Citizen Centred Healthcare

Submission to the Oireachtas Committee on the Future of Healthcare

Senator Colette Kelleher

Independent – Civil Engagement Group

26 August, 2016

Executive Summary

The Irish healthcare system has drifted from crisis to crisis for decades. Both piecemeal and radical reforms have failed to transform it. It now needs a new vision, new purpose and new focus.

This submission provides nine recommendations on how the Irish healthcare system can be recast to become a citizen centred healthcare system. At the core of each of these recommendations is a vision for a high quality, universal, single-tier healthcare system that adequately meets the needs of the Irish people. These recommendations draw primarily from my working life in social care over three decades.

Purpose, Principles & Promises

I urge the Committee to begin their deliberations at first principles – stripping back the layers and examining the values and rights that should underpin our healthcare system.

I recommend that:

1. The future of healthcare strategy be citizen focused and rights based.
2. A set of values form the foundation of the Irish healthcare system – with a clear path outlined on how these values will be promoted and embedded.
3. The right to good quality universal healthcare is established and clearly defined.

Priorities, People Focused & Population Planning

I call on the Committee to ensure that the voice and needs of the citizens are heard and met. To achieve that I recommend:

4. Tackling health inequalities and meeting the needs of the aging population be prioritised for attention and resources.
5. A pilot version of NHS Citizen and Healthwatch be established as a means of ensuring that the voice of the citizen is heard.
6. Area based, inclusive, stakeholder model of Healthcare Planning Forums be established on a statutory basis for on-going population planning.

Payments, Partnership & Politics

As legislators we are empowered by citizens to allocate resources, establish strategies and make decisions for the common good. In this regard I recommend that:

7. Adequate funding be found to bring all services up to standard.
8. Interdisciplinary working is put at the heart of health and social care delivery.
9. Political consensus, on a realistic plan, for the future of Irish healthcare be achieved and maintained.

I propose that the Committee consult with some of the experts who advocate for the proposals outlined, such as Henry Mintzberg of McGill University, Robert Yates of Chatham House, and Michael West, of the King's Fund. More importantly however, I urge the Committee to consult with as many citizens as possible - as the future of Irish healthcare is of grave importance to us all.

Background

This submission draws on my three decades of experience working to advance the rights and supports of children and young people, people experiencing homelessness, people with disabilities and people with dementia in Ireland as well as in the United Kingdom. It also draws on my formal education and learning, my life experiences and values. Above all I reflect on what I have learned from the people on whose behalf I have worked.

My professional experience spans Chief Executive roles with the Alzheimer Society of Ireland, Cope Foundation, Cork Simon Community and the Daycare Trust. In addition, I served as Special Advisor to Right Honourable Margaret Hodge MP as Minister with responsibility for early years and childcare. I'm a qualified Social Worker. I hold a Master's in Business Administration (MBA) and have recently become a Certified Practitioner in Change and Consulting at the Tavistock Institute.

Whilst I take full responsibility for this submission, I wish to acknowledge and thank those who helped me develop it.

Senator Colette Kelleher

Contact Details:

Phone: (01) 6183627
Email: colette.kelleher@oir.ie
Address: Seanad Éireann, Leinster House, Kildare St, Dublin 2.

Nine Steps to Achieving Citizen Centred Healthcare

1. Purpose & Strategy

The core purpose of the Irish healthcare system should be to enable all of our citizens to live long and full healthy lives. The strategy developed to achieve this should be rights based and citizen focused.

The overall purpose of the health system is often lost in heated debates about waiting times, new wonder drugs, consultants' salaries, poor management and under resourcing. Instead of focusing on units like hospitals and healthcare centres, I believe the committee should focus on achieving a citizen centred healthcare system whose purpose is a healthy population as a whole. Instead of thinking in terms of the patient, the client or even the voter, I believe the Committee should be orientated to the citizen and their rights to a healthy life.

Recommendation: That the future of healthcare strategy be citizen focused and rights based.

2. Principles and Values

The culture, values and guiding principles that underpin the ten year strategy for healthcare should be as important, if not more important, than the strategy itself. Management thinker, Peter Drucker, noted 'culture eats strategy for breakfast'. This maxim contains a useful challenge to the thinking that just getting the 'strategy right' will solve all the problems in the healthcare system. I believe the Committee needs to look deep at the culture, values and guiding principles of our healthcare system.

The 1984 Canada Health Act set out the values[1] that the Canadian health system would be built on. These acted as the guiding principles for the decisions taken by politicians, health administrators and clinicians in the years that followed. I believe Ireland should follow a similar approach setting out a list of shared values capable of creating a culture of compassionate healthcare.

The principles developed by the Irish Health Reform Alliance (2016) are a good starting point on which the Committee can build its recommendations for the future of Irish healthcare. These are:

- The health and social care system treats everyone equally.
- The health and social care system is focused on the need of all groups in society.
- People are entitled to health and social care free at the point of access.
- The different elements of the health and social care systems work together and are connected.
- The health and social care system is a universal and publicly funded system.

I would add *kindness* and *respect* to the list of key principles and values. These are of particular importance in light of recent scandals of abuse revealed in Áras Attracta, within the NHS, in Mid Staffordshire, England (Francis, 2013) and in other parts of the health and social care system. The consequence of a disconnection from the values of kindness and respect in health systems for vulnerable people has rightly shocked us all.

These values should be more than 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 any healthcare system, at every level, starting at the top. The nurturing of a values based culture is something that doesn't happen by itself but has to be led and encouraged across the healthcare system and organisations. This approach is currently in practice in some parts of our care services. Cork Simon Community, for example, used its values as a starting point to review its work on a quarterly basis, identifying how the organisation lived its values, as well as reflecting on how it fell short, and how it could and would do better.

Embedding and achieving a values based culture in health and social care systems has been well researched and set out by the UK's King's Fund, a charity working to improve healthcare in England (West, 2013).

Recommendation: That a set of defined values form the foundation of the Irish healthcare system – with a clear path outlined on how these values will be promoted and embedded.

3. The Promise – Universal Healthcare for All

Access to high quality universal healthcare for all should be a right, not just an aspiration. I believe there needs to be a definition of what that 'universal' system will consist of and clarity about what healthcare the citizen will have a right to.

The World Health Organisation (2016) define universal health coverage 'as ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship'. This quality should be measured using several criteria such as effectiveness, patient focus, timeliness and safety.

Recommendation: That the right to good quality universal healthcare is established and clearly defined.

4. Priorities

Tackling the gross health inequalities in Ireland and preparing for the consequences of an ever aging population should be key priorities for the ten year healthcare strategy.

Health Inequalities

A key feature of the Irish healthcare system as it stands is that it is failing particular groups and populations – this needs to be urgently addressed.

The poor health of our country's Traveller community (29,500 people) is a national scandal:

- Traveller infants are 3.6 times more likely to die than infants in the general population (HSE, 2016).
- The mortality rate among Travellers is 3.5 times higher than the general population.
- The suicide rate in male Travellers is 6.6 times higher than in the general population (The Ireland Traveller Health Study Research Team, 2010).
- The life expectancy for Traveller males was 61.7 years in 2008 compared to 76.8 years for males in the general population – a difference of more than 15 years.
- The life expectancy for Traveller females was 70.1 years in 2008 compared to 81.8 years for females in the general population – a difference of 11.7 years.

Stark health inequalities also exist for other marginalised groups such as people who are homeless:

- The average life expectancy of homeless people is 47 years for men and 43 years for women – decades short of the average (Walsh, 2013).
- In 2013, 517 people with a 'temporary place of residence' were admitted to A&E with the most frequent diagnosis 'injury, poisoning and certain other consequence of external causes'. While homeless people are high users of emergency services they have low use of planned outpatient facilities (HSE, 2016).
- 60% of lesbian, gay, bi, transgender, intersex (LGBTI) people have seriously thought of ending their own life. 40% of LGBTI people who have self-harmed and 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).

An aging population

One of the products of improving health is that the aging population is growing.

- By 2021, there will be 107,600 additional people aged 65 and over (HSE, 2016). Increasing from 11% of the population to 15.4% (ESRI, 2008).
- By 2026, the number of people experiencing dementia will grow to almost 80,000 from the current 55,000 (Pierce et al, 2014).
- By 2031, the population aged 65 or older in Ireland is projected to be 991,000 - up from 532,000 in 2011 (CSO, 2013).

This throws up a number of challenges for the healthcare system. Firstly, older people are major consumers of health services – being almost 20% more likely to be health service users in a given year

than those under 65 (HSE, 2013). They are also particularly vulnerable to abusive and inadequate care.

Second, as a result of population aging there are new unmet complex needs – for example, as people with Down Syndrome now live longer they are more susceptible to early onset dementia. Currently there is little understanding or appropriate supports for people with both Down Syndrome and dementia.

Finally, there is a clear wish of older people to remain independent (Houses of the Oireachtas, 2012), and to remain in their own homes for as long as possible (UCD, Age Action, The Alzheimer Society of Ireland & IASW, 2016). These preferences should be supported and catered for. The health and social care system needs the capacity and ability to make new services and supports available that will meet the changing and complex needs of the aging population.

There is a need for immediate and sustained long term healthcare planning and investment to tackle the health inequalities faced by marginalised groups and to adequately care for Ireland's aging population.

Recommendation: That tackling health inequalities and meeting the needs of the aging population be prioritised for attention and resources.

---

5. People Focused

The citizen in Ireland is poorly represented and protected in the healthcare system. With the exception of the regulator HIQA, who have successfully exposed poor standards and some other useful initiatives around safeguarding vulnerable adults, little is being done to ensure that citizens are involved, heard and protected.

As part of redressing the disconnect in healthcare in the UK, a project called NHS Citizen has been developed by the Tavistock Institute to connect the healthcare decision makers with the citizens they serve, actively engaging them in the planning and delivery of health and social care (NHS Citizen, 2016). In addition, a national consumer champion Healthwatch has been established. This body has statutory powers to ensure the citizen is heard by those who deliver and regulate healthcare services.

The citizen should be put in a position of influence on all deliberation on the future of healthcare – including the work of this committee. Their voice should be actively promoted and their needs and preferences listened to and met.

Recommendation: that a pilot version of NHS Citizen and Healthwatch be established as a means of ensuring that the voice of the citizen is heard.

6. **Population Planning**

Population planning mechanisms need to be put in place to allow for ongoing planning of future healthcare needs.

This could take the form of 'Healthcare Planning Forums' established on a statutory basis, and coinciding with the nine Community Health Care Areas. Such forums would include all the different stakeholders, for example, citizens, providers, commissioners, professionals and politicians. They could include outreach to marginalised groups not currently benefitting from healthcare for example Travellers, people living in remote communities and people with a disability.

The needs and priorities that emerge from these Healthcare Planning Forums could form the basis of what is then commissioned on behalf of the citizen. These healthcare population planning mechanisms would need to be well resourced to operate effectively.

A version of this kind of area planning mechanism is being commenced this autumn to assess dementia needs, the dementia gap in services and supports and to make a local multi annual dementia plan. Such a mechanism was also used to good effect in planning and developing homeless services in 2000's[2] and for the expansion of early years and childcare services in the UK[3]. Another initiative of this kind was the recent roadshow by the National Association of GP's as part of its call for a Tallaght Strategy-style consensus to deliver health reform, with meetings in Dublin, Cork and Limerick (Irish Medical Times, 2016).

Recommendation: that an area based, inclusive, stakeholder model of Healthcare Planning Forums be established on a statutory basis for on-going population planning.

---

7. Paying the Full Cost

The historic chronic underfunding of some areas of social care, as part of the overall healthcare system, must be redressed and factored into the Committee's calculations.

A key example of that underfunding is the poor standards in our community hospitals and disability centres and the funding gap required to meet the HIQA's national standards.

There has also been a fall in the level of funding for homecare 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).

Other key areas of social care have been left by the state to charities. As a result, citizens have to rely on services and supports which require fundraised income to supplement the inadequate state funding. There are well publicised examples of core services for vulnerable people being delivered by charitable organisations under question. This mode of delivery of social care has been a contributory factor in the proliferation of poorly funded and poorly governed charities. Social care services for vulnerable people should not be left to unaccountable 'do gooders' and must be transparently commissioned, adequately funded and properly governed.

Recommendation: that adequate funding be found to bring all services up to standard.

8. The Professions and Vested Interest

There are many vested interests in healthcare including the providers – public, private and voluntary; the pharmaceutical industry; insurance companies, the professionals, professional bodies and unions (Goldarce, 2013).

As with most health care systems, the Irish one is dominated by the professions or producers, with the medical profession first among equals setting the paradigm of 'the silo' mentality. The result is a dysfunctional healthcare system where the health needs of the citizen are not necessarily to the fore. This effect occurs across different jurisdictions even if the health system takes very different forms. This is cogently described by renowned academics Henry Mintzberg and Sholom Glouberman (1997) in two short papers. Their solution is to achieve 'one system', with collaborative management of the entire system. Among other things, they cite collaborative networks and guiding principles or values as necessary to create the right culture for the successful delivery of healthcare for all citizens.

Ways of promoting shared values in the Irish healthcare system should be explored across the various healthcare professions. Interdisciplinary work, training and organisational learning across the different healthcare professions in the workplace and universities should become the norm - with the focus on the healthcare team, planning and providing care around the citizen. Cope Foundation reorganised its interdisciplinary staff (nurses, physiotherapists, occupational therapists, speech & language therapists, social workers, care staff etc.) based on a model developed in the UK to achieve the right mix of accountability in decision making (Dive, 2008).

The early intervention team in Cope Foundation developed a co-ordinated approach to multi-disciplinary interventions called 'the team around the family'. This approach involved co-ordinating a range of disciplines and made a positive difference in developing child centred care that was relevant and collaborative. It also helped the parents of children diagnosed with intellectual disabilities handle the plethora of sometimes conflicting advice at a vulnerable and difficult time.

A real move to interdisciplinary working may be resisted as it will pose a challenge to current received wisdom and the role of professional bodies and unions.

Recommendation: That interdisciplinary working is put at the heart of health and social care delivery.

9. Politics

Finally, as politicians we must lead an honest conversation about what form of universal healthcare can realistically be achieved and in what time frame. Yates (2015) notes that 'for too long politicians have been less than upfront with citizens, making perhaps unrealistic promises that are popular electorally though unrealistic without radical change'. This outcome can and must be avoided here – healthcare is too important to the lives of all citizens to remain on as a political football.

Recommendation: That political consensus, on a realistic plan, for the future of Irish healthcare be achieved and maintained.

Notes

1. The values set out in the Canada Health Act were: Public Administration; Comprehensiveness; Universality; Portability; & Accessibility.
2. Cork Homeless Forum ran for over a decade and by 2011 had all but eliminated rough sleeping in Cork City, a situation now sadly reversed for all those without shelter in the City today.
3. Early Year Development & Childcare Partnerships were developed in every local authority to expand services and supports for children from birth to 14 years in England and Wales 1998 – 2002.

References

CSO (2013), 'Population and Labour Force Projections 2016-2046', available from: http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016_2046.pdf

Dive, B (2008), 'The Accountable Leader: Developing Effective Leadership through Managerial Accountability', Kogan Page.

ESRI (2008), 'The Impact of Demographic Change on Demand for and Delivery of Health Services in Ireland 2006-2021', available from: http://www.esri.ie/pubs/BKMNEXT166.pdf

Francis, R (2013), 'The Mid Staffordshire NHS Foundation Trust Public Inquiry', available from: http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffspublicinquiry.com

GLEN, BeLonGTo & TENI (2016),' The LGBTIreland Report' available from: http://belongto.org/attachments/250_Key_Findings-TheLGBTIrelandreport.pdf

Goldarce, B (2013) 'Bad Pharma: How Medicine is Broken, and How We Can Fix it', Harper Collins.

Health Reform Alliance (2016), *Our Key Principles*, available from: http://healthreformalliance.ie/wordpress/health-reform-alliance-principles/

Houses of the Oireachtas (2012), 'Seanad Public Consultation Committee - The Rights of Older People', available from http://tilda.tcd.ie/assets/pdf/Seanad%20Report.pdf

HSE (2007), 'Insight 07 – Health and Social Services in Ireland – a survey of consumer satisfaction', available from: https://www.ucd.ie/t4cms/Insight_07%20Report.pdf

HSE (2016), 'Planning For Health', available from: https://www.hse.ie/eng/services/publications/planningforhealth.pdf

Irish Medical Times (2016), 'Roadshow to push for 10-year 'Tallaght Health Strategy, available from: http://www.imt.ie/news/latest-news/2016/03/roadshow-to-push-for-10-year-tallaght-health-strategy.html

Mintzberg, H & Glouberman, S (1997), 'Managing The Care Of Health and The Cure Of Disease Part I: Integration', available from: https://flora.insead.edu/fichiersti_wp/inseadwp1998/98-50.pdf

NHS Citizen (2016), *We are enabling citizens to influence NHS England decision making*, available from: https://www.nhscitizen.org.uk/

Pierce et al (2014), 'Prevalence and Projections of Dementia in Ireland', available from: http://www.genio.ie/system/files/publications/Dementia_Prevalence_2011_2046.pdf

The Ireland Traveller Health Study Research Team (2010), 'Our Geels – All Ireland Health Study', available from: https://www.ucd.ie/t4cms/AITHS_SUMMARY.pdf

UCD, Age Action, The Alzheimer Society of Ireland & IASW (2016), 'Meeting Older People Preference for Care Report', available from: https://www.ageaction.ie/sites/default/files/aa2c_asi2c_iasw_final_research_report-a4-report_lr_for_web_2.pdf

Walsh, K (2013), 'Homelessness, Ageing and Dying', The Simon Communities of Ireland.

West, M (2013), 'Nurturing Cultures of High Quality Care', The King's Fund, available from: https://www.nwpgmd.nhs.uk/sites/default/files/Professor%20Michael%20West.pdf

World Health Organisation (2016), *Universal health coverage*, available from: http://www.who.int/healthsystems/universal_health_coverage/en/

Yates, R (2015) 'The Special Interest Politics of Universal Health Coverage' lecture delivered at Balvatnik School of Government, Oxford University, UK in February 2015.