

Submission to the Joint Oireachtas Committee on the Future of Mental Health Care

1. *The role of Sage – Support and Advocacy Service*

Sage Support and Advocacy Service exists to promote and protect the rights, freedom and dignity of vulnerable adults and older people through the development of support and advocacy services to address individual and systemic issues. Through its dedicated support and advocacy service, Sage works to ensure the will and preferences of the person can be heard and implemented, independently of family, service providers or systems' interest. Sage was established in September 2014. Sage has developed in response to an identified need for the provision of support and advocacy services following documented incidents of failure within the care system, e.g. the Leas Cross nursing home abuse scandal in 2005 and the allegations of abuse brought to public attention at Aras Attracta care setting in 2014. The model to which Sage works is of core paid staff supported by, and in turn supporting, trained volunteers. Some of these volunteers act in support roles, some are advocates and some have specialist legal, financial or other professional skills.

It is conservatively estimated that the work of Sage in 2016 impacted on the lives and practice of some 20,000 people. We have worked with over 700 people where a diagnosis of dementia, capacity and cognition issues or mental health were amongst the initial presenting issues at the time of the referral. Sage works with vulnerable adults who are at different stages in their experience following a dementia diagnosis, and works to uphold the right to self-determination and autonomy by supporting a functional approach to capacity and ensuring the person is enabled to make decisions that affect them. Since 2016 Sage has been involved in some 58 cases where the person is experiencing the challenges of ageing and has mental health needs as a result of a primary mental health disorder.

Sage works with vulnerable adults and older people at transition points in the person's life when they are adapting to a diagnosis of dementia, moving from home to residential care, in acute hospital, transitioning from hospital to residential care and when they are experiencing significant loss associated with these changes. Sage is uniquely positioned to highlight the mental health challenges for vulnerable adults and older people, and to highlight the challenges a person with a primary mental health disorder can encounter as they age. Amongst these challenges is the availability of accessible, adequate and appropriate mental health services to adapt and meet the person's changing needs.

Sage welcomes the opportunity to make a submission to the Joint Oireachtas Committee on the Future of Mental Health Care. In making this submission Sage is incorporating experience and evidence gathered by the service since it commenced supporting vulnerable adults in residential care/congregated settings, acute hospital settings and in the community in 2014.

2. *Vulnerable Adults and Older People*

- Ireland has an ageing population. Census 2016 results show that the population aged over 65 increased to 637,567. For people aged over 85, the male population increased by 25% while the female population increased by 11%. According to current population projections, by 2046 there will be between 1.3 and 1.4 million people aged over 65, and over 470,000 people aged over 80.¹
- In Ireland, approximately 4.5% of older people live in a congregated setting or residential care settings. This is approximately 40% higher than the current European average.² It is estimated that one-third of women and one-quarter of men are likely to spend some time in a nursing home before they die³.
- Nursing home care in Ireland is provided through a mix of public, voluntary and private provision. According to the Health Information and Quality Authority (HIQA), there are 580 designated residential centres for older people in the State, providing a capacity for 30,369 people. The provision of public residential centres for older people has fallen significantly over the last 30 years from almost 50% down

to 20%. In the 2011 census 4,873 people aged 65 and over recorded that they were usually resident in a hospital.⁴

- There are 1,055 residential centres providing services for adults and children with disabilities registered with HIQA. 13.5% of the population are recorded as having a disability, including 224,388 people over 65 years⁵. According to the recently available figures, approximately 4000 people with a disability resided in an institution or psychiatric hospital.⁶
- In 2011, a survey of psychiatric hospitals and units showed one third of patients were aged 65 years and over. People over 75 years recorded the highest psychiatric hospitalisation rate with over one third having been in hospital for five years or more.⁷
- 55,000 people in Ireland are living with dementia, a figure that is expected to double by 2036. ⁸ Based on recently available figures, there were almost 30,000 people with dementia living in the community, with 26,413 of these aged over 65 years.⁹
- Only 11% of Nursing Homes have dedicated dementia care units, and the majority are provided by the private nursing home sector. This compares to rates of up to 33% in other European countries.¹⁰

3. *Mental Health and Older People*

- Chronic loneliness is experienced by 10% of older people. It is impacted by health, depressive symptoms, personal factors and environmental factors such as living in an isolated area and living in an impoverished area. Social participation and social resources protect against loneliness. Chronic loneliness impacts on physical and mental health, and on quality of life outcomes.¹¹
- Results from the Irish Longitudinal Study on Ageing (TILDA)¹² in 2011 showed that 10% of older adults in Ireland (people over 50 years of age) report clinically significant depressive symptoms and 18% have 'sub-threshold' levels of depression. Anxiety was found to be more prevalent than depression in this population, 13% of participants had clinically significant anxiety symptoms, and 29% had 'sub-threshold' levels of anxiety.
- TILDA research has shown there is under-diagnosis and under-treatment of depression and anxiety among older adults. 78% of older adults have evidence of depression, and 85% have evidence of anxiety but they do not have a doctor's diagnosis. Almost two thirds of adults with depression have a longstanding illness or disability.
- People experiencing depression use the health services more, people over 75 years of age with depression visit their GP on average 7 times per year, this compares to 4 visits per year for people without depression.
- Although depression is a prevalent mental health condition in older adults and can have a major impact on a person's quality of life, symptoms are often undetected, overlooked or not treated as it can occur with other conditions and problems associated with ageing. As highlighted by TILDA late life depression requires dedicated research as the causes, presentations and impact of late life depression differs from that in a younger adult.¹³

4. *Mental Health and People with an Intellectual Disability*

- According to the Intellectual Disability Supplement to TILDA¹⁴ in 2017 there is a higher prevalence of depression amongst people with an intellectual disability than the general population.
- It was found that 52% of participants in the study reported having a doctor's diagnosis of an emotional, nervous or psychiatric condition.
- Depression, anxiety and mood disorders were the main contributors to poor mental health. Anxiety was more frequently reported in people with an intellectual disability living in community settings than in an institution.
- It was found that over 35% of people with Down Syndrome have a diagnosis of dementia, and there has been an increase in dementia screening with people with Down Syndrome in recent years. Participants

with Down syndrome reported fewer mental health conditions (26.2%) than those without Down syndrome.

5. Polypharmacy and Chemical Restraint

TILDA research shows us that depression is associated with increased medication use in older adults. Of people aged 75 and over with depression, 56% are taking five or more medications compared to 36% of adults without depression.¹⁵ Similarly for older adults with an intellectual disability medication use increases over time, with almost 40% taking five or more medicines, and almost one third of this population taking 10 or more medicines. The higher prevalence of mental health conditions and use of medications to treat challenging behaviour amongst people with an intellectual disability puts people at risk of exposure to psychotropic drugs and psychotropic polypharmacy.¹⁶

Research has shown that 41% of patients with dementia admitted to an acute hospital had an antipsychotic medication administered at some point during their stay, and 16% of patients were given a new prescription for an antipsychotic medication. It was shown that 46% of people admitted from a nursing home were already taking an antipsychotic medication.¹⁷

Continued use of antipsychotic medications risks serious harm to the person. As noted by a Consultant in Geriatric medicine "...approximately 50% of use in nursing homes is for inappropriate indications, often to ensure the smooth running of the institution or to lessen disruption for others (Murphy and O'Keeffe, 2007)."¹⁸ There is a lack of legislative safeguards to prevent the use of sedation purely for the management of a person's behaviour for convenience within care settings, including residential care centres/congregated settings for older people or for people with disabilities, hospitals, or a person's home. There are no legislative safeguards to ensure the continued monitoring and review of the use of sedation, and of antipsychotic medications for short-term intervention as a specific treatment only, and not for prolonged use.

The Department of Health's policy on restraint in nursing homes aims "to restrict the use of all forms of restraint to those exceptional emergency situations where it is absolutely necessary. Where restraint is necessary it should only be applied in accordance with the law and best professional practice."¹⁹ HIQA's guidance on restraint for residential care centres states "(a)dmistering sedatives to a person who wanders during the night primarily for the convenience of staff is an example of chemical restraint which is not acceptable in any designated centre."²⁰ The Irish Medical Council permits within their *Guide to Professional Conduct and Ethics* the use of "appropriate physical or chemical restraint where this is in the patient's best interests"²¹ if the patient lacks capacity to make a decision about treatment or examination and there is a risk of harm to themselves or others. It has been recognised that there is often misunderstanding about the distinction between medication being used for therapeutic reasons and medication used to control behaviour amongst medical practitioners in residential care centres and in acute hospitals.²²

6. Mental Health Services for People with Disabilities and Older People

A *Vision for Change* states that a ..."critical principle of service provision for older people, including those living in the community, is that – regardless of their mental health history – they should have access to the services most appropriate to their needs."²³ A person turning 65, with a previous history of mental health problems, should have the option to remain with their existing adult mental health team, or to transfer to the care of the Mental Health Services for Older People (MHSOP) team which they are entitled to. The framework for service provision recognises the interdependence of physical and mental health, outlines a continuum of care and the need for a range of integrated care options. A *Vision for Change* sets out that mental health services for people with an intellectual disability should include two multidisciplinary Community Mental Health Teams (CMHT) per 300,000 adult population which operate from community

mental health centres. The CMHT should provide multidisciplinary assessment, treatment and care with an emphasis on home based services either in the person's residence or residence provided by a service.²⁴

A review of the implementation of a *Vision for Change* carried out in 2015 by Mental Health Reform²⁵ showed that 27 Psychiatry of Old Age Community Mental Health teams were formed at that time, compared to the 39 teams envisaged in the original policy, and adjusted for population increase there should be 46 teams to meet need. The review highlighted that mental health services for older people are "...under-resourced relative to the growing demand for this age group."²⁶ It was shown that not all areas have specialist mental health teams for older people, not all areas have dedicated psychiatry of old age inpatient beds, and that existing community mental health teams for older people do not have the recommended multidisciplinary staff levels. At the time of the review by Mental Health Reform there were only 6 acute inpatient units for older people, compared to the recommended 8 beds per 30,000 population in a *Vision for Change*.

An audit of dementia care in acute hospitals carried out in 2014 highlighted the need for more consistent provision of liaison psychiatry of old age services, as many hospitals had inadequate access to mental health services for older people.²⁷

A national overview of community based Mental Health Services for Older People (MHSOP) from the Inspectorate of Mental Health in 2010²⁸ showed that there are issues for MHSOP teams to access acute and long-stay beds, and difficulties placing people with dementia in long-term care. The review found there was a high demand on MHSOP to provide liaison services to general hospitals for patients over 65 years of age. It was recognised that there was significant input from the MHSOP to nursing homes in their catchment areas, and that the expertise and support from MHSOP in relation to dementia care is important for optimal care in nursing homes. The report highlighted the significant social contact provided by home help services to community dwelling older people and the benefits this has on mental health, stating that mental health care of older people 'cannot be divorced from social care and socio-economic circumstances'. The need for mobile clinics to provide services in rural areas was identified.

Amongst the recommendations from this overview was there should be one MHSOP community team providing domiciliary and community-based care per 10,000 population of 65 years of age and over, which is an increase on the recommendation of one team per 100,000 population in a *Vision for Change*. The overview also recommends community-based and day facilities should be available to all MHSOP as at the time of the report only 50% of services had day centre or day care facilities available to them, and only 36% of services had access to acute designated beds.

7. The Role of Advocacy

The right to have your 'voice' heard and to participate in the making of decisions which affect you is a fundamental principle in a democratic society. It is about independence and interdependence. It is a principle simply stated as "Nothing about you / without you".

The underlying principle of advocacy is to facilitate and support people in speaking for themselves and in articulating their own needs. In practice, advocacy often entails the use of a number of approaches working together with supports being provided at various points along a continuum.

Advocacy is underpinned by a core set of values and principles, and acts to empower people as well as safeguarding those who are vulnerable. A recent study by Mental Health Reform exploring advocacy needs of mental health service users tells us that under 10% of those surveyed felt they had a lot of control to lead their own lives as they want, and participants felt they were "only a little" involved in their own treatment planning with their mental health team. The level of control one has over their own life is an indication of quality of life for people with mental health problems.

The concept of independent advocacy is a centrally important one, i.e., assistance provided by an organisation that is structurally, financially and psychologically separate from the services that deliver health and social care as well as from people's families. It is important to recognise that many of those who provide services to people see themselves as advocates for those they care for, although not formally designated as such. At the same time, it is also necessary to recognise that service providers may sometimes experience a conflict between advocacy and their primary role in an organisation and, for this reason, an independent advocacy service is usually seen as 'the better option'.²⁹

While the role of families and relatives as advocates is crucially important, there is an additional and necessary perspective that independent support and advocacy can bring to ensure that the voice of the vulnerable person is clearly articulated in all circumstances, and, particularly, where crucial decisions are being made in relation to medical interventions, place of living and care arrangements. A *Vision for Change* recommended that advocacy should be available as a right to all service users in all mental health services.³⁰

From Mental Health Reform's research we note that 38% of participants using mental health services indicated they would not be comfortable asking a family member to advocate on their behalf, only 12% responded that they would be comfortable³¹. A recommendation from this study is the need for independent, one-to-one advocacy for mental health service users living in the community, as current advocacy provision where available is limited in practice to people in residential care and inpatients.³²

8. Safeguarding Vulnerable Adults and Older People

It is widely contended that abuse and neglect of vulnerable adults is significantly underreported in Ireland, due to lack of public awareness of what constitutes abuse, and lack of comprehensive policy and legal safeguards to protect vulnerable adults from abuse.³³

Sage welcomes the Government's measures to explore the introduction of safeguarding legislation following the introduction of a Private Members 'Adult Safeguarding Bill 2017' to the Seanad on 5th April 2017 and subsequent debates by the Joint Oireachtas Committee on Health in October 2017.³⁴ There is a need for a legislative framework to provide safeguards to protect vulnerable adults from abuse, to ensure a standardised process of reporting and investigation of allegations of abuse by an independent body with authority, and to ensure an outcome and redress for the person affected by the abuse. The current policies and protocols in place are not adequately protecting vulnerable adults from abuse which was highlighted by the RTE Primetime Investigates television programme *Inside Bungalow 3* into abuses within Áras Attracta. This inadequacy is also illustrated by incidents of abuse reported to HIQA and identified through the HIQA inspection process of designated centres for older people, and designated centres for people with disabilities.

9. Presenting Issues to Sage

- As identified in the TILDA study, and experienced by Sage, it is quite common for an older adult to have an undiagnosed mental health condition, and have never received appropriate treatment or care. Depression and depressive symptoms in older adults are underdiagnosed as they can occur with problems encountered through the ageing process, and medical comorbidity can make depressive symptoms hard to identify. Social isolation in later life through a limiting social circle and connectedness, bereavement, loss of independence, increased dependency on others and cognitive decline contribute to late-life depression.
- Social isolation can result in inactivity, lack of stimulation and boredom for older adults in the community, and within residential care settings. The process of decongregation and deinstitutionalisation for people with disabilities has recognised that inactivity and boredom is a factor

that requires active support to facilitate meaningful engagement in activities of interest to the individual.³⁵ Transitioning from living independently or with family members in a person's own home to living amongst strangers in an institutionalised environment of long-term care results in the experience of loss. The loss of a home, family, social contact, important personal relationships, pets, familiar surroundings, routine, activities, responsibility for and control over choices and tasks, being needed, amongst other factors that give life purpose and meaning, which are not easily replaced in an institutional setting. HIQA *National Standards for Residential Care Settings for Older People in Ireland, 2016*³⁶ focus on quality of life and a person-centred approach to care, and while standards are met in many residential settings and efforts are made to provide activities for residents, the structure of care provision in medium to large institutions presents a challenge to provide for individualised needs and interests, and opportunities for quality social participation, and to give purpose and enhance quality of life. Similarly for people living in the community, level of control over life, good interpersonal relationships, opportunities for social participation at a level needed by the person, and engagement in meaningful activities are factors which contribute to quality of life.

- Access to assessment, treatment and care for a person over 65 years of age is mainly through Old Age Psychiatry, MHSOP. From Sage's experience access to this service at community or primary level is limited, therefore attendance at a hospital is required for assessment. While service provision at hospital level is good in some areas, this presents a significant challenge for an older person who is resident in a long-stay care setting with limited ability, and for a person living in the community with limited social support and social resources. From Sage's experience there is more evidence of access to services for people who have been in residential mental health services and move to long-term residential care, in comparison to people resident in the community who then move to residential care.
- While a person has a right to have treatment and care provided by MHSOP according to *Vision for Change*, due to the under resourcing of community teams there is significant variation in the level of service throughout the country, and discrepancies in liaison service provided to long-term residential facilities. Sage has identified that in some geographic areas there is limited or no support from CMHT and MHSOP to residents in nursing homes, and to staff in nursing homes to support a resident with mental health challenges. In Sage's experience it has occurred that following consultation with the MHSOP the resident's mental health issues are attributed to the person's behaviour rather than a mental health condition, and this excludes the person from accessing supports as it is outside the remit of MHSOP. There is a need for the remit of MHSOP to be broadened to respond to the more varied mental health issues that ageing adults experience, and to provide training to staff in residential care settings for older people and vulnerable adults to ensure staff are equipped with the skills to respond to a person's behaviours, are adequately supported to develop appropriate care plans with input from MHSOP, and are supported by MHSOP to implement and review the plan. In Sage's experience there is limited access to state counselling services for people in long-term residential care as counselling services do not attend nursing home facilities. The service is accessed at a local health centre, which limits accessibility if a person has mobility issues, this brings additional costs for transport and if a carer is needed to travel with the person.
- Long-term care provision for vulnerable adults and older people is heavily reliant on residential care, particularly through private providers, which is not the general public's preference.³⁷ There is a lack of alternative flexible models of care to respond to a person's individualised needs and quality of life considerations to enable a person to live with dignity according to their wishes.³⁸ Sage has encountered people in their 50s and 60s whose principle needs are mental health related with no nursing care needs living in long-term nursing home care as there are no other appropriate options available. Similarly in circumstances where decongregation to community living is not appropriate for a person, but some low level care is required, there is a complete lack of suitable care settings. The impact on adults who may

be vulnerable, due to long-term mental health condition, and/or an intellectual disability and who are ageing, is a transfer from a State supported residential centre where they have access to therapeutic and social activities and benefit from skilled care staff to a State supported placement in a private or public residential care centre for older people. Due to the focus on geriatric care in nursing homes many residential care centres for older people are unsuitable and unable to meet the needs of a person with complex and multi-disciplinary care needs. The importance of continuity of care for a person with a mental health condition, and/or an experience of dementia is recognised, however in Sage's experience a person may have to move out of the CMHT catchment area to access appropriate long-term care, resulting in a loss of continuity. In circumstances where the established CMHT are not continuing to work with the person the overall effect is the transfer of a vulnerable adult from one institution which was their home for many years and which catered for their mental health or other complex needs to another new institution with loss of such supports and services, continuity of service, and familiarity with surroundings which are essential for well-being, and to ensure a good quality of life.

Sage experience 1

Margaret has an intellectual disability, has high dependency needs and is non-verbal, she has been in an acute hospital setting in a mental health unit for 18 months. The hospital want to discharge Margaret as the hospital is not a long-stay facility, and the long-stay facility for older people connected to the hospital states it is unable to meet Margaret's needs. A move to a privately run nursing home care facility in another county is being proposed by the acute hospital, as no other suitable option is available.

Sage experience 2

John, in his 50s, lived in a semi-independent unit with mental health services. Following a period in acute hospital he was moved to a nursing home care facility. John was considered too high risk to return to semi-independent accommodation and no other suitable option was available.

- While there are separate roles for services of Community Mental Health Team social work, Primary Care social work and Safeguarding and Protection Team social work, from Sage's experience if one social work service is engaged with the person there is an unwillingness for the other team to engage although the presenting issues require specific expertise and support. It is Sage's experience that the current HSE Safeguarding and Protection Teams are not engaging or supporting vulnerable adults with mental health issues where there is a mental health social worker involved. This a worrying development for such a vulnerable population.
- In 2015, Sage wrote to the then Minister for State for Mental Health, Primary Care and Social Care and then Minister for Health to highlight Sage's experience of the administration of medications to manage behaviours in practice that "[f]or a variety of reasons, some based on a lack of skill in addressing behaviours which are challenging, some based on ignorance of basic human rights and some based on expediency, it would seem that a culture has developed in which the use of chemical restraint has become normalised i.e. it is being used as a first rather than a last resort". Sage recommended the introduction of a legislative provision on the issue.³⁹ As an advocacy service working with vulnerable adults Sage has observed the use of sedation to manage behaviours for the convenience of staff and benefit of other people in congregated settings.
- While some private nursing home providers have dedicated dementia units, Ireland is below the EU average of dedicated dementia care provision. The current model of fee negotiations between the National Treatment Purchase Fund (NTPF) for the Nursing Home Support Scheme (NHSS) and residential care centres is considered unsatisfactory, particularly, because it provides for 'bed and board' and basic equipment and laundry services only.⁴⁰ The NTPF fee takes no account of different individual support and care needs, or any social and support needs for a person in residential care. A

person on a low income or State pension can therefore be deprived of access to therapeutic care and social supports unless the person can pay for it themselves. The HIQA *Standards*⁴¹ require a level of personalised care provision which is beyond the minimum care levels funded under the NTPF agreement. This shortfall is often met by a standard charge for 'activities/services' levied on all residents regardless of the person's individualised care needs and any additional services and supports they are actually receiving.⁴² As highlighted by Sage the fact that the care package provided for in the NTPF negotiated fee is frequently inadequate to meet the actual care needs of the person is a matter of grave concern.⁴³

- Sage has identified and highlighted the lack of clarity and unfairness of some contracts of care in place for the provision of services to vulnerable adults and older people in long-term care.⁴⁴ Sage identified an imbalance in contracts in that they tend to favour the nursing home's interests over those of the resident. Sage argues that there is a need to include new contractual clauses that will protect the rights of the resident. These arrangements can severely impact a person with a mental health condition and/or dementia. Sage has been involved in cases where residents in a long-stay care facilities have been issued with a 'notice to quit' or they have been informed that the care setting can no longer meet their care needs due to a person's presenting behaviours, when behaviours are related to a dementia diagnosis or a pre-existing mental health condition. In some cases a resident has been issued with a notice to quit due to the behaviour of family members.
- Despite the signing into law in December 2015 of the Assisted Decision-Making (Capacity) Act 2015 (ADM (Capacity) Act 2015), this legislation has not yet been commenced. As a result, Ireland continues to operate a ward of court system under the Victorian-era paternalistic legislation *Lunacy Regulations (Ireland) Act, 1871*. This also means that Ireland is unable to ratify UNCRPD 10 years after signing it. The current legal framework for substituted decision making for people deemed of "unsound mind" amounts to a denial of a vulnerable adult's human rights, and can impact people with reduced capacity due to dementia, intellectual disability, mental health disorder or acquired brain injury. Nonetheless, Sage continues to encounter clients who are being made the subject of a Ward of Court order. Sage endeavours to promote alternatives to Ward of Court where possible, exploring approaches informed by the principles of the ADM (Capacity) Act 2015 which safeguard the vulnerable person and promote their autonomy. People who are existing wards at the time of the commencement of the ADM (Capacity) Act 2015 and whose capacity will be reviewed to bring them within the new supported decision making regime will be unfairly treated under the legislation as it does not grant them rights to legal aid or other representation in the reviewing court.
- Sage welcomes the Department of Health's public consultation on draft legislation in relation to deprivation of liberty and safeguards for older people, people with a disability and people with mental health issues to ensure they are not unlawfully detained in residential facilities. The current lack of legal safeguards is in contrast to the legal protections available to adults detained under the State's Mental Health legislation. In Sage's experience this deficit can lead to the HSE using the wardship system to detain people who do not meet the high standard needed to detain a person under the Mental Health Act 2001. In Sage's experience it is not uncommon for a third party, often a next of kin, to be asked to sign the contract for care to consent to care although they may have no legal authority to make decisions for that person. The third party is also consenting to provisions of the contract including to immediately terminate the contract without adequate safeguards leading to a loss of a place to live⁴⁵. Social workers working with older people have reported that only 61% of people in a sample of cases were involved in decision-making about their care, with involvement being described as tokenistic in some cases. Similarly, only 55% of people with dementia were involved in decision-making about their care.⁴⁶ Furthermore, in the absence of the commencement of the ADM (Capacity) Act 2015 there is neither a statutory obligation to use a functional approach to determine the person's capacity to consent to residence in an institution, nor a process to support and assist the person to make that decision.

Sage experience 3

Mary is in her early 50s and is living in a designated centre for people with disabilities, the service also accommodates 15 other people. The centre has been Mary's home for over 20 years. Mary has been receiving treatment and care for a mental health disorder since early adulthood, and currently receives support through the multidisciplinary CMHT and attends a review meeting every 6 weeks where she meets with different psychiatrists at each review. She does not have a mental health social worker. Mary has a diagnosis of Parkinson's disease, and recently received a diagnosis of dementia. In the past two months Mary has been exhibiting behaviours which are challenging for the service provider, and are considered to be impacting on other residents. The disability service has informed statutory services and Mary's family that they can no longer provide for her needs in the service. The service is proposing a move to long-term care in a nursing home as part of a transition plan. Mary has not yet been informed of this proposal. Mary has expressed that she is very settled and happy where she is living, and believes that she will continue to live there for the rest of her life.

The Sage Experiences illustrate the need for an integrated approach to care planning with a person with an intellectual disability, and highlights the challenge and lack of appropriate services for a person with comorbid mental health and intellectual disability, and where the person is experiencing the challenges of ageing. While many disability services have an ethos to respond to the person's needs through their life cycle, in Sage's experience there is inconsistency in service provision. In Sage Experience 3 Mary has been linked with mental health services and supports, and has been connected to a specialised service for disabilities for most of her adult life. The lack of sufficient resources within the CMHT has impacted Mary as she does not have a mental health social worker and she meets a locum psychiatrist at review meetings. From the example the onset of dementia has presented a challenge for the disability service to respond to Mary's needs, and there is a risk decisions will be made without Mary's consent. An integrated approach to care planning which is person-centred should require involvement of Mary, engagement from Mary's mental health team, service provider and other people within Mary's support network working with Mary to identify and understand Mary's changing needs, what may be causing Mary's behaviours, putting in place measures to respond to these behaviours in Mary's own home, enabling Mary to access community based services for a person with dementia as envisaged within a Vision for Change and the National Dementia Strategy (2014) and enabling Mary to continue to live in her home as she wishes for as long as possible with the continued support from the CMHT.

10. Recommendations

1. Recognition of the role and practice of independent advocacy, and the right of vulnerable adults or potentially vulnerable adults to access and be represented by an independent advocate in all care settings, including domestic homes, and of the necessity for their voice to be heard in multi-disciplinary and inter-sectoral working arrangements which relate to them.
2. Establish a National Council for Support and Advocacy to coordinate and strengthen the systems and practices of all providers of support and advocacy services to vulnerable persons, and ensure sufficient and equitable resource provision.
3. Expand the existing remit of Mental Health Services for Older People to meet the broader presentations of mental health issues experienced by older adults.
4. Expand the existing remit and adequately resource community based mental health teams to respond to the needs of vulnerable adults and older people in long-term residential care, and to provide support and training to residential care facilities for vulnerable adults and older people to ensure integrated care planning from a multidisciplinary team and continuity of service for a person moving within and outside of a CMHT catchment area.
5. Adequately resource community based mental health services for older people and adult community mental health teams with the required multidisciplinary skills and administrative support to adequately meet the targets as set out in *Vision for Change* and adjusted for population growth and changes.
6. Adequately resource the provision of acute and inpatient facilities for vulnerable adults and older people as set out in a *Vision for Change*, and adequately resource long-term care to meet the specialised care needs of people with dementia and/or a mental health condition.
7. Adequately resource provision of care in the community to prevent a person being *de facto* detained, and to enable people to receive care in accordance with their wishes and in response to their individual care needs in a timely manner, which respects, protects and upholds their human rights.
8. Address the systemic bias towards long-term residential care for older people in congregated settings in preference to care at home or in a less institutionalised environment, using a human rights, societal and public interest perspective. Promote pathfinder strategies to explore how national policies on ageing, urban and rural community regeneration and public service reform can be aligned at local level to create inclusive physical and social environments and systems which are responsive to changing needs over the life cycle, and develop sustainable local communities and economies.
9. Enact legislation to create a statutory right to care in the community or other appropriate supported environment which provides for a flexible continuum of care, addressing individual needs and respecting choice.
10. Enact legislation on Deprivation of Liberty in as short a time as possible which is in accordance with international human rights standards and norms regarding use of detention and restraint.
11. As identified by the Institute of Public Health study, identify chronic loneliness as a social health priority, recognise it in social inclusion policy and health policy and establish services and initiatives to address chronic loneliness.

Endnotes

- ¹ Central Statistics Office (2013). *Population and Labour Force Projections 2016-2046*. Dublin: Government of Ireland http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016_2046.pdf [accessed 08/06/2017]
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