a new model for residential support in the mainstream community, where people with disabilities are supported to live ordinary lives in ordinary places.*

As part of this work in it is necessary to identify **appropriate best practice models to meet the residential support needs of individuals with significant specialist support needs**. To date work has been done to identify the current national frameworks, policies, strategies and reports in place in relation to meeting the needs of people, who will have specialist support needs that may or may not have a disability. One such strategy is the **Palliative Care Services Three Year Development Framework (2017 – 2019)** which for the purpose of this paper has been reviewed with particular reference to specialist residential and /or disability service provision.

The Development Framework informs and directs the development of adult palliative care services in Ireland for the three year period from 2017-2019. It will build on existing policy and development documents, remaining true to the principles and vision described in the 2001 National Advisory Committee on Palliative Care (NACPC) Report which was adopted as government policy, and directs national palliative care strategic development.

Focussing on adult palliative care services, the overall timeframe set for compiling the report was approximately seven months. The Framework recommends that the development of palliative care services should be planned with a three phase process:

- *Phase 1: Production of the Three Year Development Framework in which as many issues as possible would be identified and addressed within available resources over the period 2017 - 2019.*
- *Phase 2: Development of new government policy based on a review of the NACPC Report for drafting in the period 2018 – 2019. This policy will guide and inform future palliative care strategic planning processes. Some preparatory work and the establishment of working groups as recommended in the Framework should commence in 2017. As this phase refers to policy revision it will be led by the Department of Health.*
- *Phase 3: Commence the implementation of the recommendations contained in the new policy in 2020.*

Engagement with Palliative Care team

The Palliative Care National Lead advised that support is provided regardless of where an individual lives and referrals to hospice services are based on need and not any other medical issue or existing disability. The aim of the National Clinical Programme for Palliative Care is to ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis.

The programme works closely with external strategic partners in palliative care including the All-Ireland Institute of Hospice and Palliative Care (AIIHPC), the Irish Association for Palliative Care (IAPC), the Irish Hospice Foundation (IHF) and Irish Palliative Medicine Consultants Association (IPMCA). As palliative care is provided in all healthcare settings, the Programme actively engages with all appropriate health service Divisions to support a system wide approach in progressing work streams and developments.

At the meeting it was noted that clarity may be needed about the level of demand for palliative care support for people with disabilities and the capacity of the Programme to respond appropriately to this, particularly where communication with the service users may be more challenging due to their disability. The National Lead will raise and discuss with colleagues in the Network Providers Group, the Clinical Programmes group and the community teams to ascertain their current understanding of the requirements of and for supporting people with an intellectual disability.

Disability Strategy and Planning - Engagement with Neuro Rehabilitation Lead

The Neuro Rehabilitation Strategy Lead is a member of the National Disability Strategy and Planning Team which facilitates collaboration and engagement on the alignment of disability policies on an on-going basis. The implementation framework for the Neuro Rehabilitation Strategy identifies the actions needed to develop the model of “hub and spoke” services across the country, that will enable supports to be targeted to maximise the rehabilitation potential of service users and enable timely access to the specialist services and step down facilities that support people to return home or to their communities.

Currently, there is only one disability neuro rehabilitation service in a congregated setting. The Project Lead has confirmed that work is on-going to determine whether this unit will be reconfigured and aligned under the Neuro Rehabilitation Strategy to provide services as a step down facility in line with the model and as part of the pilot project for the roll out of the policy.

Disability Strategy and Planning - Engagement with Mental Health of Intellectual Disability

Contact was made with the Service Improvement Lead for Mental Health Services to discuss the work on-going to roll out the Mental Health of Intellectual Disability (MHID) structures under the *Vision For Change* programme.

Since the publication of the Vision for Change report in 2006 there has been slow progress with regard to the development of the structures and teams to enable the delivery of MHID services in line with the report recommendations. A National MHID Service Development programme is now in place to drive this.

The Review Group have engaged with the MHID to ensure the needs of people with disabilities are included and considered under the actions

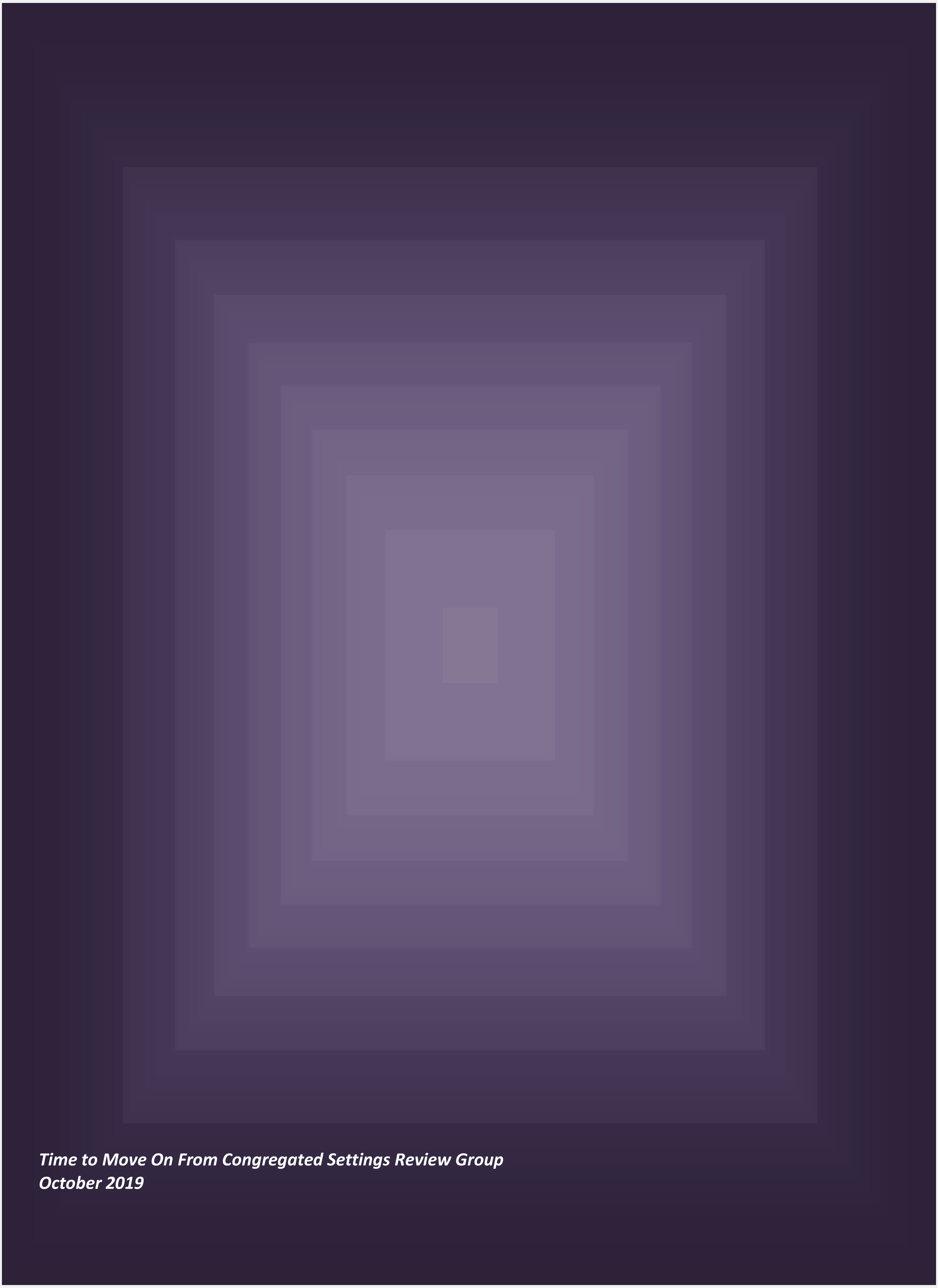
Engagement with Mental Health of Intellectual Disability

A meeting was held with the Service Improvement Lead and the National Clinical Lead for MHID who provided an overview of the current work being undertaken by the National MHID Service Development Programme (which is part of the overall Mental Health Service Improvement programme). The programme will promote a partnership model to provide a unified approach to the development of a national network of specialist, multi-disciplinary, community based MHID teams for adults and children. This work will be undertaken in conjunction with the Social Care division and the programme is working across the HSE and with other mental health and voluntary disability service providers.

The key focus is currently the development of Community Mental Health teams in each CHO. Funding has been secured and governance issues are being confirmed with each CHO to ensure that the funding agreed is allocated to MHID. This team model will support staff retention and build a critical mass at community level which will support service users in their communities.

Each Community Health Organisation (CHO) has developed a service plan in conjunction with the relevant disability service providers to agree how MHID services will be delivered and these plans are currently being reviewed by the Service Improvement Lead. There will be clear management structures to ensure governance of MHID services.

A model of service provision is currently being developed, which will include criteria, assessments, pathways and will support teams to ensure a consistent standardised approach nationally. Metrics are also being developed to support performance measurement which will support a quality improvement focus locally and nationally and work is also underway to build capacity at postgrad/NCHD level to build expertise and experience.



Time to Move On From Congregated Settings Review Group
October 2019