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Study Aims and Objectives

- Whether health and social care services and supports are responding to the care needs, required supports and preferences of older people.
- The access and availability of care and support services for older people in Ireland, including those of people with dementia.
- Older people's involvement in decision-making relating to their care planning and/or long-term care options, particularly focusing on those with a cognitive impairment/dementia.
- What additional community supports and services may enable older people to continue/return to live in their own homes?

National and International Policy

- Older people should be able reside at home for as long as possible (UNHR, 1991).
- Older people's preference to live at home (Barry, 2010).
- 'Ageing-in-place' enables older people to maintain independence, autonomy, and connection to social support (Lawler, 2001).
- Evidence shows the need for home and community care services to be established on an equitable basis underpinned by legislation and appropriate funding (Mangan, 1997; Ruddle et al, 1997; Layte et al, 1999).
- Bulk of care provided by family carers (Timonen and Mc Menamin, 2002), estimated to be 89.5% of community care provided (Care Alliance Ireland, 2015).
- Home care services are often experienced as impersonal, inflexible, underfunded and poorly integrated. Not designed around the older person, but depend organisational structures or who is providing the service (SCIE, 2014).

Spending on Homecare

Table 2: Yearly spending on Homecare 2008,2015

Service	Yearly spend in 2008	Yearly spend in 2015
Home Help	€211 million	€185 million
Home Care Packages	€120 million	€135 million
Total	€331 million	€320 million

- Funding for long term care has increased, from €920 million in 2008 (DOH, 2011) to €988 million in 2015 (HSE, 2015b).

Methodology

- A mixed methods study design was adopted.
  (i) national survey
  (ii) in-depth interviews
- Social workers contacted via IASWs' Special Interest Group for Older People (SIGA) and other IASW mailing lists.
- Survey involved social work respondents reporting on their open cases involving older people for the month of June 2015.
- In-depth telephone interviews carried out with 21 social workers, with a minimum of 2 social workers interviewed from each Community Health Office (CHO) area.
- Interviews lasted approximately 40-90 minutes.

Table 1: Total Number of Cases (N=788) Reported on by Social Work Speciality and Region

Area	Medical social work	Primary care	Mental health	Adult safeguarding	Later life psychiatry	Other including Disability	Total
Dublin region	433	16	49	45	1	39	**583**
Other region	54	42		8	90	11	**205**
Total	**487**	**58**	**49**	**53**	**91**	**50**	**788**

Older People's Expressed Preference for Care

- Findings show the preferences of older people are to remain living at home for as long as possible, receiving care when it is needed in this setting.

- This is not being realised. The present social care approach has not been resourced adequately to meet the actual needs of older people.

'[The] overwhelming majority of older people's preference is to be cared for in their own home' (A7, Community, Area E)

'I could count on one hand the number of people who want to be in the facility. Many people eventually accept their situation – they see it as having no other choice. However, some people never settle' (A8, Residential, Area B)

Assessment and Risk

- Risk was found to regularly influence the decisions of professionals and family members.

- The rights of the older person were often ignored and pressure brought to bear on the older person, for example, to move into long-term care where it was viewed they would be 'safer'.

'Panic sets in…concerns around risk. This directs families to look more towards LTC, even for those older people with only a mild dementia. Community services are often reluctant to go in because of risk.' (A15, Medical, Area J)

'For me, I'm ok with people staying at home with risk…but there are people we feel might do better in LTC. Once we are clear about the risks, that's the main thing. "I would rather take the risk and die at home" we would try and respect their autonomy. There would be a lot of concern that the older person might fall and die, but at least they will die having lived their life in the way they wanted to'. (A3, Community, Area C)

Involvement in Decision-Making

- There were inconsistencies in how older people were involved in care-related decision-making.
- Social workers reported that many older people with a mental health issue and or/cognitive impairment/dementia were excluded regardless of their level of functional capacity.

Due to:

- A status approach to dementia, where people were deemed to lack capacity
- Their family didn't want them involved
- Communication difficulties which impacted on their involvement
- No opportunity to be involved
- Their expressed preference was that they didn't wish to be involved.

'I would try to educate people about older people's right to make good and bad decisions. I would insist on speaking to the older person first, and begin by saying "You are the boss", I am here to do whatever you want, to empower you' (A10, Community, Area D)

'There is very much a service based approach in this hospital which is strongly influenced by the consultant's personal opinion ... there would be a tendency not to bring the older person into care planning meetings here' (A15, Medical, Area J)

A health and social care system focused on physical care needs

- People were prioritised differently in different areas e.g. by age, living situation, delayed hospital discharge and/or presence of dementia.

- Need was understood within the narrow parameters of 'physical care needs'; failing to capture the support required by people with mental health issue and/or cognitive impairment/dementia,

- Assessment was deficit based, if a family member provided care, they were less likely to get any formal support. Social care needs, such as help with domestic tasks and social contact, were regularly excluded and not prioritised.

'Assessment for home support is based on the assessment used for all older people. Hence the person with dementia has to have personal care needs. However, in many instances their needs may not be for personal care, but for support to go shopping, or someone to stay with the person whilst the carer takes a break.' (A7, Community, Area E)

'Often the people [in the community] we are coming into contact with…domestic tasks may be where their greatest need lies. It's that big gap, we can wash them but we can't feed them' (A3, Community, Area C)

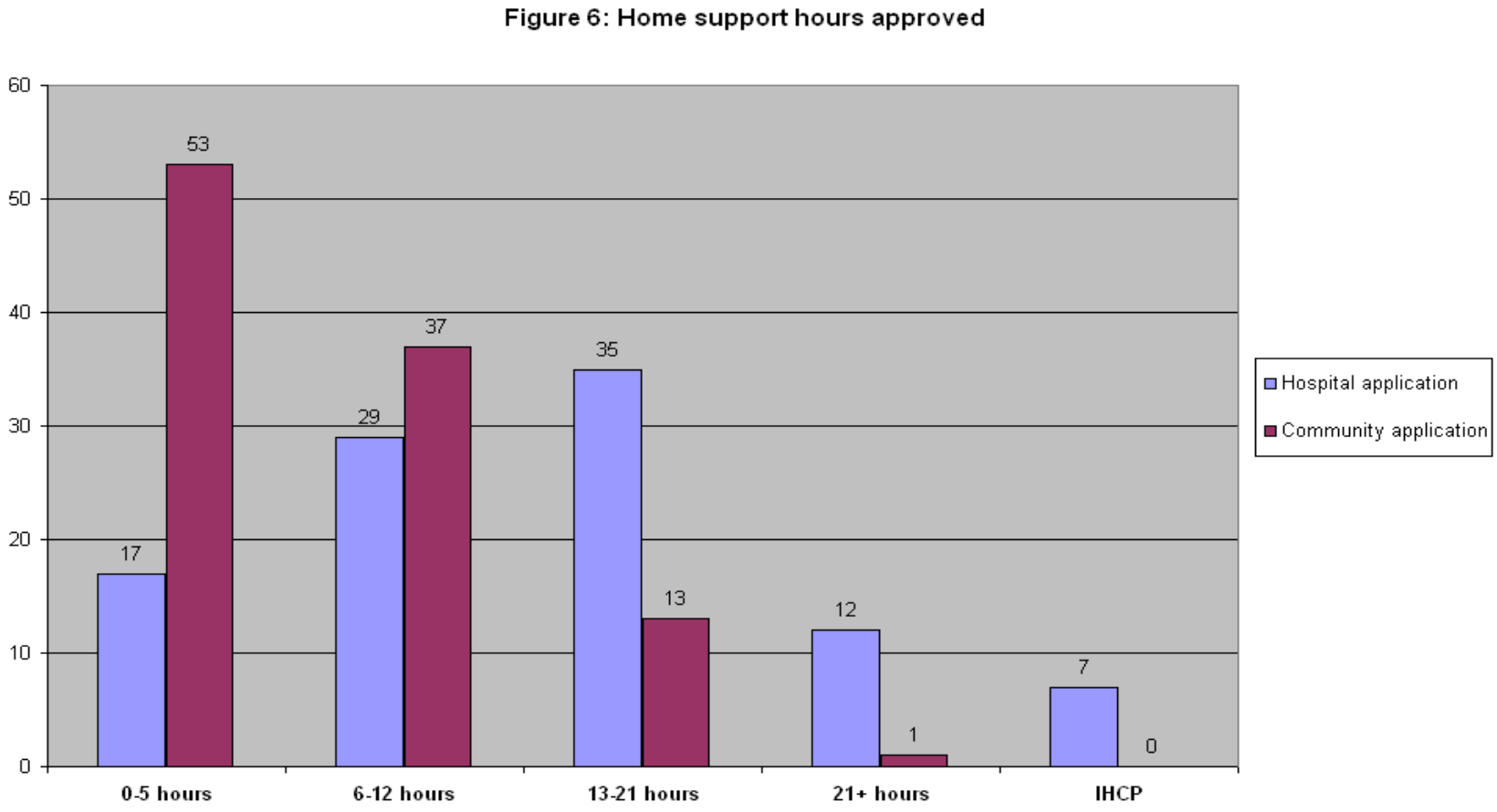
'Time to Task' and Lack of Flexibility

- Minimal service availability in many CHO areas
- Inconsistencies between CHO areas
- Operation of waiting lists
- Many recipients got lower hours of care than number applied for
- Shift from domestic to personal care not always meeting individual needs
- Time-to-task approach in allocating time for home-based care
- Lack of knowledge and understanding of the care needs of complex cases e.g. people with dementia
- Significant lack of flexibility meant applying for home care packages often deemed more straight forward than applying for home help hours

'There is no means of accessing domestic support anymore unless it is piggybacked onto personal care, for example, if a carer is helping a person get out of bed in the morning, it may also be possible for them to make the bed' (A17, Medical, Area G)

'There would be no exceptions made in relation to approving domestic support, even if the older person has no family or is socially isolated. What I am told is 'We cannot approve hours or support for domestic task' (A19, Community, Area H)

Level of home care hours approved through hospital applications and for community applications



The consequences of being unable to access appropriate supports

- Lack of transparency in relation to older people's entitlement to services - differing practices highlighted across CHO areas.
- Large disparities between services available in different CHO areas. Demand far outstripping availability.
- Situation regularly meant older people did not receive the level of service their care needs' assessment indicated. A worrying consequence of this was unnecessary or premature admission to long-term residential care.

'Household tasks cannot be replicated if there isn't a family member to do these…it's impossible for someone to continue living at home if there is no one to supervise them making tea or meals' (A19, Community, Area H)

'Lack of supervisory hours is definitely leading to more people going to LTC. Persons with dementia are often slower or need more assistance and prompting in carrying out tasks. However, HCP Case Managers often don't recognize this and don't allocate extra time to accommodate this' (A17, Medical, Area G)

LONG TERM CARE (LTC), TRAN-SITIONAL CARE AND RESPITE CARE

- Easier to access LTC and rehabilitation beds from the acute hospital than from the community.

- Participants reported that *'Nursing homes more than ever are cherry-picking who they will accept'* with even public nursing homes refusing to admit people who are deemed to have high-dependency needs (A17, Medical, Area G).

- Difficulty in accessing appropriate LTC placements for people living with dementia, with nursing homes refusing to accept people in the more advanced stages of dementia or who were deemed to have behavioural and psychological symptoms of dementia.

'Some private nursing homes say they don't take 'walking dementia' (A10, Community, Area D)

- Transition beds were seen to be the preserve of acute hospitals to facilitate more timely discharge.

- Long waiting lists for respite care.

Family Carers

- Family carers were identified as key stakeholders in the care and support of older people.
- Social workers reported that routinely older people were less likely to get formal support where an older person had family members providing care.
- Family carers were not provided with concrete, practical community supports such as HCP's or respite until they reached breaking point.

'Where family are available, people are less likely to get a service'
(A5, Community, Area A)

'If there is an adult child living in the house the expectation would be that they should provide care. I had a recent case of an 85 year old who lived with her 82 year old sister and it was expected that a family member would provide care' (A16, Mental Health, Area G)

Every Little Helps

- Access to person centred supports, such as supervisory hours for PwD, benefits both the older person and their carer and makes a huge difference to people's lives

"A *family up all night, can get a dementia support worker who will stay over for example 2 nights in the week to allow carer have a full night sleep, it keeps the family going,*

people are looking for very little" (A11, Mental Health, area D)

"The Carer's Association and the Alzheimer's Society of Ireland, there might be a bit more flexibility in relation to household tasks" (A19, Community, area H)

Social Workers as Advocates

- Significant gaps in the provision of social work supports to older people nationally.

- Social workers reported that their role as advocates for the older person was essential in many instances in getting services or involving older persons formally in decision-making.

'The real issue for me is the vulnerability of older people in the community who have no access to social work support' (A12, Mental Health, Area D)

'If the social worker doesn't advocate for them, then in my experience usually nobody does. There is a massive tension between discharge planning and what the older person and their family want.' (A15, Medical, Area J)

'They didn't see a merit in employing hospital social workers and we have continually highlighted that as a huge risk ... the hospitals then chose to spend the funding on discharge planners rather than social workers' (A19, Community, Area H)

Concluding Thoughts

- Older persons requiring care and support in many instances have no choice but to move into residential care settings, due to the under-development of community- based services and inconsistency of provision across the country.

- This is despite the overwhelming preference of older people for 'ageing in place', their right to private and family life and a State policy that commits to support older people to remain in their homes for as long as possible.

- For policy to become practice the recommendations outlined must be implemented to ensure the development and provision of services that meet the diverse needs of the increasing number of older people who will require support over the next decade.

Recommendations

- Ensure that the dignity, rights and autonomy of all older people, regardless of cognition or their level of functional capacity are respected in the planning and provision of services.
  - broaden the definition of 'risk'
  - Implement standardised approach to involving all older people in care planning

- Provide an annual centralised ring-fenced budget for community care, allocated to CHO areas based on capitation, calculated using evidence such as OECD figures on the number of people aged 65 and over likely to require care and support over the next 10 years.

- Develop and implement across every CHO a single, fair, national standard for needs assessment; it is envisaged the Single Assessment Tool can achieve this.

- Take carer's needs into account and provide a carer's needs assessment via the Single Assessment Tool scheme.

Recommendations

- Develop and implement a fair and equitable way of allocating care and support services.
  - All CHO areas should make information available about services, eligibility criteria and the process for accessing services available to all people.

- Oblige each CHO area to provide a range of services to meet the diverse needs of older people.
  - Flexible domestic supports are required and supervisory supports to people with dementia are also urgently needed.
  - Basic services should also include access to aids, home adaptations, supported housing, social clubs, day centres, meals-on-wheels, befriending services and nursing homes.

- Provide a full compliment of health and social care professionals in each CHO area, accessible to all older people and their families
  - All PCCC Teams nationally should have an allocated social worker. The new Adult Safeguarding Teams must be fully resourced. The absence of medical social work posts in hospitals within several CHO areas must also be addressed.

Thanks to…

- Social Workers across the country who participated in the survey and interviews.
- Co-authors: Dr Marita O'Brien, Dr Emer Begley and Mr John Brennan.
- Age Action, Alzheimer Society of Ireland, IASW and School of Social Policy, Social Work and Social Justice, UCD.
- Thank you for listening!