

JOINT COMMITTEE ON HEALTH AND CHILDREN

The Joint Committee met at 3 p.m., Tuesday 2nd December 2008

MEMBERS PRESENT:

Deputy Bobby Aylward,	Senator Frances Fitzgerald,
Deputy Margaret Conlon,	Senator Mary M. White.
Deputy Paul Connaughton,	
Deputy Kathleen Lynch,	
Deputy Dan Neville,	
Deputy Charlie O'Connor,	
Deputy Jan O'Sullivan,	
Deputy James Reilly,	

In attendance: Deputies Caoimhghín Ó Caoláin and David Stanton, and Senator Mark Daly.

DEPUTY SEÁN Ó FEARGHAILL IN THE CHAIR.

Residential Services for People with an Intellectual Disability: Discussion with Inclusion Ireland and HIQA.

Chairman: I welcome Dr. Tracey Cooper, chief executive, and her associates from the Health Information and Quality Authority, and Ms Deirdre Carroll, chief executive officer, and her associates from Inclusion Ireland.

Before we begin, I draw attention to the fact that members of the committee have absolute privilege whereas the same privilege does not apply to witnesses appearing before the committee. Members are reminded of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against a person outside the House or an official by name or in such a way as to make him or her identifiable.

I will take questions from members at the end of the presentations. I invite the representatives from Inclusion Ireland to make the first presentation to be followed by the representatives of HIQA. Does Ms Carroll wish to speak first?

Ms Deirdre Carroll: Our chairperson, Mr. William Shorten, will introduce our association and then myself and Ms Finlay will add our comments. Is that format in order?

Chairman: Yes, I will take both presentations followed by questions from members.

Mr. William Shorten: Good afternoon ladies and gentlemen. I am the chairperson of Inclusion Ireland and I am accompanied by Ms Deirdre Carroll and Ms Frieda Finlay.

I thank the members of the committee for this opportunity to address them and to appraise them of our thoughts, ideas, experiences and, above all, our aspirations for the Health Information and Quality Authority and the putting in place of standards for those with disabilities.

Inclusion Ireland was founded in 1961 as NAMHI, the National Association for the Mentally Handicapped of Ireland, and is the largest national organisation representing and championing the interests of all people with an intellectual disability, their families and the organisations that provide them with services. Inclusion Ireland

has a membership of more than 170 affiliated organisations throughout the country and hundreds of individual members.

Since its foundation, Inclusion Ireland has highlighted issues of concern to people with an intellectual disability and their families. It has played a significant role in ensuring the rights of people with disabilities have been firmly placed on the political and public policy agenda.

The past five years have seen important legislative changes with regard to people with disabilities, including the Education for Persons with Special Educational Needs Act 2004, which is generally known as the EPSEN Act, the Disability Act 2005 and the Citizens' Information Act 2007. Unfortunately, these Acts have not been drawn down in full and are still in abeyance. Further delays have been enforced due to budgetary constraints.

Another important piece of legislation is the Health Act 2007, which provides for the registration and inspection of residential services for people with disabilities. The Health Information and Quality Authority, established by the Act, is charged with the task of drafting standards for residential centres for people with disabilities. Inclusion Ireland warmly welcomed this because as an organisation it has campaigned for years for standards and independent inspection of residential homes where thousands of people with disabilities live.

There are over 25,000 people with an intellectual disability in Ireland, according to the annual report of the national intellectual disability database. Of those, over 8,000, or 32%, live in full-time residential settings. The proportion of people who are living in full-time residential settings increases with age, with 74.6% of those aged 55 years or more in residential care.

It often comes as a surprise to politicians and the public alike that this highly vulnerable group has no protection in law in terms of approved standards of care, or independent inspection of the places where they live out their lives. There is inspection of private nursing homes for the elderly, inadequate though it is. There is inspection of children's homes in addition to inspection of mental health approved centres or hospitals by the mental health inspectorate.

In an effort to highlight the complete lack of standards, Inclusion Ireland published its own standards of care in 1999. However, nearly ten years later, there are still no statutory standards.

I will now hand over to my colleague, Ms Deirdre Carroll.

Ms Deirdre Carroll: As Mr. Shorten mentioned, in 1999, we published our own standards. It took some time before there was any interest in bringing about such standards in this country. I have to admit, however, that in recent years great progress has been made thanks to Dr. Tracey Cooper and Dr. Marion Witton, who is the chief social services inspector of HIQA, and their staff. In the course of the last year, they produced draft national standards for residential centres with the assistance of a national standards advisory committee. Inclusion Ireland was represented on this group by myself and Ms Frieda Finlay, who is a member of our board and a parent of a young woman with an intellectual disability.

Inclusion Ireland believes that this group has come up with a set of standards that, when implemented, will not only have a major impact on the quality of people's lives but will protect them from neglect and abuse. As an organisation that represents service providers as well as people with disabilities, Inclusion Ireland is aware of the excellent standard of service provided by many groups which are doing much good work, but through our work we are also aware of poor services, cases of neglect, poor standards, bad practice and abuse. We have had the reports on Leas Cross nursing home, which had a major impact in raising standards both for the elderly and people with disabilities. The report on the Brothers of Charity services in Galway, published only last year, showed the level and type of abuse which can occur when vulnerable children and adults are placed in closed residential settings. It should also be recalled that a number of people who died at Leas Cross had an intellectual disability. That fact does not always receive the attention it deserves.

In 2004, *The Irish Times* published a draft report commissioned by the National Disability Authority, which showed that a significant number of service providers were failing to reach basic standards such as providing

services in a safe environment, respecting people's rights and not consulting family members. Today, an estimated 4,000 people with disabilities live in what are now called congregated settings. These are settings where ten or more people live together. Who is looking out for them?

The Minister for Health and Children, Deputy Mary Harney, stated recently that the new draft standards for nursing homes for the elderly, which were agreed over a year ago, cannot be put in place until an assessment of the financial impact is made. These standards were due to be in place by the end of 2008, after which the standards for services for people with disabilities would commence. This delay means that people with disabilities will remain unprotected. Inclusion Ireland has been told by the Department of Health and Children that if the draft disability standards are agreed by everybody, there is nothing to stop them from being implemented voluntarily. This is worrying because it is not good enough to say that they can be introduced on a voluntary basis. We do not need to worry about the good services which will introduce the standards voluntarily, but we do worry about poor services which will not introduce such standards on a voluntarily.

If anything has been learnt from past scandals, it is that services most in need of these standards will not introduce them voluntarily; nor will they follow guidance standards, such as those recently published by the HSE. The HSE has drafted guidance standards for residential services for children and adults. At the time, we were told their purpose was to fill the interim between the establishment of HIQA and having national standards, as well as providing guidance on services. We are now concerned that this interim period will be much longer than originally estimated, however. I am not sure what status the HSE standards have, whether they have been implemented or who is monitoring them.

The joint committee must be informed about a serious defect in the legislation to protect children with disabilities who live in residential care. The regulations under the current Children Acts have not been amended to allow for the inspection of residential homes for children with disabilities. There are approximately 400 children with disabilities in residential care, but they do not have the protection of the Office of the Social Services Inspectorate, which is offered to children without disabilities in residential care. This is a clear inequality. I believe the idea is that HIQA will come up with draft standards, and they will take over when these come in. We could be waiting for another four or five years, however, so what will happen to these children in the meantime?

Children with disabilities are three to seven times more likely to become victims of abuse. The greater the level of disability, the higher the level of risk. The responsibility to protect these children and adults lies with others, including Inclusion Ireland, legislators who provide constituency services, parents and other citizens generally. These children and adults cannot learn or internalise the self-protective skills that are taught to children at schools under the Stay Safe programme.

People in residential care will now be charged more for such care, given the increases announced in the budget. Therefore, we will charge them for the services but will not offer them protection. I have worked in this area for over 15 years and have witnessed good and bad services. We cannot wait for the next abuse case scandal before acting, and nor can we wait for an improved financial regulatory impact on such services. The stakeholders have warmly welcomed the standards, but we want to see them implemented sooner rather than later.

Ms Frieda Finlay: I appreciate this opportunity to address the joint committee. Many of us who are parents of people with an intellectual disability wonder if the Government really understands the urgency, importance and absolute necessity for the immediate introduction of these standards. If there is one message we would ask the joint committee to communicate to the Government, it is that of urgency. As I speak, there are 400 children, as Ms Carroll has said, in residential services. Can the members reassure me that they are absolutely safe and secure and that they are not subject to abuse or neglect? Do they know what sort of services they have, does anyone really know that? Are they happy in the knowledge that these services have never been inspected? Are they comfortable that these children are in services that are not subject to any standards?

Parents throughout the country find it hard to believe and cannot understand why after all these years, during which abuse was uncovered, some of our most vulnerable people have died through neglect and lives have been wasted, standards have not already been implemented. We are sure that if the public were aware that there is

no inspection of residential services for babies, toddlers, teenagers, adults and elderly people with an intellectual disability, they would be horrified.

Last year the HSE received a report in respect of the Brothers of Charity in Galway. It outlined years of physical and sexual abuse in services for people with intellectual disabilities. Against that background does anyone seriously believe that the people would begrudge the funding necessary to implement the standards produced by HIQA? Or do people with an intellectual disability have no value in our society? Do their lives not matter? Does it not matter if they sit and rock backwards and forward all day long because they have nothing to do? Does it not matter if they are neglected, abused or over-medicated for convenience sake? Do people think that because they have an intellectual disability these things do not matter to them, that it really would not make any difference to them anyway, is that what people think?

I will give the members a few examples of what is happening in Ireland today because of the absence and enforcement of standards. John is a 40 year old man who is put to bed by staff every night at 6 o'clock; Mary's mother bought her some lovely clothes but every time her mother visits Mary she does not recognise the ill-fitting clothes she is wearing; Catherine had to have two nails removed when she visited the chiropodist because she is unable to look after her own nails, she does not ask for help and nobody seems have time; Michael is 28 years of age and would love to get out for just one evening a week to go to the pub, but no one else in his house wants to go so he just has to sit and watch television every night; James missed his consultant's appointment because there were no staff to bring him even though it had been written in the house book more than three months previously; Ann does not have a choice who she lives with; Eileen has to share her bedroom with a stranger; Patrick at the age of 35 is still living in a ward with little or no privacy, having been told two years ago he would move to a new home; and Sarah who has a severe disability was slapped across the face by a staff member. I have changed the names, but these are real people now living in residential services in Ireland today.

I remind members that these residential services are people's homes. These are the conditions they will be living in for the rest of their lives unless something is done about it. Some people have been living in appalling surroundings for 30, 40 or even 50 years. I ask members to think of their own homes, do they not do everything they can to make them comfortable, secure and nice? How would they like it if there were ten other people in their bedrooms? Do they not believe that if standards could be implemented on a voluntary basis, that during the past 60 years these services would have improved? The harsh truth is that some have. Many service providers and staff are doing their very best, but poor conditions, totally inappropriate to human dignity and a decent quality of life, still exist. The reason is that there are no standards in place to force their improvement. Voluntary standards, no more than guidelines, do not work. These standards must be put on a statutory basis and implemented immediately and there must be powers of inspection in place without anyone being able to say "it's not convenient at the moment". There must be urgency about their implementation, budgetary constraints most not be the reason people are denied a quality of life, safety in their homes and respect.

Have members ever wondered why so many parents say, "I hope my son or daughter dies before I do"? Parents are afraid to die. They are afraid of what might happen to their son or daughter after they are dead. At least if they knew there were standards in place and inspection, they might not be so afraid. I thank the members for listening to me.

Dr. Tracey Cooper: I thank Mr. William Shorten, Ms Deirdre Carroll and Ms Frieda Finlay for their contributions. Good afternoon ladies and gentlemen.

On behalf of the Health Information and Quality Authority, I thank the Oireachtas Joint Committee on Health and Children for this opportunity to discuss the standards in residential services for people with an intellectual disability. I am joined today by Ms Marion Witton, chief inspector of our social services inspectorate, and Mr. Marty Whelan, our head of communications and stakeholder engagement.

The authority was established on 15 May 2007 as part of the Government's health reform programme. Reporting to the Minister for Health and Children, the role of the authority is to promote safety and quality in the provision of health and social services for the benefit of the health and welfare of the public. Underpinning the

work of the authority is a key focus on driving patient safety and enabling continuous improvement in Ireland's health and social care services.

Our mandate extends across the quality and safety of the public, private - within its social care function - and voluntary sectors. The authority has statutory responsibility for the following areas. It is responsible for setting standards for health and social services, on which members will hear more later in the presentation. This means developing person-centred standards that are based on evidence and international best practice for health and social care across Ireland. As Mr. Shorten mentioned, that is with the exception of mental health services, as the Mental Health Commission carries out that function. The authority is responsible for monitoring the quality of health care, monitoring standards of quality and safety in our health services and implementing continuous quality assurance programmes to promote improvements in quality and safety standards in health and, as required, undertaking investigations into suspected serious service failure. It is responsible for health technology assessment in terms of providing informed decision-making and ensuring the best outcome for the service-user by evaluating the clinical and economic effectiveness of drugs, equipment, diagnostic techniques and health promotion activities. It is responsible for health information in regard to advising on collection and sharing information across the services and evaluating and publishing information about the delivery and performance of Ireland's health and social care services. It is also responsible for the area we are discussing today, the social services inspectorate, in terms of inspecting and registering residential care facilities for children, older people and people with disabilities. Our functions also extend to monitoring day and pre-school facilities, children's special care units, children's detention centres and foster care services.

What is key to the board and staff of the authority is our values which underpin our work. The core values of the authority are: putting people first - we will put the needs and the voices of service-users, and those who advocate on their behalf, at the centre of all our work; being fair and objective - we will be fair and objective in our dealings with people and organisations and undertake our work without fear or favour; being open and accountable - we will share information about the nature and outcomes of our work and accept full responsibility for our actions; excellence and innovation - we will strive for excellence in our work and seek continuous improvement through self-evaluation and innovation; and, most importantly, working together - we will engage with those who provide and use Ireland's health and social care services in developing all aspects of our work.

We are very conscious of our responsibilities to Government and to the Oireachtas. It is my desire, and the clear determination of the board of the authority, that we engage openly and constructively with all stakeholders, including the Oireachtas and this committee, and I look forward to hearing the members' views on this and on all aspects of our work.

The focus of today's presentation is to update the members of the committee on progress on the development of the draft national quality standards for residential services for people with disabilities. This opportunity to engage with the members and Inclusion Ireland is particularly welcome, given the importance of the authority's standards development work in safeguarding vulnerable people and in driving quality and safety for people using these services. They mark a significant step for social care service provision in Ireland. It is of credit to the Oireachtas that the importance of setting standards in the social care sector has been clearly recognised and provided for in legislation. For the first time, the Health Act 2007, as Mr. Shorten outlined earlier, establishes a statutory obligation for the inspection and registration of designated centres, including those that provide services to people with disabilities, whether provided by the Health Service Executive, voluntary or private providers.

These draft standards take account and seek to support the implementation of relevant Irish legislation such as the Disability Act 2005 and anticipate expected changes to legislation on the issue of consent under the Mental Capacity Bill 2008. The general underlying principle informing the standards is that people with disabilities should be supported and safeguarded in living the lives of their choice, in as independent a way as possible, rather than being "cared for".

Our overall aim in creating these standards is to promote good, safe practice. We expect them to further drive continuous quality improvement of residential services for people with disabilities in the coming years. The draft standards outline what is expected of a provider of services and what a service user, his or her family and

the public can expect to receive in such residential care settings. I firmly believe these standards will contribute towards allowing people with disabilities to live in a safe, caring and respectful environment.

The standards, of which there are 19 in total, are grouped under seven headings. They all aim to cover the key components of a safe, respectful and high quality service for people with disabilities. These components include: quality of life of residents in the context of the staffing provided at centres; the protection of residents; their development and health in the context of their rights and physical environment; and the effectiveness of the governance and management of providers. Taken together, they aim to set out what should be a good quality service for people with disabilities.

The standards are intended to ensure that those who live in residential care centres receive a safe and high-quality service. They define an agreed level of quality that must be maintained in all residential services and, furthermore, enable the establishment of a culture of continuous improvement across all settings which provide social care. The authority will also continue to work with the Department of Health and Children to agree a method of monitoring the implementation of the standards for the independent assessment of need for people with disabilities and will be reporting on the Health Service Executive's work in respect of such assessments.

As a result of the wide range of experiences of people with disabilities in residential services, the standards place emphasis on enablement. For this reason, although they are clear and specific, the standards are not overly prescriptive in order to best meet the tailored needs of an individual. They will thereby provide a robust framework that will hold across the diversity of residential service settings and meet people's various needs.

The standards endeavour to ensure that people with disabilities are enabled to make choices, can participate in the running of the residential centres in which they live and can fully contribute to life in the wider community, if they choose to do so. Importantly, the standards safeguard the rights and interests of people with disabilities in residential centres, enhance their quality of life and support the development of person-centred care. By providing a benchmark against which service providers can measure the quality and safety of their services, the standards also provide a guide for service-users and their families as to what they can expect of services.

A consultative approach is key to the Health Information and Quality Authority's values of fairness and objectivity, openness and accountability, excellence and innovation, and working together. Therefore, to maximise the input of all stakeholders in the development of these standards, an extensive process of consultation was undertaken. As a result of this engagement, the draft standards have been developed with input from those who use residential services, their representatives and advocates, the providers of the services, the public and other stakeholders. By adopting an open and inclusive approach to consultation, we believe we have obtained the important support of key stakeholders, including, most importantly, those who use the services.

During the development of the standards, the work of the authority was guided by the advisory group and the following principles: evidence-based best-practice - to ensure that the standards are underpinned by the most up-to-date national and international evidence; person-centredness - to facilitate the meaningful inclusion of all stakeholders, including service-users and providers, in the development of the standards; and a focus on effective outcomes - to ensure that the implementation of the standards will be measurable and will result in tangible and lasting improvements in services.

A standards advisory group was established by the authority in late 2007 to further inform the development of the standards. This group consisted of representatives from the statutory and non-statutory sectors, along with service-users and their families. It also included representation from the Department of Health and Children, the Health Service Executive, the National Disability Authority, Inclusion Ireland and others key contributors. The group met on a regular basis to assist and inform the development of the standards. The draft standards were finally published and a comprehensive public consultation was undertaken by the authority in respect of them. This was tailored to the specific needs of the standards development project.

To increase the accessibility of the draft standards document, three formats were produced. These included a full text, plain English version endorsed by the National Adult Literacy Agency, NALA, and an easy-to-read version endorsed by Inclusion Ireland. Braille and audio versions were also available on request. The draft

standards documents were circulated widely to over 1,600 residential units nationwide, service provider representative organisations, advocacy groups, professional bodies and members of the public. All formats were also placed on-line on the authority's website. To facilitate the provision of feedback, a consultation feedback form, along with a dedicated on-line feedback area, was developed for use.

In order to further maximise participation and inclusion, the general public consultation was supplemented by 12 focus groups with service-users, their families and front-line staff. In addition to this, 16 one-to-one interviews were conducted with people with disabilities for whom participation in group discussion was not feasible. The feedback from consultation was extremely positive. The provision of alternative document formats to facilitate engagement in the consultation process was widely welcomed, with the National Disability Authority, NDA, in particular providing positive comments on the accessibility of the standards for all audiences. Stakeholders reported that they found the standards accessible and easy to read. There were no suggestions for the addition of supplementary standards and the feedback suggested that the standards covered all key areas of importance.



The feedback from the public consultation will be considered by the advisory group and will inform the authority as it finalises the standards. When the board of the authority has approved the standards, they will be sent to the Minister for Health and Children for her approval. Following this, regulations will be drafted by the Department of Health and Children to give statutory effect to the new standards. These will form the first registration of residential services for people with disabilities in Ireland. All centres providing residential services will then be inspected and, if they meet the standards, will be registered to provide such services. The standards will apply to the Health Service Executive, private companies and voluntary organisations.

We intend to work closely with service providers to ensure they understand what will be expected of them in an inspection and registration process and, most importantly, to monitor that they are able to make the changes required to improve their services. However, if there are serious concerns with a provider not meeting the standards, the authority will have the power to withdraw that provider's licence.

We are fortunate to have obtained considerable buy-in with regard to the development of the standards. We see this as a positive step towards a culture of ongoing service improvement. We very much appreciate the contributions that have been made by many people and organisations - particularly Inclusion Ireland - to develop what need to be high-quality and meaningful standards.

In advance of the formal inspection process, it is our desire that services will commence a process of review and development and particularly focus on the establishment of a culture of continuous quality improvement in the provision of social care services for all service users. In keeping with our core focus on driving safety, which underpins all of our work, our overall aim is to promote best practice in residential services for people with disabilities. We are conscious that the safety and well-being of some of the most vulnerable people in the community depends on the ability of the authority to set high standards and work in effective partnership with all involved in the delivery of health and social care. We do not take this responsibility lightly.

On behalf of the authority, I again thank the committee for the opportunity to come before it. I will be happy to answer any questions members may wish to pose.



Deputy James Reilly:   I apologise for leaving the meeting for a few moments but I was obliged to attend another engagement. I welcome our guests from HIQA and Inclusion Ireland.

A number of disturbing points were raised in Inclusion Ireland's presentation. I was not aware that residential homes for children with disabilities are not inspected. In light of that fact, it makes it even more important to ascertain when the ministerial order will be put in place and when the inspection teams will be ready.

What timeframe is envisaged with regard to HIQA's inspectorate being established and being in a position to inspect centres? If matters in this regard are uncertain, has provision been made to protect children in homes in the interim? I am sure our guests would probably agree to an institution being inspected if concerns were raised about its operation.

Inclusion Ireland's assertion that the Minister is waiting to discover what will be the financial impact is worrying. There are minimum standards of safety which will have to be set and which will, regardless of the financial impact, have to be adhered to. I would have thought this would be the primary concern of all involved.

What is the envisaged timeframe with regard to the establishment of the inspectorate, the registration process, licensing, etc.? Will the licensing apply to hospitals?

Deputy Kathleen Lynch:   I welcome both delegations. Their presentations were informative because they have great knowledge about these issues. I congratulate HIQA on the production of a set of standards. Most of us would balk at the prospect of laying down standards for such a diverse and vast area but the document is similar to a life plan. It relates to what we all do in our own homes every day. There are issues relating to medication and care but, other than that, it reflects how we would like to live as individuals. The method by which it is presented is clear. It is astonishing that everything we expect for ourselves is included. For example, the document states:



The concept of quality of life is central to these standards. The purpose of residential service for people with disabilities should be to provide them with the supports they require in order to lead a fulfilling life.

Is that not what we all want? We want privacy in how we are treated in our bedroom and bathroom, space to have a relationship, access to and control over our own money and control of our medication, where possible. The standards concern everyday items we expect for ourselves and we hope we confer equally on others we deal with.

I attended a conference about self-advocates a number of months ago and it was the most enlightening and daunting such event I ever attended. It was organised and run by people with intellectual disabilities who wanted to control their own lives. It was the most incredible conference I attended because they discussed relationships, marriage, having children and doing everything else we take for granted. I am sure most of the parents were horrified but it was very open. They wanted to control their own money and live independently but with supports. If we could combine the outcomes of the conference and these standards, none of us would worry about these children in the future.

I completely agree with Inclusion Ireland. The notion of adopting these standards as a voluntary exercise will ensure they are not implemented. They must be regulated in legislation and enforced. I have a number of questions for HIQA. The standards must be presented to the board for approval and there do not appear to be any objections. When will that happen? If they are approved, when is it hoped they will be submitted to the Minister? They are not daunting because they are about respect, and people with intellectual disabilities being allowed to live the type of life we all want to live.

There are structural issues and, hopefully, the regulations will provide that the money will be forthcoming because it would be crazy to suggest the standards could be adopted without financial support. However, if all this happens, an inspectorate will be needed. Whereas most providers are good people, in every walk of life people do not comply and treat people properly. How will the inspectorate work? How many staff will be required? Could it be facilitated by increasing the numbers in the nursing home inspectorate, given there is no point reinventing the wheel? I congratulate HIQA because the standards are no more than what we want for ourselves every day. If they were enforced, no parent would worry about leaving a child behind.

Deputy Margaret Conlon:   I welcome the delegations. I commend Inclusion Ireland for championing the cause of those who, for one reason or another, are unable to speak for themselves. Without such a group, their voice would not be heard. It does not matter whether the service is provided by the HSE, private companies or voluntary organisations, one expects the same high standard of care in all residential facilities to ensure the families of residents are not worried about neglect or abuse, given they have enough to worry about. We all recall the horrific scenes we witnessed in the television programme about Leas Cross nursing home. Nobody could condemn any person to a life of abuse and neglect under the supposed umbrella of a caring facility. Deputy Lynch referred to our own homes. As parents, we have a duty of care at home and we have a responsibility to those in our care. The owners and managers of residential facilities have a major duty of care

and there is an onus on them to ensure residents are looked after and treated with dignity and respect. Unfortunately, that is not always the case.

A consultation process is under way and it may not be moving as speedily as we would like but we are playing catch up. If family members have a concern about a relative in care currently, who can they approach if they see a dramatic change in his or her behaviour and are fearful something serious is happening? Can I have an assurance they will be dealt with in a speedy fashion?

I agree with other members regarding the timeframe. I share their concerns about when the inspectorate will begin inspections. I welcome the fact that service providers have bought into the standards. Without that level of consultation, co-operation will not be achieved. However, I am slightly worried about the internal review no more than the voluntary aspect of it. The good facilities will come out well when reviewed but the others will do what they have always done. I am concerned about that.

Senator Frances Fitzgerald: I thank the delegates for their presentations. I am listening with almost disbelief although I know the situation and am aware the standards have not been achieved yet. There is no room for complacency. I propose that the committee should take up the point made by Ms Finlay in her presentation so that the urgency of the situation will be seen for what it is. I propose we go immediately to the Minister and ask whether the resources are in place and when the standards can be implemented. This is not about HIQA, because it is only in existence since 2007. It is about the Department of Health and Children and the reason the standards have not been put in place. It is a disgrace.

Ms Finlay asked if we could be comfortable about this. We cannot be comfortable. We have a commission sitting on abuse currently and it is due to report in the new year. It is looking, historically, at issues of abuse of children and adults in residential care. Today, we are sitting on this committee and hearing about 400 children in residential care with no standards of care being applied. This is a disgrace and we should not stand over this continuing for another month.

The situation is likewise with regard to adults with intellectual disabilities and the same could be said about their situation. It is pure negligence that this group of people has not been included in legislation over the past ten or 15 years. Child abuse has been to the forefront of the political agenda. Governments have fallen because of it, yet we still do not have the required standards in place. This committee should take the issue up with the Minister immediately. We must ask if the resources are in place to ensure the standards are implemented speedily.

I put these questions to HIQA. What is its understanding of when the standards will be implemented? What is the time frame for implementation and can it give an outline of the services that will be included? Some 80% of services for people with disability are provided by private not for profit bodies. Will HIQA be able to exercise oversight on these bodies, which operate in the private area, somewhat like private nursing homes? What right of entry will HIQA have to these facilities? Is it satisfied it will be able to inspect them?

Can HIQA clarify how many inspectors are needed? Is training required for new inspectors and has it received a budget from the Government for such training? Perhaps, when we get the reply to these questions, the committee can take that information into account so that when we raise the issue with the Minister we can seek to ensure HIQA gets the resources required.

Deputy Jan O'Sullivan: I welcome the two groups. I second the proposal made by Senator Fitzgerald. We need to take up this issue as a matter of urgency and ensure the process is moved forward as quickly as possible. There is a procedure to be followed. It must go to the board of HIQA, to the Minister and be put on a statutory basis by way of regulation. The most important thing is that the funding must be provided to implement it. This committee needs to bring that forward with the utmost urgency to ensure inspections take place and the standards are implemented.



Deputy Fitzgerald referred to how the State was rocked by child abuse and to the apology from the Taoiseach. This committee dealt with the report of the Brothers of Charity to which both Ms Carroll and Ms Finlay referred.

Ms Margaret Kennedy attended the committee on that matter. The committee is well aware these dreadful things did happen. Without inspection, we have no way of knowing whether they are happening currently.

I remind people of Annie Ryan who, in the Portrane situation, insisted that the Inspector of Mental Hospitals inspect facilities where people with intellectual disabilities were resident in totally unsuitable conditions the were not inspected for years. There is a history to all this of which the committee needs to be aware in dealing with the urgency of the matter.



Our questions are all somewhat similar in that we want to know how quickly the process can be implemented, what the budgetary requirements are with regard to both the inspection side as it relates to HIQA and the implementation and compliance side from the point of view of service providers. We are aware there has been a 1% cut in the budgets to disability organisations and that other cuts affect them also. In terms of compliance, what are the implications for service providers? I think of Bawnmore in my constituency which has informed us 100 of its clients will have to have services curtailed and that 60 jobs will have to go because the centre has not been able to get the funding it needs. I know a similar situation applies to other organisations.

This issue must get priority. We are talking about the most vulnerable people in our community. What are the precise details in terms of costs and staffing. Perhaps Inclusion Ireland can give us some idea of the implications with regard to the people providing the service. What are the implications for them in terms of ensuring their standards are at the level demanded and ensuring they can provide what their residents need?

Senator Mary M. White:   I congratulate Dr. Cooper on her excellent presentation which spelled out her vision and aspirations for this area. I found what I heard from Ms Finlay very disturbing. She asked if the people of Ireland would begrudge spending the money for inspections to ensure the human rights of children with intellectual disabilities. I feel sick, embarrassed and guilty because of the lack of action on this. Every time there has been an investigation into any closed institution, evidence of abuse has been found.

We have a great cross-party opportunity to work together on this. This committee and our Chairman, Deputy Seán Ó Fearghail, have a very good relationship with the Minister for Health and Children and Professor Drumm and cross-party pressure from us could ensure this happens. Words fail me when I think of the children. As Ms Finlay said, we all want to be cosy and warm and look after ourselves emotionally and physically. It is terrible to think that children are put to bed at 6 p.m., that they cannot go out and that there are ten people in a room.

I have produced a document on suicide and suicide prevention and have spoken at different venues around the country on the issue. I have pointed out that people with mental illness or suicidal tendencies should not be written off. They can recover and participate fully in life. Anybody born into this world, no matter their physical or intellectual ability, has as much right as me to reach his or her potential. I am sorry we are still in the position we are in with regard to this issue. Ms Finlay said the people would be shocked. I am shocked.

Deputy Caoimhghín Ó Caoláin:   I join committee members in welcoming the representatives of Inclusion Ireland and HIQA and thank them for their contributions. I agree wholeheartedly with the call from Inclusion Ireland for the standards to be put in place and fully implemented. I commend HIQA on progressing the draft standards to this point. We look forward to the earliest final approval and implementation possible. This is a goal we all share.

I have a few brief questions. I am aware the focus today is specifically on those in domiciliary care in full-time settings, but I have a question for HIQA. In the outline from Inclusion Ireland, we heard the advice on the inspection of private nursing homes, children's homes and mental health approved centres in hospitals. HIQA is addressing the standards in the care settings for people with intellectual disabilities. Is HIQA addressing day-care settings, which would also be very important because a significant number of people in full-time care spend a great deal of their day in other settings as part of day activation units or whatever the case might be? A variety of organisations are providing excellent care and support. Do standards already exist in this regard and do inspections take place or are these being addressed in the course of HIQA's address of the bigger issue we have been discussing here regarding people in full-time placements?

In his opening address, Mr. Shorten said that of 25,518 people with an intellectual disability, 8,181 live in full-time residential settings. Does the 8,181 include people with an intellectual disability who are in inappropriate placements, for example, in hospital settings and psychiatric institutions? Is it inclusive of those who are inappropriately placed? Deputy Jan O'Sullivan referred to Annie Ryan's heroic efforts over the years. Ms Ryan in her *exposé* in May of this year outlined that there were then 872 people with intellectual disabilities in inappropriate settings and that the programme the Government had introduced through the Department of Health and Children had pretty well come to a halt. It had not presented itself in the programme for Government in 2007 and, therefore, is not in the existing programme for Government because that has never been revisited. Would Inclusion Ireland give us an up-to-date view of the status of that matter? Is it as worrisome as Ms Ryan pointed out at that time or has there been any further Department interest in moving that significant number of people out of those wholly inappropriate settings?

In their presentations today, both bodies, particularly Inclusion Ireland, referred to the unacceptable conditions in which they have found people placed. I listened to Senator Mary White. This is a very important vehicle to sharpen the public consciousness. As elected representatives, a significant number of us would be exposed from time to time to exactly what the witnesses have mentioned. They have an opportunity today to shock the people, because they need to be shocked. I ask the witnesses to give us examples of the types of unacceptable conditions they have encountered in residential settings. It would be a salutary lesson for everyone who might hear what they have to say or subsequently read about it.

Deputy David Stanton: Although I am not a member of the committee, I welcome both groups here today. The questions posed by Ms Finlay were very serious and apt. I would like the representatives of HIQA to address them. Can HIQA assure us that children in residential settings are absolutely safe and not subject to abuse or neglect? Does HIQA have any information on that matter? What sort of service does it have? Does anyone really know? Is HIQA happy in the knowledge that these services have never really been inspected? What kinds of inspections, controls and regulations exist at the moment? Ms Finlay asked whether we were "comfortable that these children are in services that are not subject to any standards". I would like HIQA to give us answers to those questions. Does Inclusion Ireland have any reason to believe that children or adults are not at risk at present?

The draft standards were developed by the Department and the NDA, and sent to HIQA for approval. They were published on 16 September and were open for public consultation at that stage. I believe the deadline was the end of October. How many submissions has HIQA received? Will the target date for publication by the end of 2008 be met, as promised in response to parliamentary questions I tabled on more than one occasion this year?

What is HIQA's budget? What impact will the implementation of these standards have on its budget? Does it have enough in the kitty to do the work the standards will demand or does it need more? If it needs more how much more will it need? Has it made an estimate of how much extra it might need, if it needs more? It may have enough already.

I compliment HIQA on the standards. I believe I detect a paradigm shift here. I wish to draw attention to one particular sentence from the presentation. Dr. Cooper stated: "The general underlying principle informing the standards is that people with disabilities should be supported and safeguarded in living the lives of their choice, in as independent a way as possible, rather than being cared for." This indicates a paradigm shift on which I commend HIQA. If we can keep that train of thought going, we will be moving in the right direction.

I also ask HIQA to compare what is happening here to what is happening in Northern Ireland and the UK. I know that the Healthcare Commission audit in the UK has already been carried out. It made some interesting points. Am I right in saying that we would be in the same position here? For example, it referred to an entire area that was off the radar and that services there for people with learning disabilities were not generally unsafe, but poor. The services were regularly neglected and too often old-fashioned and institutional. It operates on a system whereby too many people are not given choices and control over their lives. It stated that care is not personalised, living environments are poor and activities are few. My suspicion is that might be the case in some places here. Perhaps HIQA has some information in this regard.

I ask both groups and especially Inclusion Ireland to comment on the decision to defer the implementation of the Education for Persons with Special Educational Needs Act. I raise this matter because, as members know, the Education for Persons with Special Educational Needs Act was introduced to support children with disabilities in schools. My fear is that deferral will lead to some children with learning disabilities in schools ending up being needlessly institutionalised later. What are the views of Inclusion Ireland on this matter? Does it have any information on when the Act might be implemented?

Chairman: I ask Dr. Cooper to respond. She should feel free to call in her colleagues after which we will hear from Mr. Shorten.

Dr. Tracey Cooper: I thank the Deputies and Senators for their questions. There is much understandable consistency in questions about timescales and how and when things will happen. A number of members asked about definitions of designated centres. I will order my answers in a way that, I hope, is logical and then we will pick up some of the other questions about children's services and provide some clarity. If we fail to answer any of the questions, I ask members to let us know because I am keen for people to have the answers today.

I will first address the issue of timeframes, which is obviously and understandably a hot topic. I will then hand over to Ms Witton to give some more detail on the standards, what has happened so far and the detail on the inspection. I wish to be clear about the process about which Deputies Reilly and Kathleen Lynch, among others, asked. The standards are being concluded and will go to the board early in the new year. If they are approved by it, they will be sent to the Minister for Health and Children within a matter of days. It is obvious that the Minister will then be responsible for considering them. They are similar to the standards for residential care for older people. We will license and regulate providers in the context of these standards. If a provider does not comply with these legally based regulatory standards, the worst that can happen, by law, is that the facility can be closed. That means we need to get the law right. When the standards have been considered, it will be made clear that they are the standards for regulation. They will have to stand up in law if we need to take action which will happen in a minority of cases.

After the standards have been submitted to the Minister, the Department of Health and Children will undertake a regulatory impact assessment. I understand such assessments need to be undertaken as part of a standard approach when regulations are being introduced. We will work with the Department to endeavour to facilitate the most rapid regulatory impact assessment possible. All supports that need to be provided will be made available. When that process has been concluded, regulations will be cast and the function commenced. We will then be in a position to start inspecting the designated centres. We will define what a "designated centre" is.

We are having considerable discussions with the Department about the effect of the current economic challenges on the need to commence inspections. All of us will agree that services for vulnerable people need to be inspected. We need to know that the population is safeguarded. Ongoing conversations are taking place on how long the regulatory impact assessment will take and on the need to ensure all resources will become available at the right time. I am making a personal commitment to do whatever is needed to facilitate the rapid commencement of inspections. Some of the things that need to be done are within our control, but others are outside it. We are keen to gain clarity around dates. We are still in the process of discussing how long the regulatory impact assessment will take. It is obvious that we need to start recruiting inspectors as quickly as possible in order that appropriately qualified staff will be in place when we are up and running. We are engaging in a number of activities as we try to flesh out the detail of what form inspections will take.

I was asked about timescales. I cannot say we will start on any given date. We are doing everything we can, including participating in discussions with the Department and the Minister, to determine when inspections will begin. We are examining how we can facilitate the expedition of the various parts of the process, in so far as they are under our control. I am sure members will wish to return to this issue. We were also asked to provide clarity about standards and outline how the inspections would run. I will ask my colleague, Ms Witton, to comment on the standards and give some background information on the process of inspection before we respond to the other questions asked, including those about children.

Ms Marion Witton: I would like to take up the point that several members made about the paradigm shift with the standards. It is important to reflect on the context in which the standards were developed. We decided not to take the approach of sitting around a big table and setting out some standards. Instead, they were developed by a small working group involving service users who told us what was important to them. We held some meetings in residential care settings to try to get a feel for what such settings were like. It is obvious that over a short period of time one cannot absolutely definitively find out what it is like to live in a residential care home. The location of the meetings helped those who participated in the group to relate to what they were talking about.

I agree with the suggestion that standards should be based on ideas and what is important to people. Ms Frieda Finlay and Ms Deirdre Carroll were members of the standards working group. Some service users were also part of the group. We set up the small working groups because we recognised that it was not easy to sit around a big table. We sat in comfortable chairs, which was much better. It was difficult for service users to express their views but we encouraged them to tell us what was important to them. We asked them whether they wanted to be referred to as “service users” or as “residents”. They said they were individuals, which is why the standards refer to individuals. By the end of the process of developing standards, service users who had initially found it difficult to sit and speak in a small group were happy to talk in front of everyone. I spoke at a previous meeting of the committee about a service user who had wanted to go to a general practitioner. I am not sure whether that had happened at the time of the meeting. The person in question was absolutely delighted to tell everyone that she had been allowed to go to the GP by herself. She benefited from the confidence she developed from being part of the group. We are making a film, to be broadcast at the launch, that depicts how the standards were developed. That is the context.

It is important to make a point about the launch last year of the standards for older persons settings. The standards in question were published well in advance of the regulatory impact assessment, the outcome of which we are awaiting. There was no period in which there was a lull. Many of those involved in the various older persons settings engaged with the staff about what was possible - what could be changed, for example. They considered the extent to which their services matched the standards. The staff in these settings often go to work and behave in a set pattern, but this process gave them an opportunity to talk about what they thought could be improved. Everywhere I go I am told how the process has stimulated the providers and users of these services to make improvements, even in advance of any new regime of inspection. This does not diminish the importance of inspection in safeguarding quality control and making sure people are safe. When the standards have been considered by the board, we would like the providers of services for people with disabilities to engage with service users. Such persons should have an opportunity to tell service providers what they would like to see happen. People have already been stimulated to participate in the process.

We were also asked about the designated centres. The Health Act 2007 sets out the parameters for the social services inspectorate of the Health Information and Quality Authority. We cannot go outside these. We do not have a role in respect of day care, for example. The precise definition of a designated centre relates to people with disabilities in relation to their disability. We are in discussions with the Department about whether that definition will be explained further. As we know, there are diverse services for people with disabilities. If one considers the various types of service provision, it is clear that some interpretation is needed when deciding whether small clusters of settings are included under the definition. The legislation is what we have to work with. We would be keen for the definition to be widened by means of regulation. That is what we are talking to the Department about. There is no doubt that the definition covers public, private and voluntary settings. Any sector covered is subject to the same inspections and registration requirements. The standards apply to all of them in the same way.

I would like to speak about the inspections. We are establishing an inspectorate. The inspectors will be trained to inspect the services provided in the designated centres. We will recruit people who have the professional background, knowledge and experience to cover their duties. We will focus on what it is like to be a resident - a child in the children’s service or a person with disabilities. We will not look separately at kitchens in the way environmental health officers would do, or at nursing standards in the way nurses would do. We will look at the whole operation - what it is like to be there.

When we set up our inspectorate we will have trained inspectors to gather evidence and report to the public, the provider, service users and the joint committee on our findings. That is the function of an inspectorate. While inspectorates need to have a breadth of expertise at their disposal, they cannot be expert in everything and need to be able to access specific areas of expertise elsewhere. One cannot expect to take 20 people into an inspection but one expects to have inspectors who can report on what they find.

HIQA's approach to inspecting services for people with disabilities will be exactly the same as the approach we will take to inspecting services for children and older people. We will gather evidence against the standards to enable us to report. In addition to inspections of individual settings, we expect to examine the matter on an area wide basis. When we talk about communities we mean more than an older person or person with disabilities living in isolation in residential care homes. The issue is one of finding out what it is like to live in the community in question. For this reason, we will inspect areas, which will mean inspecting children's homes, disability services and older person's services. We must use our inspectorate in a way that reports on services for people who need care. We will report on what is good about the services.

In line with the way in which we develop standards, we also consulted on standards. We held public consultations, receiving more than 100 on-line responses, and established focus groups to enable service users, parents and representatives to participate in the consultation process. Whereas some consultation processes pay lip-service, we wanted a proper, participatory process to give people an opportunity to tell us what was important. We had 12 focus groups around the country and held 16 interviews with individual service users who could not take part in a group. In addition, each of the voluntary organisations represented on the group provided us with feedback following their own internal discussions. The process was as wide as possible. We received helpful comments and had widespread support for the standards produced.

Chairman:   Do our guests wish to raise any other points?

Dr. Tracey Cooper: Yes, I will address a number of related points. Deputy Conlon asked about the internal review. The purpose of the meeting is to discuss the development of the standards. In the early new year we will discuss the implementation of the standards, which is key. The important point is to get the standards right and ensure they are meaningful. Thereafter we will examine how the service needs to respond.

I described the processes which must be completed prior to commencing an inspection function. We will not sit back and wait for a button to be pressed. We expect public, private and voluntary providers to examine whether they are currently providing a service against the standards we have produced. This can be done as a voluntary self-assessment because these are the standards against which they will be inspected. This is important because they provide serious care.

What we mean by an internal review is that we expect any owner, manager or care provider to assess the services they provide, identify gaps and start to implement the necessary changes. They should not have to catch up given the type of people who are residents in their facilities. That is what we mean by an internal review. While we are waiting for the button to be pressed for commencement, we are keen to maintain impetus and, with Inclusion Ireland, ensure the system does not operate in a vacuum. The only question is one of commencement, and quality improvement should wait for an inspection. While inspections are important, especially in the case of less strong providers, quality improvement should start from the publication of the standards. We know it is already under way in some cases.

We seek, in an appreciative way, that our colleagues, Inclusion Ireland and other key stakeholders, maintain the momentum with us in advance and anticipation of inspections by means of awareness, development tools and ensuring that providers inform themselves as to what will take place. That is what is meant by internal review.

Members asked about the budget. This is a programme of quality improvement under which an inspectorate will commence, which will inspect 1,250 potential designated facilities providing residential care for people with disabilities. The figure depends on how we define the word "designation". This is important because we do not want facilities to reclassify themselves to remove themselves from registration.

From a budgetary perspective, we are working through the detail on the number of inspectors and support teams. The latter will support the registration function because it is important the information is processed correctly to enable us to use it without fear or favour in the areas of improvement and legal issues. These matters form part of the discussions we are having with the Department. Dialogue is still taking place, almost daily, on what exactly will commence next year and our budget. We are defining what will be the costs of commencing the function.



The international evidence for regulation is that if one regulates, one must do it properly. This is our mantra because we are engaged in a serious business in which serious care is being provided.

Deputies Reilly and Stanton asked about the children's function. While inspection of children's homes takes place currently, the potential loophole arises with regard to facilities in which children with disabilities are residing. I ask Ms Witton to clarify the matter.

Ms Marion Witton: As members will be aware, we have not commenced our part of the Child Care Act. This means the inspections being carried out by the social services inspectorate in my Department are those which were previously carried out by the Department of Health and Children under the current child care and children legislation, namely, inspections of public children's residential care and special care units. We will shortly commence inspection of detention centres. The HSE still inspects private and voluntary residential care homes for children. As members stated, this does not include specific homes for children with disabilities but general children's homes where children with disabilities reside.

While departmental standards are in place, they are not HIQA standards because they transferred with the social services inspectorate. One of our key jobs for next year is to review the children's services standards. To pre-empt a possible question on why we have not included children with disabilities in the standards we launched, the group had long conversations on this issue. Our view is that children are children first and while all children have needs, some of them have special needs. Therefore, the standards for children with disabilities are correctly under the umbrella of children's standards and are not lumped in with adult standards. This is the reason we decided to consider children as a whole. Having a disability does not mean one should not enjoy the same rights as children generally. The group took this decision after long discussions.

We will review standards for children's services, foster care, detention centres, special care, residential care and disability and produce a suite of children's standards.

Chairman:   For the purpose of clarity, are many centres accommodating children not subject to investigation?

Ms Marion Witton: If the Chairman refers to HSE inspections, the answer is "Yes". The position has not changed because we have not commenced our part of the Act yet.

Chairman:   I ask spokespersons for Inclusion Ireland to comment.

Ms Deirdre Carroll: I shall start and then hand over to Ms Finlay and Mr. Shorten. Prior to HIQA, the Children Act 2001 was enacted in April 2002. The purpose of section 267 was to amend section 59 of the Child Care Act 1991, which was intended to provide for the registration and inspection by the health boards of non-statutory residential centres for children with disabilities. However, legal opinion obtained at that time said that an amendment would allow only for the registration and inspection of non-statutory residential centres in which children with disabilities were resident in the care of the Health Service Executive, such as children coming from troubled backgrounds who might happen to have a disability also. There is a lacuna at present in regard to children specifically in voluntary disability groups. The intention was that there would be an amendment to the Child Care Act, which would allow for that, but then that ran into some legal difficulties and when HIQA was mooted it was decided that we should wait for HIQA, and that is what is happening. Our concern is that if there are delays because of budgetary constraints this matter will not be addressed. I hope that clarifies the point.

In answer to Deputy Ó Caoláin, the situation is that approximately 800 people are in inappropriate settings and it was Government policy to move them to more appropriate settings under the Department of Health and Children. That decision came as a result of a report to the European convention on social and cultural rights where the issue was raised specifically by Ms Annie Ryan. The Department of Health and Children gave a commitment that there would be a programme to remove people from what were considered inappropriate settings. Those inappropriate settings include where people with disabilities live in psychiatric hospitals or in HSE non-psychiatric, long-stay hospitals.

Chairman: I must interrupt Ms Carroll as a vote has been called in the Dáil. With the co-operation of members we will suspend the meeting until 5.05 p.m., when we will resume and conclude our questioning. Is that okay?

Deputy Kathleen Lynch: Are there outstanding questions?

Chairman: There are outstanding replies. Alternatively, if the witnesses would prefer to correspond with us we can circulate the responses?

Deputy Jan O'Sullivan: In fairness to Inclusion Ireland we should give its members the opportunity to answer if they wish.

Senator Mary M. White: I can stay.

Deputy Kathleen Lynch: We will come back. It is not a big deal.

Sitting suspended at 4.43 p.m. and resumed at 5.05 p.m.

Chairman: I ask Ms Carroll to proceed.

Ms Deirdre Carroll: In reply to Deputy Ó Caoláin, there has been some progress but not enough. The policy did disappear from the programme for Government but has been superseded by the creation of a Health Service Executive national steering committee which is examining what it calls congregated settings which include HSE settings, inappropriate placement settings and the settings of voluntary service providers with people living on large campuses or buildings. The group is due to report at the end of the year. Government policy actually concerned the 700 to 800 people in the dedesignated centres but it is estimated that there are over 4,000 in what we call congregated settings. We would certainly like to see them moved into community homes sooner rather than later.

I was asked to describe the unacceptable positions and not to hold back in doing so. We are always reluctant to describe the very bad circumstances because we are conscious that there are families and young people with disabilities who might recently have been diagnosed. While we recognise there have been improvements and that there are excellent services, we cannot forget that there are bad services. I was asked what I had seen. I have seen people sitting around in day wards doing nothing all day, people sleeping in dormitories with more than 15 others, people with no personal belongings, people with no access to their own disability allowance or no choice regarding what they spend their money on. I have seen people tied to chairs during meals and people kept in locked wards. These are some of the unacceptable circumstances I have seen.

Deputy Stanton has asked me whether I have cause for concern regarding children because of the lacunae to which we have drawn attention. I have some concerns for children, particularly because it has been estimated that children with disabilities are three to seven times more likely to be at risk of abuse, both sexual and physical. The higher the level of disability, the higher the risk. Children availing of residential disability services tend to be those with a much higher level of disability, including severe and profound disability. Most parents do not put young children into residential care because they do not want to. Those who are in residential care are those with the most severe disabilities.

My colleague, Mr. Shorten, will address Deputy Stanton's question on education for persons with special educational needs. Ms Frieda Finlay would like to say a few words about quality of life and why we need standards.

Mr. William Shorten: The Education for Persons with Special Educational Needs Act was enacted into law in 2004 and the National Council for Special Education was established in October 2005. A consultative forum was established to advise the council which, in turn, advises the Minister for Education and Science. It has been very positive and active in considering education and drew up the book on how to implement the Act. The consultative forum, of which I am a member, spent a lot of time in Trim advising the council on what was best. One issue raised was that implementation of the legislation would not be cheap, but costly.

One feature of the Education for Persons with Special Educational Needs Act was that it was to intertwine with the Disability Act 2005. Many of the issues related to both Acts, including those associated with health and education, are intertwined. Very often education cannot survive in its own right because it needs support services from health, particularly in relation to psychology, physiotherapy and speech and language therapy. In recent years the nurse in a special school, for dealing with severe and profound cases, is available and has become a necessity. At the same time education will not fund nursing but a child with such special needs cannot access education without a nurse.

As regards the Act not being drawn down, this has given rise to many dilemmas across the board in relation to the assessment of need and individual educational plans. These are not being done or acted upon, because it has not been drawn down. As to the designation of schools, for example, where it is accepted that the schooling of a child should take place in his or her own environment, that very often does not happen because schools can refuse entry to a particular child. I know of several cases where children have to travel up to 40 or 50 miles per day to schools that will accept them. The SENO has the task of placing the child. A taxi and an escort must be involved and then there is the amount of time the child spends in the taxi to be considered.

At present we are very much involved in inclusive education enabling the child to access a mainstream school with supports. Those supports are not in place, however, and we are looking very closely at special schools, or special classes within mainstream schools. While the resources are not there, various programmes are being proposed, and the main issue at present is inclusiveness. The national council, on 10 December, will finalise its programme on inclusive education. It is a question, however, of how this can be achieved if the supports are not in place and the EPSEN Act is not drawn down.

Inclusive education is enormously important, but its absence will necessarily mean, what I call, incarceration in special schools. Special schools do an excellent job in their own right, but should be used as resource centres for people with special disabilities. Such persons, on maximising their potential in such schools should move on into mainstream schools, but that is not happening. Effectively, there is a block in the drain. The Department of Education and Science, possibly for financial reasons, although I am not sure, is saying, in effect, that it is not going to happen. This is causing a depression within the education system.

Ms Frieda Finlay: There are no standards or inspections for day services as regards adults with intellectual disability. What stands out in the set of standards developed by HIQA is that the first section is about quality of life. People should no longer be in a service because they need to be looked after. We must do more than that. We have to give people a life.

The second section is about staffing and that is very important. The whole emphasis has changed. We have to look at the person, not how the service is being run or how the staff manage. We must consider what quality of life we are giving people. Are they becoming part of the community? A great many people are well able to have the quality of life we enjoy, but have not got the opportunity. Obviously they cannot go out in the evenings and need support in that regard, but in many cases they are not getting that support. That is why these standards are so important because, as I said in my submission, this is about quality of life and how people will live for the rest of their lives.

Some people with intellectual disabilities have a great life because they get the supports, but others do not and again it depends on the standards within the services. Unfortunately there are services that do not have

standards and there are those which are run for the staff and the service, rather than for the person. That is so important because people must be given a life. They are just like us, and I cannot emphasise that sufficiently. It is so important that this quality of life issue is addressed immediately and that people who inspect and evaluate the services ask questions such as “How many times have you been to the community? Are you enjoying the Tidy Towns? Do you go to the local pub? Have you been out, and are you able to access the services in your local area?”

No longer can we have people missing appointments because the staff cannot drive, or not going out because there is no one to take them. We, the public, the service providers and staff have to change our mindset and realise that this is about the individual person’s life - and the quality of that life is so important to the individual concerned.

Deputy Jan O’Sullivan: Perhaps I might have clarification on one matter. Ms Witton said that next year HIQA will be looking at standards for the care of children. We do not know what the timeframe is for what we have been discussing today. When the children’s standards are being set will HIQA be in a position to inspect services for children with intellectual disability in particular under that heading sooner than under the other heading. Is that a possibility, having regard to timeframes?

Senator Mary M. White: I would like to respond to Ms Finlay. Individual bad management is unforgivable. These institutions must be appallingly managed if a person misses his or her consultant appointment. If we read about it in Romania or wherever, we would say that it was an awful place. It is no different to what we read about in other countries. Can anything be done in the short term to put the heat on people who run these organisations and to let them know that the microscope is on them and that they must manage their-----

Chairman: I should hope that when we have concluded the responses, we can go into private session for a period of time and decide what approach the committee might adopt to advance the case, as we have heard it. However, I want to go back to HIQA. Do Dr. Cooper or Mr. Whelan want to raise something else?

Dr. Tracey Cooper: I have a point of clarification as regards our role in day-care, which came up earlier. I shall also ask Ms Witton to respond to Deputy O’Sullivan’s question about the children’s standards.

Ms Marion Witton: At the moment we are mandated to develop standards. However, until the health care Act commences which allows us to carry out inspections, we have no mandate for doing that. It requires the regulations to commence. We can develop the standards but we await the green light for commencing the inspections.

Dr. Tracey Cooper: Having heard the comments today, this is something that we have discussed with the Department and the HSE. We have taken on board what people have had to say here today and we shall take these comments away and look further into these matters. I thank the committee for that.

Deputy Caoimhghín Ó Caoláin: Dr. Cooper indicated, in deferring to Ms Witton, that she would address the issue of day-care standards. That has not happened. Could she elaborate on this and tell the committee precisely whether HIQA is pressing for the required introduction of standards and their implementation? Ms Finlay referred earlier to the fact that there are no standards currently in place. This was something I highlighted earlier and I should like to know. Rather than just having affirmation of that fact, I should like to know whether HIQA intends to address it.

Deputy James Reilly: I shall be very brief. What about home-care packages and home help? Are the providers inspected and supervised? Many of these providers operate on a voluntary basis, receiving a stipend from the HSE. What is the situation as regards monitoring them and will all hospitals, public and private, be licensed and subject to loss of licence? When can we expect this to happen because it is not predicated on money, or is it?

Deputy Kathleen Lynch: Will the inspectorate have to be recruited and will it be subject to the embargo? I am not certain HIQA can give us that information today, but perhaps it is one of the questions it should ask when its representatives meet the Department.

Senator Frances Fitzgerald: I also seek clarity that budgetary considerations are not delaying the process at present. While this is a difficult issue for the witnesses to comment on, I wish to make that point. Second, I refer to the work on which HIQA has been engaged thus far regarding inspection. Dr. Witton and Dr. Cooper should indicate whether, from their observations and international studies in this regard, areas exist in which there are gaps at present. While I refer in particular to child protection areas, are there others? The issues of the 400 children in residential care and the day care services have been discussed today. Can the witnesses from HIQA comment on other areas that might be subject to legislation in future?

Deputy David Stanton: Mr. Shorten referred earlier to incarceration in special schools because of the blockage in the system. He spoke about children who are obliged to travel 40 to 50 miles per day because their local school would not accept them due to their intellectual learning disabilities. He should elaborate on this point a little. Am I correct that the international day of persons with disabilities is coming up shortly?

Ms Deirdre Carroll: Tomorrow.

Deputy David Stanton: It is opportune that members are discussing this issue this evening. A cultural, as well as a paradigm, shift is needed in this regard. Having listened to Ms Finlay and Senator Mary White, I believe the entire mindset as to how people with disabilities are viewed, particularly those with learning disabilities, must be changed. One must dig deep in this regard.

Chairman: I thank everyone for their contributions and I seek succinct responses, if possible.

Mr. William Shorten: The national council is looking at special schools, special classes and inclusive education. As the Education for Persons with Special Educational Needs, EPSEN, Act still has not been drawn down, schools that are not designated to accept such people will state they have no room or cannot cope and, consequently, they are obliged to travel further. The special educational needs organiser, SENO, who has a large budget, must place these people. Consequently, a person may travel with an escort in a taxi from Templeogue all the way to Celbridge, County Kildare, which is not cost-effective. Similarly, another person may travel from the far side of Naas to Celbridge. These are factual situations. People are passing by Educate Together schools as they will not be accepted there. People now are invoking section 29 of the Education Act 1998 in response to schools' refusal to take such children, to oblige schools to do so. It is a trína chéile situation until the EPSEN Act is drawn down.

Dr. Tracey Cooper: First, I must apologise to Deputy Ó Caoláin in respect of his question. I will ask Dr. Witton to cover the issue pertaining to our function in respect of day care and to pick up Deputy Reilly's question about home care help. This is to remind members what are our functions because, obviously, we only can work within our jurisdictions, as well as giving them an idea of where our remit begins and ends at present.

Dr. Marion Witton: To restate Dr. Cooper's comments, the Act only covers residential services and does not cover home care services or day care. Therefore, we can only register that which comes under the definition. The same is true for child protection and any other services provided by the HSE that are not specifically residential services. The definition is one under which we must operate.

Dr. Tracey Cooper: I wish to respond to Deputy Reilly in respect of licensing. Obviously, we are talking about social care providers, which covers public, private and voluntary at present. As for hospitals, as members may be aware that at present, our remit covers the Health Service Executive and providers on its behalf but does not cover private institutions. I refer to the report of the Commission on Patient Safety and Quality Assurance that was published a number of months ago. We hope it is in a position to be progressed and considered by the Government in the near future. One of the report's recommendations pertains to a licensing system for public, private and voluntary hospitals, which would be based on the same principles of inspection and

registration and regulation that have been under discussion today. Moreover, the recommendations in the report are to apply equally across all the sectors.

Obviously, the implementation of licensing will be subject to a decision to take on the report's recommendations. The report also specified that the entity responsible for such licensing should be HIQA. In the coming months, we will start a process of reviewing standards for what constitutes a high-performing and safe hospital. We will engage with people in the system and will give everyone an opportunity in this regard. Obviously, if and when licensing is introduced, these standards will apply to that licensing approach. In anticipation that it may be agreed to implement this measure, we are starting the process as early as possible to develop the standards that would be used as regulatory standards for licensing.



Deputy James Reilly:   In Dr. Cooper's view, would this require legislation?

Dr. Tracey Cooper: Yes.

Ms Deirdre Carroll: On behalf of Inclusion Ireland, I wish to state we are appreciative of the invitation to appear before such an august joint committee as it is extremely important that members hear from groups such as ours. I stress that many people have no families or are not fortunate enough to have a person such as Ms Finlay, who takes a great interest in her daughter's care, as a mother. This issue is both ours and members' responsibility. The services are located in their constituencies and we are aware of the cases. A lacuna exists, which will continue for the next two years. Consequently, it is extremely important that there is a commitment from all members present, on a cross-party basis, to make the strongest representations to the office of the Minister for Health and Children.

Mr. William Shorten: Being a realist with regard to the current financial constraints, were the Government at least to endorse the national quality standards, many measures included therein would be cost-effective and would not cost money, which the Minister for Finance would like to hear. The Government should at least state it will bring it in within a timeframe, contingent on money flows. Then at least, the various organisations could be told the standards exist, the inspector is coming and they can undertake X, which does not cost money. This would cause a change of thought, philosophy and ethos that would change the quality of life of the people affected.

Dr. Tracey Cooper: I thank members for this opportunity and we all would appreciate having an ongoing engagement with the joint committee. I heard the word "inspectors" coming from the other side of the room. Everyone is aware of the current challenges in respect of the budget and the public sector embargo. We have been engaged in ongoing discussions with the Department on how to unlock this issue to make this happen. While I appear to be making that point a lot, it is the truth. This is all we can do collectively at present but it must happen. Without comprising our quality, we also must be creative and realistic about making it happen in respect of the current climate as it must do so on the basis of a sustainable footing in the future. These discussions are taking place and we certainly are not waiting for something in a number of months. This pertains to longer-term thinking and to implementing something as soon as possible.

Chairman:   On behalf of the joint committee, I thank everyone for their presentations and HIQA for the obvious quality of the work in which it has been engaged and its level of engagement with the partners in the process. It is rare to have such commonality of approach between a statutory body and representatives of the voluntary sector, which points to the success of the work in which HIQA has been engaged. Members are deeply grateful to Inclusion Ireland. I have family members and many good friends who work in the disability sector and I was probably guilty of a cultural assumption that standards were both superb and continually rising. While this probably is true in many instances, complacency is the enemy of certainty and we must have in place a regulatory and supervisory system. The joint committee will have a chat after the witnesses have left to ascertain what it usefully can do to support the work in which they are engaged.

The joint committee went into private session at 5.29 p.m.