



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Remarks by HIQA CEO, Phelim Quinn, to Safeguarding Ireland Roundtable on Advocacy

17 October 2018

In addressing the topic of independent advocacy from a regulator's perspective, I want to acknowledge the detailed paper that has been prepared for this event by Dr Michael Browne. Michael's paper encapsulates the characteristics and requirements for the provision of independent advocacy in Ireland. It sets out clearly how independent advocacy needs to be regarded from a citizen, policy and practice perspective. It also clearly sets out the legislative imperative for independent advocacy, ensuring that Ireland complies with the international agreements and conventions it has ratified.

Whilst I appreciate that I have been asked to speak as the regulator of health and social care services, HIQA's functions extend beyond the specifics of regulation and I believe that our role in the development of standards and guidance as a service improvement agency is also of relevance to today's conversation.

When looking in the first instance at what advocacy is, we need to look at how we encounter service providers' understanding of advocacy or how indeed service providers are required to know and address their responsibilities in ensuring that service users are enabled to avail of advocacy services.

The definition of advocacy in the 2013 care and support regulations for children and adults living with a disability living in a designated centre outlines that 'advocacy' means a process of empowerment of the person which takes many forms and includes taking action to help communicate wants, secure rights, represent interests or obtain services needed. I believe it is vital to understand how this definition is not only acknowledged and adhered to when a person may require the services of an advocate but also how this process of empowerment is experienced by service users in their day-to-day care.

The culture of service provision within Ireland's long-term residential care sector, the sector that we regulate, has been one of paternalism and one that focused on the condition or the medical diagnosis of individual residents. As a result, service delivery has been diagnosis and task focused, shaped around the service and not necessarily based on the individualised needs and rights of service users. Residents have been seen as the grateful recipients of care not necessarily as citizens with rights, will and preferences. The regulation of services has gone some way in moving services to adopting models that are reflective of person centeredness. This has been further supported and promoted through the development of national standards and monitoring of those standards by HIQA. But our work has identified that there is still a significant journey to travel in long-term residential care.

In our overview report for 2017, published earlier this year, we noted a number of critical findings in our assessment of residential care for older people and people with a disability.

In residential disability services, we noted that the sector faces many challenges in providing a good quality of life for people living in residential care. While a number of service providers are responding positively to those challenges and are providing a good service, HIQA's disability team continues to engage with providers who are failing to deliver the standard of care and support that people are entitled to. Significantly, these findings indicate that services remain challenged in transforming from that paternalistic culture I referred to earlier to one that recognises the rights-based principles clearly outlined within Michael's Paper. These services specifically have limited regard for residents' autonomy and their right to self-determination and personal agency. Therefore, the concept of affording residents access to independent advocacy is a distant goal in the minds of some service providers.

Current Government policy commits to moving people from congregated settings into community-based residential services. Our inspectors have seen many positive examples where such a transition has resulted in significant improvements in people's lived experience in residential care. Legislative developments in assisted decision-making and deprivation of liberty should also provide additional safeguards and supports to people who may lack the capacity to make choices that impact on their care and support arrangements as they transition to integrated, community-based service models.

Progress of the integration of residents into smaller, community-based care settings, as set out in the HSE's *Time to Move on from Congregated Settings* report, has been slower than expected. Advocacy organisations have expressed their concerns that, based on the current rate of progress, it may take up to 20 years to achieve this objective. Figures published in 2016 by the HSE showed that there were 2,579 people living in congregated settings. Data from the Health Research Board suggests that there are a further 2,164 people with intellectual disabilities who will need a residential service between 2017 and 2021.

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Whilst we have seen improvements in long-term residential services for older people, during 2017 HIQA's older people's services team identified a number of key areas for improvement areas that point to the need for care that is individualised and orientated at promoting and respecting the rights of service users.

We continue to find centres where each resident's right to dignity and privacy is not upheld. It is not acceptable that some of the most vulnerable people in Ireland live

in an environment where the culture is for residents to spend their entire day within the confines of their bed space, with no access to their own belongings, social dining experiences or meaningful activities. In such a context, the lived reality of an older person quickly shrinks to that bed space and it is very difficult to reverse that institutional practice for a person.

In his paper, Michael Browne sets out the concept and role in advocacy of health and social care professionals. He states that, despite the assertion that professionals claim to advocate for services users, it is important to recognise that service providers and professionals may sometimes experience a conflict between advocacy and their primary role in an organisation. One further relevant finding in our inspection work in older persons' services in 2017 was the continued evidence of some service providers who collect pensions and other social welfare payments on behalf of residents. This is a key area of concern for HIQA in the management of residents' finances. The practice of paying residents' social welfare payments into a central bank account (held by the service provider) rather than into an individual account in the person's own name puts this money beyond the independent reach of residents on a day-to-day basis.

In 2017, the contracts of care for residents in designated centres received a lot of public attention. HIQA inspectors found good levels of compliance with the regulatory requirement to provide residents with contracts for the provision of services. Such contracts ensure that residents and their families are informed of the services provided and provide clarity and transparency on the charges they are required to pay. However, there remain some concerns in relation to vulnerable residents' contracts, that include:

- providers seeking to change existing contracts of care without proper consultation with residents and their representatives
- residents being charged for services that residents did not, or could not, avail of, such as particular social activities
- charges for accessing the services of a general practitioner (GP) when the resident has free access to a GP through a medical card or GP visit card
- visiting charges for chiropody services which is in addition to the charge for the actual treatment covered by their medical card
- charges for religious services.

The Competition and Consumer Protection Commission (CCPC) is currently engaged in a process to develop guidelines on contracts of care for providers of residential care. HIQA supports this initiative and has participated in the process of informing the development of these guidelines. The guidelines will set out the obligations and responsibilities of service providers.

I mention these examples to try to reflect the cultural context within which some services currently operate. I appreciate that residential services for people with a disability have been challenged in adopting to a regulatory framework, but we must see all services moving beyond the basic expectation of providing a service that is safe and compliant with regulations to a service that promotes the rights, will and preferences of people using that service and a service that recognises the need and circumstances for independent advocacy.

The commencement of the Assisted Decision Making (Capacity) Act will further challenge service providers to adjust their thinking and the culture of their organisations to interact with service users to support them to make their own decisions as far as possible and, where their capacity to make a decision is in question, provide all practicable support to facilitate their decision making.

We welcome the development of the statutory codes under the Act for the Decision Support Services (DSS), but feel that the Health Act 2007 and its regulations should be amended to ensure that the guiding principles of the capacity legislation are fundamentally integrated into the regulations. We particularly welcome the fact that the Assisted Decision Making (Capacity) Act makes provision for the development of guidance for 'persons acting as advocates on behalf of relevant persons'. HIQA believes this would further strengthen and more explicitly define the role of the independent advocate. We are strongly of the view that the term 'independent advocate' should be a protected term, particularly when used in the context of deprivation of liberty, the Assisted Decision Making (Capacity) Act and any future safeguarding legislation. We have highlighted this fact in our recent submission to the Department of Health's consultation on the general scheme for Deprivation of Liberty: Safeguard Proposals.

The statutory code on independent advocates being developed for the DSS should assist service providers and indeed HIQA as a regulator know how and when independent advocates should be used in regulated health and social care settings.

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As I referenced earlier, HIQA not only regulates services but develops standards as a framework for improvement in Ireland's health and social care services. In the development of these standards, we have recognised the importance and value of advocacy.

The *National Standards for Safer Better Healthcare*, published in 2012, apply across all of our health and social care services. A feature at Standard 1.8 outlines that 'structured arrangements are in place to ensure that service users who make a

complaint are facilitated to access support services, such as independent advocacy services’.

Michael made reference to a recommendation we made in our investigation report into services at the Midland Regional Hospital at Portlaoise. We welcome the efforts being made by the National Patient Safety Office in developing a mechanism to advocate for patients or their families when they wish to make a complaint or raise a concern within the health system. More recently, in the *National Standards for Safer Better Maternity Standards* published in 2016, feature 1.9 outlines that women or families who make a complaint are helped with accessing support services, such as independent advocacy services.

In this vein, in recent weeks, we have seen the development of a specific patient advocacy service for women and families who have been impacted by the cervical screening review.

In the *National Standards for Residential Services for Children and Adults with Disabilities* published in 2013 and the revised *National Standards for Residential Care Settings for Older People in Ireland* published in 2016, it is outlined in standard 1.6 that ‘Each person makes decisions and has access to an advocate and consent is obtained in accordance with legislation and current best practice guidelines’.

As many of you may know, we are currently developing new National Standards for Adult Safeguarding in conjunction with the Mental Health Commission. This is also a shared objective with Safeguarding Ireland. Empowerment is included in those standards as one of the six core principles. This principle includes the basic tenet of autonomy and supporting people to make decisions about their lives and be fully involved in decisions about their care. The standards recognise that advocacy may take different forms, including supporting people to self-advocate, informal support and also more formal independent advocacy services as may be required.

In addition, in 2015, HIQA published a guidance document on supporting service user autonomy and a supporting document for people using services. This includes supporting people to make their own decisions. It explains what people can do to promote their own autonomy, including:

- taking an active role in making decisions
- bringing somebody to appointments to support them if they wish
- considering the use of an independent advocate.

On behalf of Safeguarding Ireland, HIQA is also currently developing guidance to support a rights-based approach to care for adults in health and social care services. Through this guidance, we aim for human rights values to be embedded within the culture of an organisation by increasing awareness and accountability among management and practitioners who are responsible for respecting, protecting and fulfilling human rights. We also aim to empower people using services to know and claim their rights.

As part of this exercise, we are currently holding a scoping consultation on this guidance. This consultation is running until October 31st and is available on the HIQA website. The scoping consultation provides people with an opportunity to:

- identify the key areas that this guidance should address and to provide examples of good practice
- provide key sources of evidence to inform the guidance
- suggest key stakeholders to be consulted during the development process.

As CEO of HIQA and a member of the National Safeguarding Committee, I welcome today's roundtable and hope that, in line with Safeguarding Ireland's objective to influence national policy and the basic thrust of the capacity and adult safeguarding legislation, we realise the need for a cross-sectoral approach for independent advocacy in Ireland.

Thank you

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