Opening Statement to the Oireachtas Committee on the Future of Healthcare

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Senator Colette Kelleher

Independent – Civil Engagement Group

Introduction

I'd like to begin by thanking the Committee for the invitation to present here today. I fully support the initiative taken to set out a ten year, cross party, vision for the future of Irish healthcare. I have been closely following the work of this Committee, as well as making the submission which you will have received.

Before I get into the detail of the submission, I would like to tell you a bit about myself and my background – as that has informed the submission, my presentation today and the work I will do in the Seanad into the future.

My professional experience includes Chief Executive roles with the Alzheimer Society of Ireland, Cope Foundation, Cork Simon Community and the Daycare Trust in the UK. In addition, I worked as an Advisor to Minister Margaret Hodge MP who had responsibility for early years and childcare. I'm a qualified Social Worker. I also have a Master's in Business Administration (MBA) and have recently become a Certified Practitioner in Change and Consulting at the Tavistock Institute, and in May much to my surprise, I was appointed by the Taoiseach to the Seanad.

Overview

As you will all be too well aware the Irish healthcare system has drifted from crisis to crisis for decades. Both piecemeal and radical reforms have failed to transform it. It now really needs a new vision, new purpose, new focus, backed by political consensus.

My submission sets out nine recommendations on how the Irish health and social care system can be recast to become citizen centred. At the core of each of these recommendations is a vision for a high quality, universal, single-tier

health and social care system that adequately meets the needs of people living in Ireland. I will briefly take you through these recommendations and then focus my presentation on the area of social care.

Purpose, Principles and Values

To begin, I would urge this Committee to start your deliberations at first principles – stripping back the layers of the health and social care system and examining thoroughly the culture, values and rights that underpin it. The Committee should set out a list of shared values capable of creating a culture of compassionate health and social care. These values should be more than just words. They should be discernible, actively lived and tangible in the governance, leadership, management, training, education, professional development, everyday actions and decision making of those working in the health and social care system. A similar approach was successfully taken in Canada in 1984. The principles developed by the Irish Health Reform Alliance (2016) are a good starting point on which the Committee can build its recommendations. In addition, access to high quality universal healthcare for all should be enshrined as a right.

Health Inequalities

There are a number of groups that have been seriously let down by our healthcare system – over the next 10 years we have to tackle these stark health inequalities head on.

The poor health of our country's 30,000 Travellers is a national scandal.

- Traveller infants are 3.6 times more likely to die than infants in the general population according to the HSE (2016).

- The suicide rate in male Travellers is 6.6 times higher than in the general population (The Ireland Traveller Health Study Research Team, 2010).
- In 2008 the life expectancy for Traveller men was 61.7 years, compared to 76.8 years for men in the general population – a difference of more than 15 years.
- The life expectancy for Traveller women was 70.1 years compared to 81.8 years for women in the general population –A decade in the difference.
- The Director of the Irish Traveller Movement, Bernard Joyce, recently said 'The direct correlation between Travellers quality of life, physical and mental, is linked to the quality of their accommodation.' The state of some traveller accommodation is truly shocking. There is a halting site in Cork city, Spring Lane, that was built for 10 families but now houses 30. Traveller representatives have said that 'The reality of life on Spring Lane site is that many families remain without water or toilets, some continue to live in old damp mobile homes, all families live with daily overcrowding, and the almost 100 children on site continue to have no safe place to play. People's health, mental health and life expectancy are suffering as a result of this.'

Stark health inequalities also exist for other marginalised and minority groups:

- The average life expectancy of people experiencing homelessness is 47 years for men and 43 years for women (Walsh, 2013).
- 60% of lesbian, gay, bisexual, transgender, intersex people have seriously thought of ending their own life, with almost half of these considering it in the past year. Younger LGBTI people are most vulnerable. 30% who have attempted suicide did not access mental

health services, with cost, stigma and lack of understanding of LGBTI issues cited as the main barriers (GLEN, BeLonGTo & TENI, 2016). These barriers can and must be overcome.

Population Planning

Health planners need to hear the voices of these marginalised groups, who live with the effects of health inequality. In my submission, I propose the establishment of a pilot version of NHS Citizen and Healthwatch UK. In addition, area based, inclusive, stakeholder based Healthcare Planning Forums, should be established on a statutory basis for on-going population planning. These would allow the voice of the citizen to be heard loud and clear in the planning process. I have seen first-hand in the UK how effective these can be. I note that calls for a similar initiative were made by the GP's from Carlow – Kilkenny in their presentation to the Committee.

Social Care

We cannot put together a comprehensive plan for the future of Irish healthcare without looking too at social care, because for the healthcare system to function properly we need to have a properly functioning social care system. Both health and social care are intertwined. When I talk about social care I mean provision of social work, personal care, home care, day supports, therapies, counselling short breaks & respite, support services to children or adults at risk, caring for needs that arise from disability, old age or poverty. If you don't develop social care you create a demand for acute care by default. And we haven't developed that social care infrastructure or safety net.

In many ways social care is the Cinderella of the healthcare system – its neglected and overworked, and is having a disproportionate effect on acute

care. Social care services are patchy, disjointed, dysfunctional and too often paternalistic. In many cases availability of services are determined by a postcode lottery. There is no clear strategy, vision or plan. As you will know from your families and constituents, everyday this lets down citizens and their carers at their most vulnerable. It's undermining people's dignity, independence well-being and shortens lives and life expectancy.

Up to now, key areas of social care have been left by the state to poorly funded and poorly governed charities. As a result, very often citizens have to rely on services and supports which require fundraised income to operate. There are well publicised examples of core services for vulnerable people being delivered by charitable organisations under question. Social care services for vulnerable people must be transparently commissioned, adequately funded and properly governed.

While I recognise that the state invests in social care, the existing spend is inflexible as well as chronically underfunded. There is no room in the budget allocation for the expansion of services. Of late there has been some welcome moves towards personalised budgets for people with disabilities, and I'm glad to have been appointed to a reference group on that. But on the whole, the budget needs examination and increases in key areas.

We should think of social care infrastructure like we would think of a transport system - for an effective transport system to operate you need all the parts to connect and to work together. We are unfortunately missing lots of pieces of the social care infrastructure. Just like we are retrospectively joining up the Luas lines, at huge cost and upheaval, we also need to join up the social care

infrastructure to create webs of care. In the long run, just like the Luas lines it will be a worthwhile investment.

One key part of that infrastructure is home care. A properly functioning home care system would and should serve people with a variety of support needs including people with dementia. Just taking that group - there are currently 55,000 people with dementia in Ireland – 63% of whom live at home. The National Dementia Strategy (2014-2017) co-funded by Atlantic Philanthropies, promised to provide 500 home care packages to people with dementia. To date just 72 people have benefitted from these. As a result many people who could be living at home are living in acute hospitals and other institutions. In fact, according to the Department of Health, 25% of people in acute hospitals have dementia. The National Dementia Strategy just like 'A Vision for Change' or 'Time to Move on From Congregated Settings' and many other plans in the social care sector has become a victim of Ireland's 'implementation deficit disorder'.

In one week in August there were 31 people, in three hospitals, ready to be discharged who were waiting on a home care package. Over the course of the entire month of August just 1 home care package was provided in these three hospitals. As a result there were 30 delayed discharges. This is economically illogical because an intensive home care package would only cost €1,000 a week, while a stay in acute care costs €1,000 a night (Health Amendment Act 2013). If you scale this up over the year and across the state the savings are significant. Minister Harris told the Joint Health Committee last week that there are currently 629 people whose medical care is complete who are still in hospital because other necessary care, support or accommodation has not been provided. Remarkably, there has been a cut in the level of funding for

home care over the last number of years in spite of its need, demand and unequivocal citizen preference, as well as its cost effectiveness (UCD, Age Action, The Alzheimer Society of Ireland & IASW, 2016). This is just one example – a similar picture could be painted in the area of people with disabilities, people with chronic conditions and older people.

The lack of home care and other social care provision has many knock on effects. People are too often forced to give up employment to take on caring duties full time. This burden predominantly falls on women. The 14.4% pay gap and 37% pension gap (NWCI 2016) can partly be explained by women dropping out of paid work to take up caring duties.

Looking forward

If we accept that the social care structures are not fit for purpose for today, then the time for action is now – because with an ever aging population, thanks to the miracle of medicine, and the emergence of unmet complex needs such as older people with Downs syndrome and dementia, these systems and structures are certainly not suitable for the future.

We need a comprehensive plan for social care, underpinned by compassionate values and rights and informed by population planning and health forums. We need to dismantle old systems and shut down many of the institutions. This project I accept maybe beyond the scope of this committee, and it may require a committee or commission in its own right. But, we must make it happen - because if we don't adequately examine social care all the rest of the work of this committee will be put in jeopardy.

As a crucial first step, over the life time of this government, we could significantly invest in home care. This investment in home care must coincide

with the introduction of robust regulation, a legal entitlement to guarantee access and proper work force planning. We know that it will result in long term cost savings. We know there is a demand from citizens and we know it's a key missing pieces of the social care puzzle.

The Taoiseach said this week in the Seanad that he wants 'an Ireland that looks after its people from the time they come into the world to the time they leave' – a transformative investment in home care will go some way to making this vision a reality.

Thanks again for the invitation and I welcome your questions.