How long-term care and support for older people is currently provided in Ireland

Presentation to Citizens Assembly
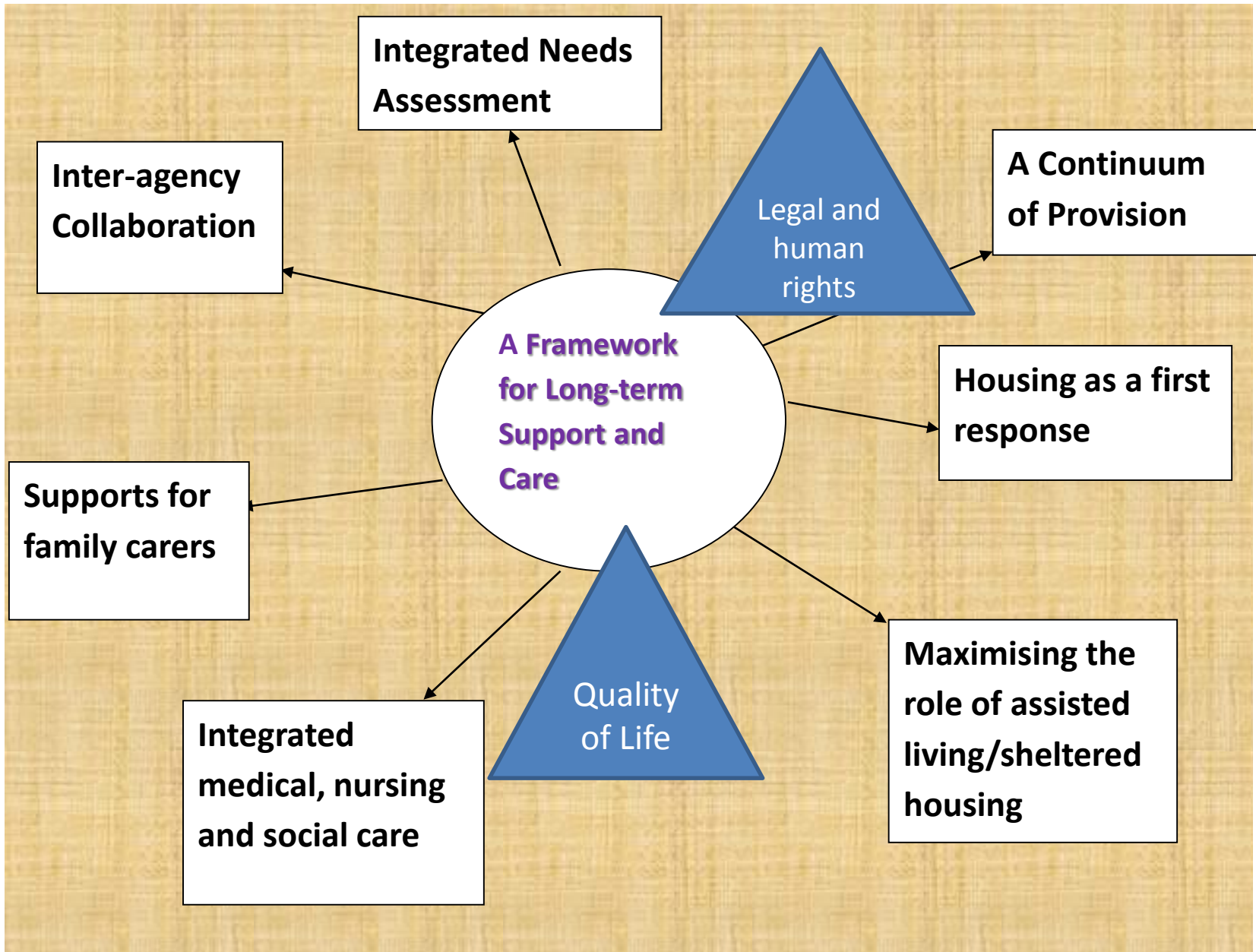
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The Older Population: Contextual Points

- Make an enormous social, cultural and economic contribution to society**;**
- A minority of people in their later years are ill and/or have a disability (most disability is acquired over the life-cycle);
- Older people clearly have equal legal and human rights with the rest of the population;
- Most people want to receive care and support at home;
- The Assisted Decision-making (Capacity) Act 2015 is hugely important for older people with cognitive impairment

Key Question

- *A huge body of research and analysis on the topic*

Why, despite decades of policy reports and recommendations to government, is there still a systemic bias towards care in congregated settings and no formal legislative basis for support and care in the community?

A Framework for Long-term Support and Care

- Integrated Needs Assessment
- Inter-agency Collaboration
- Legal and human rights
- A Continuum of Provision
- Housing as a first response
- Supports for family carers
- Integrated medical, nursing and social care
- Quality of Life
- Maximising the role of assisted living/sheltered housing

Support and Care Options

- The Nursing Home Support Scheme

- Home Care Packages

- End-of-life care provisions

- Role of appropriate housing

- Potential role of assisted living/supported housing

- Sage Forum on Long-term Care Report
  http://www.thirdageireland.ie/assets/site/files/pr/Report_of_Forum_on_Long-Term_Care_for_Older_People_FINAL.pdf

The Nursing Home Support Scheme

- Legislative basis for NHSS significant

- Resources are made available

- Successful in providing access to nursing homes for older people of all financial means

- Does not and cannot deal with lifelong inequalities

The Nursing Home Support Scheme: Difficulties

- Fee negotiated with nursing homes by the NTPF providing only for 'bed and board'

- No provision for access to therapies, suitable chairs, aids and appliances

- Legally binding contracts – an ad hoc approach to the signing of contracts

- Disjoint in relation to the respective roles of the NTPF, the HSE and HIQA

- Little focus on the support and care needs of individuals or on facilitating their will and preferences

- Failure to take account of the complexity and challenging nature of the care required by people with dementia

- Additional charges on residents

- Particular difficulties of people whose sole income id the non-contributory pension -- e.g. people over 80 left with €47

Home Care Packages

- Significant in enhancing the quality of life for people

- People who get HCPs are generally satisfied

- Recently published research by the Health Research Board
  http://health.gov.ie/wp-content/uploads/2017/04/FINAL-HRB-Evidence-Review-7-4-17.pdf

- Much recent discussion on the matter at political level

- Public consultation on legislative change mooted

Shortcomings
- Absence of legislative entitlement

- Limited access to these packages due to under-funding

- Entitlement arbitrary in the sense that eligibility is not clear

- People having to remain in hospital or go to a nursing home

- The absence to date of formal national quality standards

- Little or no focus on outcomes

End-of-life Care

- Consistent commitment by successive governments, the Department of Health and the HSE to deliver equal access to hospice and palliative care services
- Significant progress recent years, provision for hospice and palliative care is not uniform across the country.
- Some people cannot get access to hospice beds
- Two-thirds of Irish people express a preference to die at home but only 26% of deaths take place in the home
- More people could be supported to die at home
- Different practices and outcomes in different parts of the country.

Maximising the role of housing in long-term support and care

➢ Respecting the right of people to stay in their own homes if that is their wish and enabling this through the provision of appropriate supports

➢ Addressing the issue of accommodation that does not meet people's needs as their mobility decreases

➢ Housing adaptation should be a matter of priority

➢ The Housing Adaptation Grant (available from Local Authorities) can be a crucially important support in enabling people to remain living in their own homes

➢ As it currently operates, it falls far short of what is required due to both its limited funding and long processing time-frame

➢ Strong evidence for this from both queries to CISs and Sage advocacy casework

Assisted living housing/housing with care (Sheltered Housing)

- Sheltered housing has long been promoted

- Focus in Ireland to date has been primarily on providing units for older people capable of independent living.

- Specific high level care services, which are indicative of tenants with higher needs are the least provided services.

Assisted living housing/housing with care (Sheltered Housing)

o The need to take account of the potential of new residential models, including housing with care is referenced in the National Dementia Strategy.

o The 2016 Action Plan for Housing and Homelessness, *Rebuilding Ireland,* notes that older persons have specific housing requirements

- Being in proximity to their family and social networks

- The need for access to public and other essential services, recreation and amenities

o Refers to a new cross-Departmental/inter-agency approach including a the development of appropriate pilot projects by Local Authorities.

Current Provisions

- Voluntary housing associations have been the largest provider of sheltered housing
- Many useful schemes in operation, including some by local authorities
- However, there is a relatively limited supply of fully developed sheltered housing as defined by the Irish Council for Social Housing.
- Data from a 2011 ICSH Survey shows that that the majority of respondent housing associations provided units for older people capable of independent living and that specific high level care services (indicative of tenants with higher needs, were the least provided services.

Need for more intensive support sheltered housing

- There is a clear need for the development of more care and support intensive sheltered housing.

- Of critical importance here is the availability not only of communal facilities and services but, also, homecare packages and easy access to medical and nursing care as required.

Need for a new public initiative

- Legislation requiring all developments above a prescribed size to include a specified proportion of assisted-living accommodation

- A system of tax incentives to developers and builders who meet specified criteria in relation to assisted-living accommodation

- The HSE financing or directly providing the health care and social services needed to enable the assisted-living programme to operate.

A Longer-term Approach

The concept of 'sustainable communities' outlined in a 2007 Government Statement on Housing Policy, *Delivering Homes, Sustaining Communities,* should be developed and promoted as an underlying approach to meeting the diverse needs of current and future citizens.

Sustainable communities are seen as communities that are well planned, built and run, offer equality of opportunity and good services for all across the life-cycle.

Need for stronger inter-agency collaboration

- Policy emphasis on partnership, coordinated services, networking, inter-agency co-operation and service integration

- Separate functional responsibilities and budgetary processes on the part of the HSE, the Department of Housing, Planning, Community and Local Government and local authorities

- Results in compartmentalisation of service planning under categories of 'health' and 'housing'

- No overall national strategic framework for meeting a range of different care and support needs, e.g., the higher costs associated with high support sheltered housing, because of

Need for stronger collaboration between health and housing

- Housing and health and social care can no longer remain parallel lines.

- Focus on local government and administration as much as on national government;

- On housing policy as much as health and social care policy.

An Alternative Model

- The Social Support Act 2015 in Holland requires Municipalities to help people to live at home for as long as possible.
- Municipalities are responsible for assisting people who are unable to independently arrange the care and support they need.
- Services provided by Municipalities include:

    Coaching/companionship and day activities

    Temporary respite for informal carers

    A place in sheltered accommodation

- The municipality may award a personal budget which people can use to arrange and pay for their own support services

Multi-purpose and integrated community-based developments

- Multi-purpose community-based developments in mainstream settings

- Providing a continuum of support and care (social activities, day facilities, sheltered accommodation, nursing units) in enabling people to live independently or semi-independently

- Some good models in place in Ireland and some being developed

- Relevant initiatives in other jurisdictions

- An integral part of town planning and the social and economic infrastructure rather than an add-on

- Could be developed initially in locations where existing public long-term residential care facilities have been deemed to be no longer fit for purpose

- County and City development plans need to reflect the ned to plan for an ageing population and provide for infrastructural development accordingly.

Multi-purpose and integrated community-based developments

Government might establish 3/4 pilot projects around the country based on:

Developing integrated and sustainable inter-generational communities

An integrated funding model (as distinct from the current silo funding model)

Provision for all of the activities and engagements required for daily living and social interaction

Located within regeneration zones and/or in locations where health and social facilities have been operating but are no longer being provided

Basic social care and health services located within the zone

Maximising the use of supportive technology – both as social support and health aid but also as a means of enhancing social connectedness

Include space for 'normal' activities associated with daily living, e.g., coffee shop, newsagent, pub, clothes boutique, hairdresser, betting shop.

A focus on outcomes – people having optimal quality of life in terms of social connectedness and living (and dying) in the place of their choice

Exploring the potential of a local social enterprise model

Integrate and make accessible current separate and disparate initiatives and provide for easier access to services by older people who need support.

- Community navigators to advise and support on accessing services
- Micro-working systems to manage paid, bartered and donated time
- Organising volunteers
- Transport
- Greater use of assistive technology
- Group-purchasing schemes to reduce the cost of heating or respite breaks
- Befriending, telephone contact and support services
- Care, repair and maintenance of home and garden
- Urgent adaptations to home to enable return from hospital
- Advice and assistance on financial and legal matters
- Emergency response in crises
- Advance planning for end-of-life care

Concluding Comments

- Shifting the balance from long-term care in nursing homes to long-term care in a range of community-based settings (including people's own homes) and within the normal social and economic infrastructure

- Need to address major discrepancy in the Irish health care system

- LAs taking on much more responsibility for the development of integrated multi-purpose schemes.

- Proactively planning for the financing of long-term care of an older population who are living longer

- Respecting people's right to self-determine and right to be supported in making decisions for themselves

Need for Innovation

"We should be prepared to experiment and innovate, in the interests of quality and cost, to discover what are the best ways to achieve wide-spread high standards in Ireland's human services".

NESC (2012) *Achieving Quality in Ireland's Human Services*

NURSING HOME

Source: Cluid (2017) Changing Perceptions Stigma and Social Housing in Ireland

Two Contrasting Approaches

Nursing Home Model

Integrated Multi-purpose Development (Cluid 2017)

A different approach needed

We have the positive ageing strategy;

We know what people want;

We know what the current policies and aspirations are;

We know what current practice is and where the gaps are and we know the models that need to be developed;

No report on long-term support and care has proposed the current model.

THANK YOU