



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

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**Opening Statement**

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**Joint Committee on Health and Children**

**Discussion on Advocacy Services**

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## **1. Introduction**

I would like to thank the Committee and especially Chairman Jerry Buttimer and Vice-Chairperson Ciara Conway for inviting Inclusion Ireland to contribute today.

Inclusion Ireland is a national advocacy organisation that works to promote the rights of people with an intellectual disability and their families.

As I address you, children with a disability are being restrained and secluded in schools; children have been waiting years for essential speech & language therapy; persons with a disability are living in residential settings which in many cases provide little in terms of a good quality of life and are often neglectful, demeaning and sometimes brutal where physical and sexual assault are most likely significantly under-reported.

The number of adverse events recorded by Irish hospitals and healthcare facilities in 2011 included 10,000 incidents of violence, harassment, aggression or abuse of patients and over 4,300 of these incidents involved a physical assault on patients, including persons with disabilities.

It is the experience of Inclusion Ireland, based on over five decades of work, that persons with an intellectual disability require advocacy support in a broad range of areas, throughout their lifecycle.

These include accessing education and employment; obtaining or changing other public services; when they are victims of crime (because they are invisible in the criminal justice system); in family law (because they are represented disproportionately in child care proceedings), when making healthcare decisions (because consent is rarely obtained)

## **2. Aras Attracta / Residential Care Homes**

The issue of congregated settings has come to the forefront of popular and political debate and concern as a result of a December 2014 Prime Time exposure of conditions in Aras Attracta. This is, however, an issue that stretches beyond this one institution in one location.

The conditions exposed in the programme reflect the inevitable consequences of the stripping of human dignity from people with disabilities as a result of institutionalisation.

In December 2014, the Health Information Quality Authority (Hiqa) reported on a facility in Meath operated by Redwood Extended Care Facility Ltd. Among the findings were the following

- Inspectors were not satisfied that the designated centre was operated in a manner that ensured adequate safeguards of residents' civil and legal rights. Inspectors found that residents did not have freedom to exercise choice and control in their daily lives.
- Inspectors found that there was a high level of restrictive practice and restraint used in the centre. Restrictive practices included locked doors, both internally and doors that exited the centre, and residents confined to specific rooms, sometimes for significant periods of time. Physical restraint included the enforced removal of residents to designated areas of the centre, and a number of staff physically holding residents in a position, sometimes for extended periods of time.
- There was a lack of adequate safeguards and external scrutiny to ensure residents' rights were vindicated. Suitable arrangements were not in place to ensure each resident had access to advocacy services and information about his or her rights.

### **3. Health Information & Quality Authority (Hiqa)**

In 2014, Inclusion Ireland conducted an analysis of the first 50 Hiqa inspections of over one hundred centres accommodating over 700 people.<sup>[1]</sup>

We found that extensive non-compliance with regulations in areas such as health and safety, independent advocacy, restrictive practices and use of medications.

We also noted in our report that in many cases residents had no choice about where they would live or with whom, what they could eat, when they could go to bed. Inspection reports provided evidence that living arrangements often bordered on the abusive.

Specifically HIQA has reported:

- Inhumane and degrading treatment
- Allegations of abuse and unexplained deaths which were not reported to HIQA.
- Multiple uses of restraint, physical and chemical, often for hours at a time.
- Residents not being brought for trips out of centres for weeks and sometimes months.
- No access to food for up to 15 hours.
- A lack of basic privacy and dignity.
- People's civil and legal rights not being safeguarded.

Deputy Fergus O'Dowd has reported through his own FOI endeavours allegations that disabled or elderly people were being physically, psychologically or sexually abused in HSE or privately run centres where they lived.

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<sup>[1]</sup> Meagher M. & Conroy P., The Distant Voice, A working paper on the first 50 Health Information and Quality Authority (Hiqa) inspections of residential services for people with disabilities, Inclusion Ireland, 2014.

He has noted what Inclusion Ireland hears regularly: people will suffer in silence rather than face the repercussions of making a complaint or for fear of losing their service.

#### **4. National Patient Advocacy Service**

Inclusion Ireland are of the view that the recent commitment by Minister for Health Leo Varadkar TD to in regard to simplifying complaints procedures and enhancing the powers of the Office of the Ombudsman and Hiqa; and the establishment of an Independent National Patient Advocacy Service, while welcome, do not go far enough in the context of what we now know.

Inclusion Ireland would recommend to the Committee that any proposal to develop a statutory advocacy service should be informed by a broad consultation and in the context of a deeper understanding of existing advocacy types and arrangements and of the challenges in providing advocacy.

#### **5. Lack of Coordination**

In our view, the landscape of advocacy services for persons in receipt of health and personal social services is characterised by a lack of coordination, consistency or oversight.

A range of advocacy services are currently being funded by the Exchequer and available to persons in receipt of health and personal social services – including advocacy services provided by the National Advocacy Service (NAS), the Irish Advocacy Network, Patient Focus, SAGE (Support and Advocacy Service for Older People) and EPIC (advocacy for children and young people in care).

These services are available to persons with disabilities, mental health issues, children and young people and older people. The models of advocacy provided by community and voluntary organisations are varied and include peer advocacy, representative advocacy and citizen advocacy.

Despite the investment in advocacy services in the community and voluntary sector certain things remain the same:

- There is currently no coordinating or oversight body for advocacy development or its provision.
- There is no central funding stream.
- Funding is only provided on an ad hoc basis.
- No public body has responsibility for developing standards or codes of practice.
- There are no national standards or codes of practice for organisations providing advocacy services.

## **6. Statutory Bodies**

Operating alongside the advocacy services provided by community and voluntary organisations are a number of statutory bodies with responsibility to either investigate complaints or provide support to persons to make complaints.

These public bodies include the Office of the Ombudsman, the Office of the Children's Ombudsman, the Irish Human Rights and Equality Commission and the Citizens Information Board.

An important new development will be the Decision Support Service – provided for in the Assisted Decision-Making (Capacity) Bill 2013 – which will operate under the aegis of the Courts Service.

The Decision Support Service will have a role in providing information and guidance, the development of codes of practice and powers of investigation in respect of decision-making arrangements under the Act.

However, none of the existing public bodies provide a signposting service to persons making complaints or requiring advocacy support in a broad range of situations and circumstances.

In addition to this, there is often a scarcity of information in such situations and none of this information is available in an accessible format for people with a disability.

Persons in receipt of health and personal social services should have access to a broad spectrum of advocacy.

The incidents of violence towards adults with severe to profound disabilities – as witnessed in the RTE Prime Time programme regarding Áras Attracta care home in Co Mayo last December – are not isolated.

Nor are they confined to residential services.

## **7. Case Study #1**

“Sophie attends her local special school. She exhibits some behaviour that is challenging. Sophie is restrained by 3 staff at a time holding her face down on the ground. This happened almost 400 times in one year. Sophie’s parents asked the school to stop this practice and look at alternative responses. The school refused. In the end Sophie was expelled from the school as her parents would not allow the continued use of restraint.”

## **8. Broad Spectrum of Advocacy**

For persons with disabilities, access to a broad spectrum of advocacy was first recommended by the Commission on the Status of People with Disabilities as far back as 1996.

Building on the recommendations of the commission’s report, the Goodbody report in 2003 recommended:

- A programme of support for organisations providing advocacy services and supports;
- An independent advocacy service with statutory powers;
- A community visitors' programme for persons in long-term residential care.

However, none of these recommendations have been implemented; the following has occurred:

- Funding for community and voluntary organisations providing advocacy services and supports has been cut;
- The relevant section of the Citizens Information Act 2007 that would afford legislative powers to an independent advocacy service has not been commenced;
- The community visitors' programme for persons in long-term residential care has not been introduced.

## **9. Lack of Coordination**

There is little or no coordination between the advocacy services provided in the voluntary sector and the public bodies with responsibility for dealing with complaints or investigations of complaints.

There is also a lack of coordination among the organisations currently funded to provide advocacy services to persons in receipt of health and personal social services.

There is also clear evidence that current services are unable to meet demand.

## **10. National Advocacy Service (NAS)**

The National Advocacy Service (NAS) for persons with disabilities employs only 35 advocates nationwide. About 3,500 people with an intellectual disability live in congregated settings – that is settings of ten or more

people living together, often in hospital or dormitory type arrangements, a further 4,000 or so live in a community group homes or other residential settings.

Many of these smaller settings are, we know from Hiqa reports, little more than mini-institutions. A single NAS advocate may cover a number of counties; not surprisingly the service has long waiting lists.

According to a recent report by the Office of the Ombudsman, people in receipt of health and personal social services are often afraid to speak up to complain about health services and the Ombudsman has called for an action plan to ensure that people have access to an effective independent advocacy service.

## **11. Case Study #2**

“Tony lives in a residential service. The service decided to build a small link corridor between Tony’s house and another one just beside it. The service used €4,000 from Tony’s bank account to help pay for the work. Tony’s family did not want to make a big deal of this as the service told them “if you are not happy go elsewhere.”

## **12. Recommendations**

In her statement to the Joint Oireachtas Committee on Education and Social Protection in June 2015, Ita Mangan, Chairperson of the Citizens Information Board, called for “a coordinated approach to advocacy services across a number of areas but particularly in the context of the implementation of the assisted decision-making legislation and the needs of patients within the health services.”

In concluding Inclusion Ireland makes the committee members aware an immediate action which could be taken is the introduction of the Personal Advocacy Service as provided for in the Citizens Information Act, 2007.

With this in mind, Inclusion Ireland has a number of recommendations that it would like the Committee to consider:

- Inclusion Ireland proposes the establishment of a National Advocacy Authority. This new body would have responsibility for coordination and oversight for all advocacy services to persons in receipt of public services. Working alongside the existing public bodies (Hiqa, Citizens Information Board, Ombudsman, Children’s Ombudsman and the Irish Human Rights Equality Commission).
- Inclusion Ireland recommends that such an authority would have responsibility for setting standards and developing codes of practice for advocacy services. Coordination and resourcing advocacy would be its remit.
- Inclusion Ireland recommends that one of the first tasks of such an authority would be to develop a national strategy for advocacy. This strategy would include provision of a broad range of advocacy models.
- Inclusion Ireland would recommend the introduction of a national signposting service under the aegis of the new body. This service would be modelled on the complaints signposting service operating in Wales.

### **13. Abuse and Mistreatment**

From what we have seen today, advocacy provision for persons in receipt of health and personal social services is characterised by a lack of coordination, consistency or oversight.

We have also seen that given the abuse and mistreatment that people with a disability experience in many walks of life, different advocacy models are an essential support.

The current system can be summarised in a number of points:

- There is urgent need for a broad spectrum of advocacy supports
- There are no national guidelines or standards for advocacy provision
- There is no national information campaign on the right to advocacy or how to access advocacy services
- There is a little or no coordination of advocacy services.
- No funding exists for the development of a range of advocacy models
- Funding for patient advocacy services has been cut in recent years.

Thank you again for considering Inclusion Ireland's input.