



Workstream 4 Location Review

Literature Review

Dated: November 2018

This document gives a summary of international strategies, policies, reports and research papers reviewed to support the work of the Work stream 4: Location Review under the Time To Move On Sub-Group.

This review aims to gather evidence on the challenges, the outcomes, benefits and recommendations arising in relation to models of residential supports for those with significant specialised support needs. Where a reviewed document includes any recommendations on residential services these are outlined.



TRANSFORMING LIVES

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

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1 General

1.1 Report of the Rapporteur on the rights of persons with disabilities - Human Rights Council

27 February -24 March 2017 http://www.un.org/ga/search/view_doc.asp?symbol=A/HRC/34/58

Aims and Objectives:

Guidance for States on how to ensure the provision of different forms of rights based support and assistance for persons with disabilities, delivered in consultation with them. The report reinforces that “In this regard, support must ensure that persons with disabilities are able to exercise choice and control over their own lives...”

Considering multiple and intersectoral approaches to support the guidance says that “States need to acknowledge the different layers of identities within the disability community.” In particular it highlights that “Older persons with disabilities also have difficulties in accessing support arrangements for daily life, such as personal assistance, assisted living arrangements and palliative care ... “and “The provision of in-home support services, including personal assistance and help with household chores, can avoid institutionalization and improve the quality of life of older persons by enabling them to stay at home (see A/HRC/30/43, para. 72).”

Finding:

The Special Rapporteur has identified four interrelated and essential elements of the obligation to provide support to people with disabilities:

- Availability – fullest possible range of support in sufficient quantity
- Accessibility- geographical reach and affordable
- Acceptability – rights based approach and of good quality
- Choice and control- plan and direct own support

In relation to Living Independently in the Community the report states that Under article 19 (2) of the Convention States are required to ensure access to a range of in-home, residential and other community support services for persons with disabilities, to support living and inclusion in the community. It also states that persons with psychosocial disabilities can benefit significantly from community support services and that evidence shows that, when adequately planned and resourced, community services are much more cost-effective than institutional care.

Key Message:

Support measures are vital to enable persons with disabilities to benefit from all policies and programmes and to live fully in the community on an equal basis with others. States should guarantee the full and equal enjoyment of human rights and fundamental freedoms of persons with disabilities in the provision of support.

2 Residential

2.1 Exploring the regulation of health and social care services Disability Services – HIQA

March 2017 <https://www.hiqa.ie/sites/default/files/2017-05/exploring-the-regulation-of-health-and-social-care-services-op.pdf>

Aims and Objectives:

This document outlines the current definition of a designated centre as it is framed in the Health Act 2007, in addition to HIQA’s interpretation of this definition. Looking at current care and support models for people with disabilities, the document also outlines relevant national policy or research in the area. It includes a section on how similar regulatory frameworks are structured in other jurisdictions.

Findings:

The document confirms that in relation to secure units “A small number of applications have been received by HIQA in the recent past to register designated centres for people with highly-specialised care needs... the service users ...have very complex presentations which require significant support interventions and can include a mental health condition along with a learning or intellectual disability — a dual diagnosis... evidence to suggest that there is extensive use of environmental restraints such as locked doors and high fences surrounding the centres... Providers have advised that these measures are necessary for the safety of the residents and the general public...these units require a level of service and expertise well in excess of the average designated centre for people with disabilities. There are significant challenges in applying the current regulations to these kinds of environments.”

Key Message:

In considering what, if anything, should change in Ireland with regard to regulating service provision and the limitations of the existing definition of a “designated centre” the report notes that “services are not uniform, and the needs of service users vary greatly” and notes that the majority of other regulators “follow a model of registering and or certifying the service provider as opposed to the physical location at which the service is provided” and the report details the advantages of this model, noting that “the question of the fitness of the provider would be a key consideration when assessing the quality of a service” and that “Providing clear definitions of each model and devising guidance for providers will limit confusion in terms of what is being regulated. “

2.2 People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK

<https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1360-2322.2004.00187.x>

D.J. Thompson, I. Ryne and S. Wright c/o The Foundation for People with Learning Disabilities, 83 Victoria Street, London SW1H 0HW, UK Journal of Applied Research in Intellectual Disabilities 2004

Aims and Objectives:

This research focused on the circumstance of older people with intellectual disabilities living in generic residential services for older people. Several potential indicators of low quality of Life were identified and the study also noted that there was also a clear difference of opinion about whether older people's homes could provide suitable accommodation for people with intellectual disabilities between services which did and did not have people with intellectual disabilities currently residing. Some of the issues identified include a lack of specific training, insufficient staffing, could not provide appropriate activities and that people with an ID did not "fit in".

Some service providers surveyed had not provided residential services for people with intellectual disabilities as they felt that the placement was inappropriate. 40% of the people were placed in older people's services prior to their 65th birthday (average age of people with Down's syndrome was 60) and the average age of the people with intellectual disability was more than 10 years younger than the mean age of all residents in the homes.

Findings:

This paper identified three major areas of concern:

1. People's general quality of life ...relatively low levels of regular activity available ...
2. Difficult to be confident that the specific needs of people with intellectual disability are being met because of limited contact they have with ID services and intellectual disability professions...
3. Placement of relatively young people with intellectual disabilities amongst large groups of older people raises many different issues. These include...congregate settings...choice...potential effect of having to spend many years watching people die.

Key Message:

The paper identifies two challenges. The first is "quality of life of people already placed in older people services" and the second challenge "is to try to prevent further inappropriate placements. Ensuring intellectual disability services have the capacity to meet age-related need is only one part of this..."

While this UK study was published in 2004 an Australian study published in 2014, while smaller in scale, identified similar issues – see 2.3 below

2.3 Residential aged care for people with intellectual disability: A matter of perspective

Ruth Webber School of Arts and Sciences, Australian Catholic University, Melbourne, Victoria, Australia; Barbara Bowers School of Arts and Sciences, Australian Catholic University, Melbourne, Victoria, Australia; and School of Nursing, University of Wisconsin-Madison, Madison, Wisconsin, USA; Chris Bigby School of Allied Health, La Trobe University, Melbourne, Victoria, Australia
<https://onlinelibrary.wiley.com/doi/abs/10.1111/ajag.12086> Australasian Journal on Ageing, Vol 33 No 4 December 2014, E36–E40 © 2013 ACOTA

Aims and Objectives:

This study used data drawn “from a three-year longitudinal study of 17 older adults with ID living in group homes in Victoria, Australia. This paper reports on the experiences of 10 older adults who moved to residential aged care during the study, from the perspectives of aged care staff, group home staff and family members. It outlines their perceptions of the positive and negative outcomes for residents with respect to their health and social inclusion”

Findings:

The primary concern of staff from the residents' former group homes was social isolation. Families acknowledged the health benefits but were equally concerned about social isolation.

Key Message:

The study suggests that there is no simple answer to the question of how residential aged care can address both health and social needs of people with ID but notes the following key points:

- People with intellectual disability (ID) are living to old age and are experiencing the same aged- related health problems as other older adults.
- As people with ID move into aged care facilities their health needs are addressed but they may experience social isolation.
- Aged care facilities need to build up expertise in working with people with ID and both the aged care and disabilities sectors would benefit from working closer together to address the needs of this population.

3 Ageing / Dementia

3.1 Global action plan on the public health response to dementia 2017-2025: WHO

http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

Aims and Objectives:

The goal of the global action plan is to “ improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on them as well as on communities and countries.”

Findings:

While no specific recommendations are made in relation to residential services the plan is grounded in seven cross-cutting principles. The Plan identifies seven priority areas for action on dementia, namely dementia as a public health policy; dementia awareness and friendliness; dementia risk reduction; diagnosis, treatment and care; support for dementia carers; information systems for dementia; and dementia research and innovation.

The new Global Action Plan sets targets for each priority area over a nine year period (2017-2025) and requests governments across the world to commit to and prioritise all seven actions and to report to the WHO on a regular basis and proposes a number of actions, which will also impact on disability service provision.

These actions outline the need to:

19. Develop, strengthen and implement national and/or subnational strategies, policies, plans or frameworks that address dementia, whether as separate instruments or integrated into other planned actions for ...and disability (or equivalent)... should give consideration to equity, dignity and the human rights of people with dementia and support the needs of carers, in consultation with people with dementia and other relevant stakeholders.

51. Develop, deliver and promote evidence-based, age-, gender-, disability- and culturally sensitive interventions and training to health professionals,..., to improve knowledge and practices of such staff, and proactively manage modifiable dementia risk factors when conducting counselling about risk reduction. Routinely update these interventions...

Key Message:

The plan also identifies a number of indicators for measuring progress towards the action plan targets including:

Global target: 75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025.

Indicator: Existence of an operational national policy, strategy, plan or framework for dementia, either a stand-alone instrument specific for dementia or integrating dementia into other relevant policies, plans or strategies (for instance, on mental health, ageing, noncommunicable diseases and disability).

3.2 Guidance on Dementia Care for Designated Centre for Older People – HIQA

July 2016 https://www.hiqa.ie/sites/default/files/2017-01/Dementia_Care-Guidance.pdf

Aims and Objectives:

HIQA undertakes thematic inspections and provides practice guidance and self-assessment tools to assist providers to measure performance and identify areas for improvement. In July 2016 HIQA published its Guidance on Dementia Care for Designated Centre for Older People. In outlining why dementia care is important HIQA stated that:

“Each person with dementia is unique and has a different range of abilities and need for support, which change over time as the disease progresses. Residential care staff can determine how best to serve each resident by knowing as much as possible about each resident’s life story, preferences and abilities. Good dementia care involves using this information to develop “person-centred” care, which is designed to ensure that services are tailored to each individual’s circumstances.”

Key Message:

The report examines the health and social care needs of people with dementia, resident’s rights, dignity and consultation and the environment. It also notes that staff need “need education, support and supervision, appropriate to their role that empowers them to tailor their care to the needs of residents and recognises problem-solving approaches to providing care.”

This will help support staff to be “ aware of the signs, symptoms and disabilities associated with dementia and know how to seek further advice and assistance on how to effectively support a resident who is experiencing difficulty with: memory, communication, recognition and co-ordination, orientation, changes in behaviour, judgement and completion of daily life skills.”

3.3 Developing and Implementing Dementia Policy in Ireland

EDITED BY Eamon O'Shea, Suzanne Cahill and Maria Pierce

<https://www.atlanticphilanthropies.org/wp-content/uploads/2018/01/Developing-and-Implementing-Dementia-Policy-in-Ireland.pdf>

Aims and Objectives:

This report is a reflection on various aspects of care for people with dementia in Ireland and internationally with a view to informing future developments in dementia policy in the country.

Findings:

The report finds that Policy documents in the ageing field have consistently pointed to community-based care as being the way forward for dependent older people, while funding has continued to be biased towards residential care; funding for residential care is currently three times as much as home care in Ireland (HSE, 2015) and notes that this bias is probably not unique to Ireland.

People with dementia are a diverse group and acknowledging this may help to open up discussion about the need for more nuanced understandings ..., as well as drawing more attention to the unique and complex challenges posed by gender, age, disability and ethnicity....highlight the importance of responding to these issues through personalised approaches

While considerable progress has been made ... the majority of people with dementia still do not routinely receive person-centred care. Transitioning to a culture where person-centred care becomes the norm will, however, require more than simply training front line staff. It will necessitate senior managers valuing and nurturing their staff, helping to create a care culture that rewards them for positive risk taking and for delivering creative personalised care services and interventions that promote peoples' human rights

Key Message:

- Timely diagnosis will remain very important in any new Strategy, and will need to be
- Supported by a post-diagnostic system that emphasises knowledge, information, peer support, cognitive interventions, continuity of care and integration, leading to higher levels of self-determination, choice and control on the part of people with dementia.
- Personalisation needs to be expanded to ensure that services and supports adequately reflect the wishes and preferences of people with dementia rather than the providers of care.
- Flexibility in provision and enhanced communication are the bulwarks of person-centred care, but without significant investment in education and training neither will be achieved.
- Primary prevention should also be deeply embedded in any new Strategy. So too should the voice and realities of people with dementia in acute care settings and in residential care.
- This includes generating alternative placement options between home care and residential care for people with dementia.

3.4 Irish National Dementia Strategy / Mid-Term Review of the implementation of the National Dementia Strategy

<https://health.gov.ie/wp-content/uploads/2018/06/National-Dementia-Strategy-Mid-Term-Review-Final-English.pdf>

Aims and Objectives:

The first National Dementia Strategy was launched in 2014 and during 2015 an Implementation Plan for the Strategy was developed identifying key deliverables and some indicative timelines including the establishment of a National Dementia Office (NDO).

In order to translate these principles into practice, the Strategy identifies 14 Priority Actions and 21 Additional Actions (detailed in Section 2), which are grouped under the following 6 Action Areas:

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

A mid-term review of the implementation of the strategy has been published in May 2018 and provides an overview of work completed to date and work on-going for each of the priority actions and additional actions identified in the Strategy.

Findings:

There are no specific actions relating to disability specific residential services.

Key Message

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.

The review also notes that National Dementia Office are commissioning a literature review on long-term care options including alternatives to traditional residential care models and home care supports which is due to be completed by Quarter 4 2018.

A position paper is being drafted to engage with National Dementia Office on the basis of specialist residential services and also on broader engagement to represent the disability agenda in the roll out of the strategy.

3.5 Care and support of people growing older with learning disabilities - NICE

Published: 11 April 2018 <https://www.nice.org.uk/guidance/ng96>

Aims and Objectives:

The purpose of this guideline is to help commissioners and providers identify, plan and provide for the care and support needs of people growing older with learning disabilities and their families and carers. It includes guidance on commissioning and planning; service delivery and organisation; identifying and assessing people's changing needs; and supporting access to services including end of life care.

Key Message:

The Guideline makes the following recommendations that commissioners and service providers should in the planning and commissioning of local services:

1.2.4 ... provide housing options that meet the changing needs of people with learning disabilities as they grow older. This includes:

- making reasonable adjustments to support people to stay in their current housing as their physical and emotional needs change, for example providing equipment or housing adaptations
- arranging housing for people with learning disabilities who are in unstable housing situations, for example those who are homeless or in temporary accommodation (including people seeking asylum)
- supported living residential and nursing care, which reflect gender, sexual orientation and cultural preferences.

Furthermore the guidelines recommend establishing links between and across services:

1.2.10 ... between specialist learning disability services and mainstream older people's services. This could be done by bringing them together to help identify gaps and inform service development, sharing information and learning, and linking into voluntary sector umbrella groups.

The guidance documentation also references end-of –life care recommending that it is “person centred” and that services should:

1.6.5 Make it possible for the person to die where they wish. This might include adapting their home, working with other practitioners and advocates, and talking to other residents or family members about changes that could be made (for example, moving the person to a room on the ground floor).

1.6.12 Mainstream end of life care services should make reasonable adjustments to support the person, their family members, friends and carers and other people they live with, throughout palliative and end of life care and bereavement.

3.6 My Thinker's Not Working' A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports

National Task Group on Intellectual Disabilities and Dementia Practice. (2012). *'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports*. www.aadmd.org/ntg/thinker • www.rrtcadd.org/ • www.aaid.org http://aadmd.org/sites/default/files/NTG_Thinker_Report.pdf

Aims and Objectives:

'My Thinker's Not Working' is a summative report issued by the (American) National Task Group on Intellectual Disabilities and Dementia Practices, a planning and advocacy group organized to produce a national plan on dementia and intellectual disabilities. The report offers 20 recommendations for the improvement of services nationally and locally The document reviews the main issue facing adults with intellectual disabilities as they age when they are affected by dementia, as well as their families and provider organizations.

Findings:

In reviewing community living settings the Task Group considered and identified a number of scenarios where an adult with an intellectual disability might need assistance and potentially require greater levels of support once dementia symptoms become pronounced. These could include any of the following:

- Adults who live alone or with a housemate. In such instances when mild cognitive Impairment might be suspected or early stage dementia may be present... there would be benefits from outreach, support such as visitations, and personal support arrangements. It is critical to consider and plan for an alternative living arrangement ... when dementia progresses from early to later stages. If the person is unknown to any formal services, recognizing a need for and gaining access to specialized dementia supports may be difficult.
- Adults who live in a group home or apartment. At times it is prudent to move an adult to a formal community residential setting, such as a group home or a cluster apartment. When a commitment is made to enable the person to continue to live in this setting, it is referred to as 'aging-in-place'... in these instances dementia-related care, directed toward supporting a particular individual, is usually modified as the person experiences progressive decline. Further, individual supports are adapted and modified at each stage of dementia to permit the individual to remain within that home for as long as possible (often until death).
- Adults who live in a specialized 'dementia-capable' residence. Some agencies maintain a home or multiple homes which specialize in dementia care. Such homes generally use an "in-place progression" model. This model usually involves a cluster of persons with varying levels of dementia residing in one or more specialty group homes... there may be multiple homes providing 'stage-related levels of supports. These homes are usually staffed by caregivers who

have received specialty training and the physical environment is adapted or designed to accommodate progressive decline in physical and mental abilities.

Key Message:

The report makes the following recommendation:

Recommendation #12: Plan for and develop more specialized group homes for dementia care as well as develop support capacities for helping adults affected by dementia still living on their own or with their family.

In 2014 the National Task Group on Intellectual Disabilities and Dementia Practices requested a report for submission to the National Research Summit Care, Services, and Supports for Persons with Dementia and Their Caregivers – see below

3.7 Caring and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities

Tamar Heller, Haleigh Scott, Matthew P. Janicki, and Pre-Summit Workgroup on Caregiving and Intellectual/Developmental Disabilities (2017, August) Chicago: Department of Disability and Human Development, University of Illinois at Chicago.

<https://aspe.hhs.gov/system/files/pdf/257461/IDD%20PreSummit.pdf>

Aims and Objectives:

This report was developed by a working group of experts in caregiving, dementia, and intellectual and developmental disabilities (IDD) and examined the similarities and differences affecting people with dementia, both with and absent IDD. While acknowledging that there are similarities it also noted a number of differences ... These included “differences in the trajectory of dementia, often with earlier onset of dementia, a shorter duration of dementia, and greater difficulties in diagnosing dementia given the life-long cognitive limitations. Secondly, individuals with IDD often require life-long services and supports...” The report noted that “there was little or no cross-over discussion between the fields of aging and IDD” and that this “is an important gap to bridge for both groups”

Findings:

The report considered a number of housing models but noted that there a “there is a greater need for more IDD and dementia-capable group homes and research to determine best practice application”. While existing research has compared dementia special care units (SCUs) to group homes and found that group homes tend to provide higher quality care (because they provided a home-like environment and they operated according to a therapeutic philosophy of care) the report also noted that the funding of more staff intensive care models may become an issue given “the increase in the number of older adults with IDD affected by dementia, this may become a significant issue in determining whether aging-in-place and in-place- progression dementia care supports can be viable in the long term.”

Key Message:

Recommendation 2 of the Report: Increase research and community programming to support people with IDD and dementia living in group home settings by

- b) Develop and test models of residential supports that are dementia capable for both adult with IDD and other older adults with dementia.
- c) Provide sufficient training and financial supports for dementia capable homes

Recommendation 5 (c) of the Report: Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDD and dementia.

3.8 Improving services for people with learning disabilities and dementia: Findings from a service evaluation exploring the perspectives of health and social care professionals

Melanie Chapman; Huma Lacey; Nicola Jervis 2017

<https://onlinelibrary.wiley.com/doi/abs/10.1111/bld.12210>

Aims and Objectives:

This study, conducted as part of a wider service evaluation, explored community learning disability team perspectives on screening, pathways, training, information and supports developed to improve services for people with learning disabilities and dementia. Noting that there is “little research evidence to inform interventions for people with learning disabilities and dementia” and that “interventions and services developed for, and evaluated with, older people who have dementia but do not have learning disabilities may not be appropriate (Department of Health, 2009, 2012, 2015) and will need to be adapted to make them age appropriate and accessible which may impact on their effectiveness.”

Findings:

This study also references “the potential need for support and training for a person’s housemates and peers with learning disabilities. Lynggaard and Alexander (2004) found that housemates living with someone with learning disabilities could experience confusion and frustration at changes in fellow resident who they may have known for many years. They describe a group intervention with four residents living with two other people with Down’s Syndrome and a diagnosis of dementia to help explain dementia and provide a space to discuss the impact of living with someone who develops dementia. The group helped participants to recognise that changes in their housemates were the result of an illness over which the people with dementia might not have control and provided knowledge of practical ways in which they could support their housemates with dementia. Dodd (2008) also describes successful short courses for people with learning disabilities living with someone with dementia”

Key Message:

This study in line with many others calls for a further research, on the effectiveness of different approaches and models of service provision with participation by people with ID, their families and caregivers.

4 Palliative Care

4.1 Surveying community nursing support for persons with an intellectual disability and palliative care needs

Maria Bailey, Owen Doody and Rosemary Lyons, Department of Nursing and Midwifery, University of Limerick, Limerick, Ireland 2014 John Wiley & Sons Ltd, British Journal of Learning Disabilities, 44, 24–34 <https://onlinelibrary.wiley.com/doi/epdf/10.1111/bld.12105>

Aims and Objectives:

The aim of this Irish study was to describe the provision of community nursing support for persons with an intellectual disability and palliative/end-of-life care needs in one region, from the perspective of community nurses. Public Health Nurses (PHN), Community Nurses, Practice Nurses, Hospice at Home Nurses and Palliative Care Nurses were included in the survey, against a backdrop of the expansion of palliative care services and integration of people with intellectual disability into their communities.

Findings:

As part of the survey open ended questions captured respondents' opinions which may have been overlooked or unknown to the researchers in the construction of the questionnaire. While similarities to questionnaire responses were noted, new information was generated and captured in the following three themes: the requirement for further education, communication and collaboration is critical in particular in overcoming some knowledge deficits and, access to and availability of resources was raised as a concern. Five resource categories were identified: physical aids, services including specialised services, time, advanced care planning and funding

Key Message:

The survey results suggest that intellectual disability and palliative care disciplines are largely working independently of each other. Most nurses in the survey had limited experience of caring for patients/clients with an intellectual disability, and many felt that they lacked the knowledge and skills required to support this group but did identify their intellectual disability nursing counterparts as a possible resource for support. The study concluded that a "good starting point would be to build links" between palliative care and ID services and palliative care educational programmes should be relevant to care for persons with an intellectual disability.

4.2 Supporting Persons with Intellectual Disability & Advanced Dementia – Fusing the Horizons of Intellectual Disability, Palliative & Person-Centred Dementia Care Final Report

Submitted to the Health Research Board & The Irish Hospice Foundation. School of Nursing & Midwifery Trinity College Dublin <https://nursing-midwifery.tcd.ie/assets/publications/pdf/fusing-horizons-of-care.pdf>

Aims and Objectives:

The aims of this study were to “explore the experiences of staff in intellectual disability and specialist palliative care services in supporting persons with intellectual disability and advanced dementia” and educational interventions that are “responsive to the experiences ... and ... educational needs of intellectual disability staff and specialist palliative care staff ...”

Findings:

The report notes that the traditional focused of services has been maintaining people with intellectual disability in the community for as long as possible. “... there has been a danger ... that with the changing needs of persons with dementia, providers will seek a transfer of the person to other, often more expensive, institutional alternatives...Instead there are also opportunities and efforts to support ‘ageing in place’ and a growing interest in understanding the role of specialised units for people with intellectual disability and Alzheimer’s dementia (Janicki et al., 2002; McCarron et al., 2005).

The report references the Report of the National Advisory Committee on Palliative Care (DoH&C 2001) which recommends that ‘...specialist palliative care should be considered for people with intellectual, physical and sensory disabilities (DoH&C 2001:48) and also notes that: “... further research is required to identify the needs of these persons; furthermore links should be formed between disability service providers and specialist palliative care services in order to promote a quality service for all (DoH&C 2002:48)”

Focus group interviews were held with a range of staff from different settings representing community group homes, institutional settings, campus group homes, specialist dementia facility, specialist ageing type units and specialist palliative care settings.

Key Message:

The report made a number of recommendations for future work and research including:

2. Integrated packages of care are needed, ...
3. ...memory clinics are needed within intellectual disability services with collaboration and specialist support from main-stream dementia services.
7. Specialist palliative support for staff in intellectual disability services is needed to help develop and operationalize emerging end-of-life care guidelines.

8. ... a different relationship is needed with acute care settings to ensure that care planning for end of life is supported when persons with advanced dementia are transferred to these settings; ...

4.3 Providing end-of-life care in disability community living services: An organisational capacity –building model using a public health approach

Grindrod A, Rumbold B. Providing end-of- life care in disability community living services: An organizational capacity-building model using a public health approach. J Appl Res Intellect Disabil. 2017; 30:1125–1137. <https://doi.org/10.1111/jar.12372>

Aims and Objectives:

This study was designed to look at the knowledge, attitudes and practises of disability care staff in relation to end-of life outcomes for clients, looked at factors “categorised as enablers or barriers of care provision” and to develop a “solution-based framework to inform systemic and sustainable organizational change”

Findings:

The framework model developed “primarily...seeks to identify and mobilize the assets that already exist within community living services and build end-of-life care capacity upon this foundation. It emphasizes a health promoting approach to end-of-life care...”

Results:

The research concludes that end-of-life care requires the collaboration of disability and palliative care services, but for care to achieve palliative care goals, the collaboration must be led by disability services as “Relinquishing clients to the sole management of palliative care services disadvantages them in their dying by removing them from their social networks”

5 Behaviours that Challenge / Mental Health

5.1 Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

Service model for commissioners of health and social care services UK October 2015

<https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

Aims and Objectives:

This document sets out to provide clarity on 'what good looks like' for health, social care and housing services for people with a learning disability and/or autism. This service model is intended for a particular juncture in the transformation of services for people with a learning disability and/or autism. It builds on existing NICE guidance (such as that on challenging behaviour and learning disabilities and that on autism) and will be superseded as good practice develops and in particular once NICE service model guidance is published in 2017. (see 5.2 below)

Findings:

The model considers what good service and support looks like for people with an intellectual disability and or autism who display behaviours that challenge. The model is structured around nine core principles based on the perspective of a reasonable expectation of the service. The model states that the "starting point for everyone should be "about **access to support that is based on individual need**, Care and support should then be delivered with the aim of improving the person's quality of life. "

Key Message:

Principle 7 outlines the requirement for specialist health and social care support in the community with the model detailing that:

7.1 Everyone should have access to **integrated, community-based, specialist multidisciplinary health and social care support for people with a learning disability and/or autism in their community** that is readily accessible, when needed ...

7.2 ...Support should be built around the needs of the individual through a '**Collaborative Care' model, or by combined teams** (e.g. all age, learning disability and autism) ...

7.3 Anyone who requires additional support to prevent or manage a crisis should have access to hands-on **intensive 24/7 multi-disciplinary health and social care support** at home, or in other appropriate community settings, including schools and short break/respite settings... The interface between specialist routine multi-disciplinary support services (described above) and this type of intensive support service should be seamless.

In terms of hospital settings Principle 9 outlines that when needed:

9.1 Everyone who is admitted to a hospital setting for assessment and treatment should expect this to be **integrated into their broader care and support pathway**, with hospitals working closely with community mental health, learning disability/autism and other services, including those providing intensive community and/or forensic support (see principles 7 and 8).

9.2 When people are admitted for assessment and treatment in a hospital setting they should expect support to focus on **proactively encouraging independence and recovery**. Services should seek to minimise patients' length of stay and any admissions should be supported by a clear rationale of planned assessment and treatment with measurable outcomes.

9.3 People who present an immediate risk to those around them and/or to themselves may require admission to a hospital setting when their behaviour and/or mental state is such that assessment and/or treatment is temporarily required that cannot be provided safely and effectively in the community. They should have access to high quality assessment and treatment in **non-secure hospital services** with the clear goal of returning them to live in their home... People with a learning disability and/or autism should be assessed and treated in mainstream inpatient services where this is the most appropriate option... This might require providers to designate particular wards as suitable for this purpose. People whose learning disability and/or autism is more significant and who require an adapted environment and/or intensive specialist treatment and care should be admitted to a specialist unit if they require inpatient care. These specialist beds should be increasingly co-located within mainstream hospital settings as part of integrated specialist inpatient services, rather than in isolated stand-alone units. With the right support at the right time in the community, use of inpatient services should be rare and only for clearly defined purposes.

('Hospital' in this context refers to those hospital facilities (registered by the CQC) which are providing mental or behavioural healthcare in England for people with a learning disability and/or autism)

5.2 Learning disabilities and behaviours that challenges: service design and delivery – NICE

Published: 28th March 2018 <https://www.nice.org.uk/guidance/ng93>

Aims and Objectives:

This guideline provides evidence-based recommendations to support children, young people and adults with a learning disability (or autism and a learning disability) and behaviour that challenges to live their lives in the community like everyone else.

Key Message:

1.8 Making the right use of inpatient services: Exploring alternatives to inpatient admission

Recommendations for commissioners, service providers and practitioners

1.8.1 Admit children, young people and adults with a learning disability and behaviour that challenges to inpatient units only if assessment and care planning show that their needs cannot be met safely in the community, and all possibilities for doing so have been considered and exhausted.

5.3 Building the right support

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

Aims and Objectives:

In February 2015 NHS England publically committed to a programme of closing outmoded inpatient facilities and establishing stronger supports in the community.

Findings:

This plan sets out how that will be achieved. It talks about the new services needed:

1.6 People with a learning disability and/or autism who display behaviour that challenges are a highly heterogeneous group. Some will have a mental health problem which may result in them displaying behaviour that challenges..., will display self-injurious or aggressive behaviour unrelated to any mental health condition... display behaviour which can lead to contact with the criminal justice system... in hospital for many years, not having been discharged when NHS campuses or long-stay hospitals were closed. The new services and support we put in place to support them in the community will need to reflect that diversity.

And highlights that

1.11 Just like the rest of the population, people with a learning disability and/or autism must and will still be able to access inpatient hospital support if they need it. What we expect however is that the need for these services will reduce significantly. The limited number of beds still needed should be of higher quality and closer to people's homes.

This will require systemic change and the plan notes that:

1.15 In every part of the country there are people with the skills and experience to deliver effective care and support... within health and social care services, and amongst the families and carers who support individuals in their own homes. Successful delivery will depend on them. Their insight will be key to designing, developing and launching new services in the community, and their skills and experience will be central to delivering them.

1.16 ... we will work with provider organisations to mobilise innovative housing, care and support solutions in the community. Our collaboration will focus on supporting commissioners to redesign services, scaling up community-based services, developing the workforce, accessing investment to expand community services, and securing the capital to deliver the new housing needed.

The Plan details some of the service transformation plans in a number of "fast tracked areas", who were supported with additional funding. Some of the initiatives undertaken in support of the plan included:

2.18 Recognising that occasionally the needs of individuals can increase, they are also investing, this year, in six local crisis beds and an in-reach/outreach team providing safe short intensive support when needed. Greater Manchester

2.20 A cornerstone of the plan is their intention to retain and build the confidence of the staff, as well as families/carers, to improve quality of care in the community. To do this they intend to deliver a three year family and staff development programme. Nottinghamshire

Staff retention and upskilling is also a central part of the plan across a number of the fast tracked areas with Positive Behavioural Support training being rolled out. This will help ensure that “staff have a consistent understanding and approach to working with people ... which enables individuals to remain in the least restrictive setting.”

Key Message:

The plan acknowledges that people with a learning disability and or/autism who display behaviours that challenge are a highly heterogeneous group and that service delivery will need to reflect this diversity to meet a “range of common sets of needs” including:

- Have a mental health condition ... which may result in them displaying behaviour that challenges
- Display self-injurious or aggressive behaviour (not related to severe mental ill health), some of whom will have a specific neuro-developmental syndrome where there may be an increased likelihood of developing behaviour that challenges
- Display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system

The proposed new National Service Model acknowledged that “each local area is different” and “the mix of services required will need to be put in place to reflect that diversity”. It also noted that the model was “developed with the support of people with learning disability and/or autism, as well as families/carers, and a group of independent experts ..., sets out how services should support people with a learning disability and/or autism who display behaviour that challenges” and in terms of specialist services outlines that:

“People with a learning disability and/or autism should be able to access **specialist health and social care support in the community** – via integrated specialist multi-disciplinary health and social care teams, with that support available on an intensive 24/7 basis when necessary”. And

“When necessary, when their health needs cannot be met in the community, they should be able to access high-quality assessment and treatment in a hospital setting, staying no longer than they need to, with pre-admission checks to ensure hospital care is the right solution and discharge planning starting from the point of admission or before.¹”

The plan also stated that “people with a learning disability and/or autism as well as their families /carers should be supported to co-produce these plans.”

¹ See also Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy – Prepare by the Department of Health Chapter 7 Supporting people with complex needs whose behaviour may challenge or who may lack capacity

5.4 Vision for Change – Report of the Expert Group on Mental Health Policy

<https://www.hse.ie/eng/services/publications/mentalhealth/visionforchange.html>

Aims and Objectives:

A Vision for Change 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.

Findings:

A Vision for Change builds on the approaches to mental health service provision proposed in previous policy documents. It proposes a holistic view of mental illness and recommends an integrated multidisciplinary approach to addressing the biological, psychological and social factors that contribute to mental health problems. It proposes a person-centred treatment approach through an integrated care plan, reflecting best practice, and evolved and agreed with service users and their carers. The involvement of service users and their families and carers at every level of service provision is emphasised with interventions aimed at maximising recovery from mental illness, and building on the resources within service users and within their immediate social networks to allow them to achieve meaningful integration and participation in community life.

Section 8.7 outlines a structure for mental health services for individuals with an intellectual disability as follows:

Intellectual disability mental health services

- two multidisciplinary CMHTs for adults with intellectual disability per 300,000 population
- one multidisciplinary CMHT for children and adolescents with intellectual disability per 300,000 population
- based in, and operating from, community mental health centres providing individual multidisciplinary assessment, treatment and care, with an emphasis on home assessment and treatment if possible, either in the individual's family home or at a residence
- provided by an intellectual disability service
- five acute beds in the acute in-patient unit*
- one day hospital per 300,000 with ten places
- ten rehabilitation beds in intellectual disability residential centres which have approved centre status

Vision for change also recommends that there should be:

- one national intellectual disability forensic mental health team and national unit to provide secure care to those with intellectual disability
- In acute settings : five beds for mental health services for people with intellectual disability (sub-unit)
- ten-bed national secure unit for those with intellectual disability

Chapter 14 outlines best practise in the provision of mental health facilities for people with intellectual disability and outlines the core multidisciplinary team to deliver mental health services. It also looks at the needs of specific groups (including older people with ID) and makes a number of recommendations including:

RECOMMENDATION 14.6: 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. These services should be 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.

RECOMMENDATION 14.7: The multidisciplinary MHID teams should be provided on the basis of two per 300,000 population for adults with intellectual disability.

RECOMMENDATION 14.9: 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.

RECOMMENDATION 14.12

1. The process of service delivery of mental health services to people with intellectual disability should be similar to that for every other citizen

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. These services should be 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.

6 Autism

6.1 Models of good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community – NDA 2017

<http://nda.ie/Publications/Disability-Supports/Autism/Models-of-good-practice-in-effectively-supporting-adults-with-autism.html>

Aims and Objectives:

The National Disability Authority was asked to identify models of good practice in effectively supporting the needs of adults with autism, without a concurrent intellectual disability (ID), living in the community. This exploratory report “looked at evidence of good practise from Ireland and around the world with most of the literature coming from grey literature”

Findings:

Section 6.2 of the report Residential Services (page 15) states that:

“A number of the submissions to the HSE Review of autism services (2012a) indicated a lack of capacity and appropriateness of adult residential options for people with autism, particularly in their local area. This causes particular problems around the time of transition from child residential to adult residential services... The HSE reported 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. Some residential service providers also provide respite services giving families and the person with autism a break”.

Section 6.7 identifies gaps in service and says that there is “a lack of knowledge of the number of adults with autism, their location and their needs.”

Findings:

Recommendation 11 of the report relating to service improvement says:

Establish a shared understanding regarding what services should be delivered by mainstream versus specialist services in the context of adults with autism without an ID and in the context of New Directions. There should be a clear outline of what is envisaged for a local community level service and the long-term role of the voluntary sector.

6.2 Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

See 5.1 above

6.3 Building the right support

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

See 5.3 above

7 Complex Needs / Medical Fraility

7.1 The Complex Needs Working Group Report

June 8, 2017 Ontario

http://www.health.gov.on.ca/en/common/ministry/publications/reports/complex_needs/docs/complex_needs_report.pdf

Aims and Objectives:

The Complex Needs Working Group was tasked with providing recommendations for improving home care and community services for adults with intellectual disabilities and complex needs. The report prepared by the Working Group contains eight recommendations to improve home care and community services, enabling adults with intellectual disabilities and complex medical needs to remain where they wish to be, at home and in the community. In line with other policies the needs of people and patients are placed at the centre of the health care system with a view to delivering better coordinated and integrated care in the community, closer to home.

Findings:

The report recommends the introduction of criteria to measure complex need and recommends a definition incorporating care, complexity and needs. The report recommends that expanding and improving training and education for care providers would “enhance provider confidence in their ability to support this unique group” and “increase professionalism and consistency of care”. The report notes that “Collaboration enables information sharing and knowledge transfer” and recommends that “more research is needed on individuals who have intellectual disabilities and complex medical needs” with “a knowledge transfer plan” to ensure that research findings are circulated widely.

Key Message:

In terms of residential models the report notes that “small-scale integrated living models may be a community alternative to long-term care or acute care” including activities of daily living, effective support system and cross sector collaborative partnerships. The Working Group recommended that “two to three pilot projects utilizing a coordinated care model for individuals with intellectual disabilities and complex needs be tested to support clients and their caregivers”

7.2 The Impact of Support Services Teams: Community- Based Behavioural Health Support Interventions

Randall Owen, Anne Bowers, Tamar Heller, Kelly Hsieh, and Robert Gould Department of Disability and Human Development, University of Illinois at Chicago, Chicago, IL, USA

<https://doi.org/10.1111/jppi.12186>

Aims and Objectives:

This paper notes that “With the increase in the number of people with IDD transitioning to living in community settings from institutions, the availability of community-based services is essential for people with a dual diagnosis (IDD and mental illness), as these services can help prevent returns/admissions to institutional settings and/or reduce the length of stays in these settings. However, the capacity of community-based services to work with this population is often inadequate (Norris, 2014)...”

Key Message:

The discussion outlined that “Persons with a dual diagnosis experience unique challenges over the life course “ and “...additional community capacity to work with people with complex dual diagnoses is needed as an alternative to institutional stays. One area of particular need is a short-term solution in the community where people can go to stabilize changes to their medications.”

7.3 How best to support individuals with IDD as they become frail: Development of a consensus statement

Ouellette-Kuntz H, Martin L, Burke E, et al. How best to support individuals with IDD as they become frail: Development of a consensus statement. *J Appl Res Intellect Disabil*. 2018;00:1–8.

<https://doi.org/10.1111/jar.12499>

Aims and Objectives:

The authors note that studies have shown have reported higher rates and the presence of frailty at earlier ages than in the general population, there is no evidence of effectiveness of specific interventions to address the needs of frail or pre-frail individuals with IDD. The authors note that “In the absence of a body of research to inform best practice, a consultation was undertaken with the aim of producing a consensus statement regarding the best approaches to supporting individuals with IDD as they become frail.”

Findings:

There was agreement that the “purpose of the statement would be to promote awareness of frailty and guide care planning and that two core principles underpinned these efforts: use of a person-centred approach to planning care and ageing in place” but reported concerns about ageing-in-place because while often the “desired option ... it is likely not to happen in the absence of planning.”

As well as the two core principles the statement identifies seven essential and interconnected considerations for action.

1. Frailty must be considered earlier than in the general population.
2. Improvement and maintenance are viable goals.
3. Intersectoral collaboration is needed to coordinate comprehensive, multidisciplinary assessments and actions.
4. Safety is a priority.
5. Planning for the future is important.
6. Informal and formal caregivers also have needs.
7. The evidence base must be grown.

Key Message:

In conclusion the authors note that “it is important to recognize that with careful person-centred planning to support the person with IDD and his/her family to age in place, their resilience to live well with frailty can be enhanced”. They acknowledge the lack of research on frailty and advocate for more research to inform future practise.

7.4 Time for action Priority actions arising from national consultation Áras Attracta Swinford Review Group

<https://www.hse.ie/eng/services/publications/disability/aasrgtimeforaction.pdf>

Sufficient community resources to minimise any requirement for admissions to institutional settings – for example, funding to develop support teams to assist local services in responding to people whose behaviours challenge. (PA 8)

Full implementation of the recommendations in the Vision for change document, especially with regard to the establishment of MHID teams. (PA 17)

8 Forensic

8.1 Supports for Offenders with Learning Disabilities in the Irish Judicial System: A Critical Review

Gillian McNamee & Dr. Ciara T. Staunton School of Applied Psychology University College Cork
Copyright Irish Journal of Applied Social Studies ISSN 1393-7022 Vol. 17(1), 2017, 94-105.
<https://arrow.dit.ie/cgi/viewcontent.cgi?article=1291&context=ijass>

Aims and objectives

To examine the supports and resources currently in place to support people with learning disabilities through each stage of the Irish judicial process. The rationale for conducting the present review is based on the following five identified issues:

- 1. A lack of programmes and supports to help identify those with a learning disability who may be at risk of becoming an offender;*
- 2. A lack of identification of people with a learning disability amongst offenders;*
- 3. Inadequate training and education about learning disabilities for professionals working in the judicial system;*
- 4. A lack of alternative rehabilitation settings for those with a diagnosed learning disability;*
- 5. Insufficient preparation and supports in place to assist offenders with learning disabilities to integrate back into their own community*

Findings

The present paper highlights the prevalence of learning disabilities among offenders and the pre-existing risk factors that identify a person with a disability in their pathway to becoming an offender. Irish data for the prevalence of offenders with a learning disability within the Irish Prison system is limited but the literature reviewed suggests it may be in line with international statistics.

Key messages

Learning disability services are rarely party to local health and criminal justice policy and service planning and as the literature demonstrates, a more universal, multiagency approach may prove a more beneficial approach for all the stakeholders. The literature identifies the lack of resources in place to support the prisoner with a learning disability to integrate back into their own community. A person with a learning disability is likely to have limited social skills, be unemployed, come from a dysfunctional home and their conviction will add to their list of challenges. The paper suggests that “the introduction of a support worker to start working with the individual while they are in prison to help them develop their social skills, provide support around training skills to equip them for possible employment when they are released would help prepare them for integration back into their own communities”. This paper finds that a multidisciplinary and multi-agency approach is vital and should be governed by national guidelines.

8.2 Long-stay patients with and without intellectual disability in forensic psychiatric settings: comparison of characteristics and needs

Verity Chester, Birgit Völlm, Samuel Tromans, Chaya Kapugama and Regi T. Alexander 2018

<https://www.cambridge.org/core/journals/bjpsych-open/article/longstay-patients-with-and-without-intellectual-disability-in-forensic-psychiatric-settings-comparison-of-characteristics-and-needs/E8FA6D7C81D3EDF2461619F45AFECD19>

To compare the characteristics, needs, and care pathways of long-stay patients with and without intellectual disability within forensic psychiatric hospital settings in England.

Aims and objectives

To compare the characteristics, needs, and care pathways of long-stay patients with and without intellectual disability within forensic psychiatric hospital settings in England.

Findings

Of the 401 long-stay patients, the intellectual disability and non-intellectual disability groups were strikingly similar on many sociodemographic, clinical and forensic variables. The intellectual disability group had significantly lower lengths of stay, fewer criminal sections, restriction orders and prison transfers, and higher levels of behavioural incidents and risk assessment

“Although concerns have been raised that on occasion challenging behaviour has been ‘forensified’ in order to inappropriately detain people with intellectual disability within forensic settings, largely because of a lack of appropriate placements and expertise for this group,... If the principles of the Transforming Care programme are inappropriately applied, with pressure being put on clinicians to discharge patients ‘as quickly as possible’, patients’ rehabilitation can be hurried and/or truncated, patients can be discharged before they are ready or without the receiving community services being properly prepared to manage ongoing risks and there can be inappropriate admissions to acute mental health wards when a forensic admission would better suit the patient’s needs. The forensic intellectual disability population therefore represent a number of challenges to current government policy, and clarifications regarding their status is required.

The paper proposes that improving “training of community intellectual disability teams on issues of risk assessment and management, thus supporting them to safely manage people with intellectual disability and offending behaviours, to reduce and minimise hospital admissions, and better facilitate discharge into the community, while noting that this would not negate the need for all in-patient beds.”

Key messages

In spite of similar offence histories and higher risk levels, those with intellectual disability appear to be diverted away from the criminal justice system and have shorter lengths of stay. This has implications about the applicability of the Transforming Care programme to this group.

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