
NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability

**NDA Review of the implementation of the
HIQA Standards and Regulations for Residential Services
for Adults & Children with Disabilities
June 2015**

Introduction:

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability warmly welcomes the opportunity to provide feedback to the NDA Review of the Implementation of the HIQA Standards and Regulations for Residential Services for Adults and Children with Disabilities.

Recognising the importance of the regulatory process and its contribution to the quality of life of the people we support and the safety of the services provided, the aim of the National Federation in making this submission is to provide information that will contribute to the shared aim of ensuring that the process is streamlined and provides the best outcomes for the person supported, whilst ensuring efficient use of time and resources and good communication between the service provider and HIQA.

This submission is being made in addition to, and should be viewed alongside, ongoing feedback which has been provided to the NDA by the National Federation of Voluntary Bodies over the period of time since Registration began, which includes the following:

- National Federation paper to HIQA – ‘*Feedback to HIQA regarding Registration and Inspection of Residential Services for Children & Adults with Disabilities*’,(December 2014)
- National Federation submission to HIQA regarding ‘*What Constitutes a Designated Centre?*’ (January 2015)
- Submissions regarding housing matters - *Regulations Residential Standards for Children and Adults with Disabilities* (May, 2015) / *Additional Feedback* (June 2nd & June 11th 2015)
- Inputs from individual service providers unique to their service experience.

(1) The National Federation’s own response to quality improvement (How have you responded to the implementation of standards by HIQA?)

- **Level of awareness within National Federation member organisations:** The level of awareness amongst organisations in relation to the development of the standards and the subsequent introduction of the regulations for residential services for children and adults with a disability was very high. There was a large attendance by Federation members at the various HIQA related briefings prior to the introduction of the regulations and the commencement of monitoring and registration inspections during the first year. The introduction of the regulations has been one of the priority areas of work for the National Federation and its

member organisations over the past two years.

➤ **Specific actions undertaken by the National Federation in relation to the development of the standards and the introduction of the regulations include the following:**

- *Discussions at Federation Board / General Assembly and relevant Sub Committee meetings – aimed at ensuring that members were fully briefed in relation to the introduction of the standards / regulations.*
- *While the National Federation had an existing Quality and Standards Sub Committee in place, whose membership was drawn from across member organisations, the role of the group was expanded to include a central focus on the implementation of the regulations.*
- *Nomination of representatives to / participation at the HIQA Provider Forum meetings and the sharing of information / minutes with all member organisations to inform the work of organisation’s internal regulations related Steering Committees.*
- *Meetings with key personnel within HIQA to discuss issues of concern to Federation members.*
- *Submissions made by the National Federation to HIQA on specific issues (e.g. What constitutes a designated centre?, Guidance Document on Medication Management, etc). The National Federation has also sought to address key issues as they arise for member organisations e.g. access to the Capital Assistance Scheme (CAS).*
- *A ‘Persons-in-Charge’ conference was organised by the National Federation (October , 2014) which focused on the role of the PIC and included a range of presentations from experts in the area.*
- *Facilitating the sharing of experiences and feedback from the organisations that volunteered to participate in the early registration process was very informative for other agencies (‘pilot’ organisations).*
- *Since the introduction of the regulations there has been on-going interagency sharing of information and experience, leading to problem resolution across services.*
- *A number of shared learning & dissemination events have been organised by the National Federation on major quality improvement initiatives – e.g. Next Steps, Immersion, Enabling Excellence, David Pitonyak Workshop – all aimed at supporting the on-going development / provision of quality services.*
- *Other presentations to inform the understanding of regulations were made to the Quality and Standards Sub Committee which included a presentation on experience of regulation in older persons services, independent living, etc.*
- *A resource point was developed by the National Federation on its website – www.fedvol.ie - to facilitate the sharing of HIQA related policies and documentation. Organisations were invited to share their policies and procedures with documents being made available through the website.*
- *At a practical level the National Federation co-ordinated the distribution of standards documents to organisations.*

➤ **Specific problems and actions identified by National Federation member organisations:** Since the introduction of the regulations a range of issues have emerged for Federation members, key amongst these are the following¹:

- **Ethos of the Regulations:** The regulations should be supporting organisations to implement key national policies (e.g. congrgated settings, new directions, etc), the

¹ For additional comments refer to submission document ‘Feedback to HIQA regarding Registration and Inspection of rediedntial Services for Children & Adults with Disabilities’, National Federation of Voluntary Bodies, December, 2014.

movement to more individualised supports and services and the implementation of key legislation (e.g. the UN Declaration of the Rights of Persons with a Disability). However, in many instances the regulations are focused on the nursing home model and as a consequence don't readily fit disability services, promote individualisation and encourage organisations to build real, inclusive lives for people with an intellectual disability. Rather they are seen as restricting positive risk taking within organisations.

- Regulatory Impact Assessment : The lack of a comprehensive regulatory impact assessment which would have addressed, amongst other areas, the resource implications and the impact on the implementation of national policies which support the development of “ordinary lives in ordinary places”.
- Resource Pressures: The commencement of the inspections process has placed considerable additional pressure on organisations in terms of funding (both capital and revenue) and staffing requirements.
- Lack of consistency: The lack of consistency in relation to inspections / inspectors around the regulations and their interpretation of same has caused on-going difficulties for organisations. (A specific example here relates to organisations policies with organisations being repeatedly requested to amend policies and to develop site-specific policies which from an organisational management perspective is very challenging). There can also be a lack of consistency amongst inspectors in terms of how they interact with providers – ranging from being very professional and courteous to being abrasive and uncompromising.
- Appointment of Persons-in Charge: Typically the higher order decision making level required by the PIC alongside the detailed day to day knowledge of the service needed lies somewhere between the regional manager and the frontline manager but within the regulations this has been merged into the single role of the ‘PIC’. The imposition of this model on organisations does not necessarily fit with organisation’s existing management structures and as a consequence is causing difficulties for organisations at both management and industrial relations levels. In some places HIQA inspectors have been pragmatic and worked around this but it has caused significant confusion and it remains the case that very different or contradictory arrangements are required by different inspectors.
- Training: There is a lack of clarity and an inconsistency amongst inspectors in relation to the frequency of refresher training - the focus tends to be on training provision rather than the impact on behaviour of the training (e.g. fire safety - the provision of frequent training is not necessarily a solution as it fails the essential test of problem definition - preventing fires and evacuating people safely is the challenge and how this is done can vary. This does not necessarily involve an expensive training based solution if the person can evacuate safely and if there is evidence of safe practice around fire prevention). Also in relation to training organisations have been requested to provide training which is not specific to the needs of the group / individuals living in a particular designated centre – e.g. epilepsy and challenging behaviour where these issues don't arise for the individuals involved.
- Institutionalisation of community houses: as a result of the level of signage, fire and safety related equipment required e.g hand rails, raised banisters, window restrictors, etc.
- Lack of knowledge by Inspectors of disability services: HIQA inspectors have a mixed case load (nursing homes / disability services) and some inspectors appear to have a limited knowledge of the disability sector and have varying comfort levels in meeting and speaking with clients. The move to a programmatic approach in which inspectors would work solely in the disability sector would be very welcome.
- Administrative Requirements: The requirements placed on organisations in relation to

the registration / inspection / notification process has placed huge administrative requirements on organisations.

- Designated Centres: The lack of clarity in relation to what constitutes a designated centre has caused on-going difficulties for organisations.

➤ **Issues to highlight as good practice / what works well for National Federation member organisations:**

- There is more direct involvement from management in the frontline delivery of services and with a more frequent presence on site.
- The registration / inspection process has led to extensive focus on best possible health, safety and risk which addressed some gaps in this area.
- The introduction of the regulations has highlighted the problems associated with older buildings and some larger settings. They have also highlighted the need for ongoing investment within the sector (at a time when there is a shortage of core funding).
- The training days and information documents provided by HIQA have been useful.
- The establishment of the HIQA providers Forum has provided a formal forum for raising / addressing issues of concern arising for National Federation member organisations.

(2) Views on HIQA registration process and feedback?

➤ **Specific problems and actions in registration process:**

- The registration process is seen as extremely bureaucratic with a hard copy system, unnecessary duplication of documents, leading to an overly complicated cumbersome system.
- There is evidence of poor internal administration and communication within HIQA e.g. documentation mislaid, inspections being cancelled but providers not being informed of same.
- The costs associated with the registration and application process are onerous for organisations e.g. HIQA fees, GP visits (and repeat visits), staff time allocated to the completion of the required documentation, etc.
- The lack of a named person within HIQA that an organisation could liaise with on an ongoing basis throughout the registration process was unhelpful (while organisations could contact HIQA and speak to staff it would have been more helpful to have been allocated a single contact person at the outset to assist with queries).
- The registration of new designated centres is a key issue for organisations. As designated centres need to be registered in advance of opening resulting in potentially significant wasted resources as it can take some months to secure 'permission to open'.

'We applied in Dec (2014) to open 2 new houses and we are still not permitted to open them as the registration has not officially be granted. Inspections are complete, all paper work is complete but the final 'sign off' is not yet complete. We have 2 vacant properties all ready to be used but no permission from HIQA to use them. A second point relating to the opening of new centres is that inspections are carried out before anyone lives there. The expectation is that all paper work will be completed and all risk assessments done even though the group do not live in the house yet- this is evidence that the focus is not on people but on building compliance and paper work compliance'. (Quote from National Federation member organisation).

- Particular issues have arisen for organisations in relation to 'what constitutes a designated

centre?’ and so needs to be registered with HIQA. There are a diverse range of residential services supported by organisations and there needs to be a flexible understanding of the variances that can occur in the supports provided and living arrangements - particularly as people move to more individualised community-based supports. There is still a lack of clarity on how more individualised arrangements are treated and how the policy direction of moving to individualised and independent, community-based living can be progressed within this.

As has been articulated by one organisation we need to ensure that if people’s homes are brought under HIQA’s remit that there is not a *‘...significant displacement of attention and energy – **from** a single-minded focus on making sure things are happening in respect of building a meaningful, going-somewhere, inclusive life **to** defensive practice in which the emphasis will move to investing in generating impressive audit trails, curating documentation to create the impression that the processes and procedures detailed throughout the regulations are the actual drivers of the work and any resulting positive outcomes.’*

- The perception of HIQA that mistakes which they make are due to pressure but that administrative errors by providers or a lack of paper work in a small community group home do not warrant a similar degree of understanding, even if the service provision is manifestly positive, suggests an inequity between the parties. This is very frustrating and will breed cynicism and defensive practices amongst organisations and also militates against a good collaborative working relationship.

➤ **What was useful in the HIQA registration process?**

- Information days provided by HIQA were valuable but were arranged late in the day.
- Internal Committee being established within organisations to oversee the registration process.
- Appointment of a lead person within organisations to take responsibility for co-ordinating the registration process.
- When HIQA began to assign a dedicated person to liaise with individual organisations (some case assignment is now happening).

(3) Role of the Person in Charge

➤ **Training for PIC:**

- The appointment of PICs has resulted in a very significant role change for the individuals involved. Training has been offered at a local level by many organisations - provided either inhouse or through the recruitment of private consultants. The training provided has included information on the regulations, action planning, supervision of staff, etc. (In relation to action planning there was little understanding within HIQA that PICs may not have the necessary expertise to develop effective action plans. The onus was on organisations to provide this type of training inhouse).
- The National Federation also organised a one day conference on ‘The role of the PIC’.

➤ **Role of the PIC:**

- While PIC’s are expected to have decision making authority within their organisation they are also expected to have detailed/hands-on knowledge of the people they support. This is a difficult balance for organisations which is not always recognised by HIQA. Guidance on the level of seniority of the PICs would have been helpful at the start of the regulation process.

- Some PIC's were appointed at very short notice and did not have a lot of time to grow into the role – more clarity early on in the process might have led to different choices by organisations in how they appointed PICs and the number of designated centres that they are responsible for.
- The moratorium on recruitment within the public sector has impacted on staffing levels within organisations particularly in middle/senior management grades. This in turn has had an impact on the appointment of PICs.
- PICs now need to be very knowledgeable across a range of administrative activities e.g. maintenance, human resource, finance, administration etc where previously they would have relied on support from these function areas.
- Specific regulations state “the PIC shall...” this is interpreted by some inspectors literally whereas in reality it should be stated that it is the ‘registered provider’ that is responsible in certain areas (e.g. instigating investigations).

➤ **Any internal issues with PIC's and the outcomes:**

- Some PICs resigning/stepping down as a result of added pressures associated with regulation.
- In early reports which were published the PICs name was detailed on the reports and this made it easy to identify individual designated centres and as a result the individuals living there. Also because they were named on the report PICs were perceived as being responsible for the findings within the report (rather than the registered provider being responsible).
- Extra time needs to be devoted by PICs to administrative duties, supervision of staff and governance duties at the cost of time spent on the frontline.
- The appointment of PICs has led to some issues with the Trade Unions as some staff have objected / refused to take on the extra responsibilities of the role.

(4) Views on HIQA inspection process and feedback

➤ **Specific training for HIQA inspections:**

- While the early HIQA briefings were useful there was confusion and in some cases contradictory information provided at the briefing sessions.
- Following the introduction of the regulations organisations needed more preparation time before monitoring/ inspection visits commenced. A phased approach to the introduction of the regulations, similar to that taken with the Nursing Home Regulations, should have been implemented.
- The sharing of information from the initial volunteer ‘pilots’ were very useful as there was considerable learning from this.
- It was very useful when an inspector met with the registered provider / management in individual organisations before the registration/inspection process began.
- Some organisations employed external consultants to provide training and undertake mock inspections which proved positive but had resource implications.
- Many agencies arranged internal briefings as information became available.

➤ **What is good practice in preparing for inspections /what works well?**

- When the initial (individual) inspections were completed the individual PICs provided a briefing to all other PICs/management.
- A system of ‘peer support’ for PIC's established to share learning / information.

➤ **Positives about the inspection process:**

- This is an external regulatory authority with a statutory remit and it brings objectivity and

expertise to the process.

- The process is rigorous and aims to be consistent/uniform across designated centres.
- The process places a high level of accountability on the registered provider and the staff employed.
- Because of the weight of HIQA as a statutory body it has the ability in some cases to bypass union opposition to the introduction of certain systems or processes.

➤ **How to improve the HIQA inspection process?**

- HIQA relies on a triangulation of evidence but in reality paper evidence is weighed heavily. Inspectors should spend more time interacting with people in receipt of services and observing what is happening on the ground.
- While there has been significant learning gained by some organisations for example in the areas of effective risk management, health and safety, management of residents' finances, etc this should not be at the expense of the effective implementation of national policy and the development of individualised supports and services.
- It is organisation's experience that there has been on-going minor amendments required to policies and procedures which poses a challenge to organisations in updating the documents and briefing all staff on the amendments. It is symptomatic of the services in silos model of inspection and this narrow view becomes myopic at times as it actually destabilises the policy and procedure oversight in organisations and increases the risk in the entire document control process. As one organisation outlined:

'it is a good example of a short sighted approach which seems to value polices and procedures very highly but has no apparent capacity to identify the unintended consequences of frequent tinkering with policy & procedural minutia. What is more frustrating is the inconsistency of these demands from inspectors which at times appear almost whimsical. The degree of time and effort that goes into maintaining a major volume of polices and procedures and the cost and time expended in doing so is not considered in any of this. However if there was a question about use of resources then HIQA would be causing the provider to fall short'.

- The use of key words with predictive text and copy and paste within HIQA reports takes from the validity of reports as they relate to individual centres.

➤ **Any issues in relation to who and how HIQA engages during the inspection process?**

- More interaction with the people living in designated centres and family members.
- Inconsistency of conduct amongst inspectors in relation to their engagement with registered providers.
- Unannounced visits should only occur when people are in their homes (inspectors should not visit a house at times when it has been advised that no-one will be at home) .

➤ **Particular challenges / Implications for organisations in addressing compliance:**

- There have been huge challenges for organisations as a result of the introduction of the inspection process – costs associated with actions required, need to appoint additional staff, responding to actions required within a specific time frame, etc.
- In seeking to reach compliance agencies have had to negotiate with the HSE in relation to securing additional resources to address areas of non compliance. This has included the appointment of additional staff which has impacted positively on the quality of service provided. In some instances the HSE has authorised organisations to recruit staff in place of the usage of agency staff.
- However in other cases the expenditures associated with staff time and the implementation of particular actions has created serious financial problems for providers which under

another type of scrutiny would not be considered best use of resources (e.g. expenditure on maintaining/upgrading older buildings which ideally residents should be moving out of into more individualised or community based arrangements).

- The reports published by HIQA, particularly where major non-compliances have been found, are of considerable concern to registered providers, staff, residents and their families. Providers are eager to ensure that areas of non-compliance are addressed and that issues of concern arising are effectively dealt with. Where there are resource implications associated with the actions required it is essential that the HSE, as the core funder of services, is willing to engage with services to agree and implement the required solutions.

➤ **Could organisations challenge the findings of the report?**

- Yes in many instances it has been possible for agencies to successfully challenge report findings. Agencies can complete the factual accuracy form where required. However, there appears to be a rigidity on the part of some HIQA inspectors to change certain findings (e.g. where a PIC was unable to locate a particular document during an inspection visit and while it was provided shortly afterwards the inspector was not prepared to amend their findings).
- Organisations can also respond to inspectors judgments as to the fitness of providers and their staff and as to the levels of compliance with regulations and standards using the HIQA document entitled '*Policy and procedure for managing submissions made by registered providers in respect of regulatory judgments made by the Chief Inspector of Social Services of the Health Information and Quality Authority*'. However some organisations were unaware of this process.
- In certain cases inspectors have indicated that a particular issue would not be noted in the report drafted but it was included in the subsequent report.

(5) Views on appropriateness of specific Standards and Regulations one year on

- During monitoring and inspection visits it is the regulations for residential services that are focused on and not the standards. The following are concrete examples of where particular regulations are not appropriate to disability services:

Regulation 5 Individualised Assessment and Personal Plan:

- Regulation 5 (1): 'all service users should have an assessment and PCP' – however not all service users wish to have a PCP.
- Regulation 5 (4): As some individuals have lived in services for many years there would not be 'admissions' documentation on file.
- 5(6) some care plans do not need a full multi-disciplinary team assessment.

Regulation 8 (3) Protection:

- The regulation indicates that the PIC shall initiate and put in place an investigation but it should be the registered provider who undertakes this.

Regulation 9 (2a) Residents Rights:

- Clarity is needed around consent if no next-of-kin exists.

Regulation 11 (3) Visits:

- Regulation states that a suitable private place beyond a person's bedroom is available to receive visitors. This is impractical in many domestic / community houses (nursing home model).

Regulation 14 (2) Person in Charge:

- The requirement that a PIC should work full time is challenging, restricts organisations in terms of who they can appoint, and in instances is at odds with employment law entitlements e.g. the entitlement for staff to avail of parental leave. This regulation is also indicative of an over focus on process rather than the result; if a manager demonstrates capacity to run a good service then the exact number of hours or arrangements is not really relevant. While some inspectors are flexible on this requirement the particular regulation needs to be reviewed.

Regulation 14 (3b)

- This regulation requires PICs to have an appropriate qualification in health or social care management at an 'appropriate' level. There is a lack of clarity on what constitutes an 'appropriate' qualification.

Regulation 16 (1) Training and staff development:

- Clarity is required in relation to the frequency of refresher training e.g. fire safety, manual handling, Client Protection. It is proposed that a period of every **3 years** would be the standard period for undertaking refresher training (unless there is a legal requirement specified).

Regulation 17 Premises:

- A number of the requirements set out in regulation 17 are more appropriate to a nursing home model rather than a social care model.

Regulation 28 Fire Safety

- The fire safety standards that are in place are more suited to larger nursing homes or institutions and are not at all suited to regular / domestic houses. The implications of this regulation are very serious for organisations and residents – the costs involved in upgrading premises can be very onerous for organisations and there are implications in terms of securing suitable premises for residents and getting agreement, where necessary, from private landlords to amend properties. In addition where there is a requirement for residents to move out of a designated centre while it is being upgraded considerable delays can be experienced in getting alternative premises registered / approved so that the residents can move while such refurbishments are being made. This is in addition to the difficulties in identifying suitable premises to rent given current pressures on private rented accommodation.

Regulation 29 Medicines and Pharmaceutical Services:

- (6) Numerous issues have arisen for organisations in relation to the implementation of this regulation e.g. GP's unwilling to complete individuals' files (which some inspectors expect to see updated by the relevant GP); further guidance required on medication management.

Schedule 5 Policies and procedures to be maintained in respect of the designated centre:

- Inspectors have looked for policies that are not outlined in Schedule 5 e.g. Hazard Analysis and Critical Control Points (HACCP).
- Clarity needs to be provided in relation to how frequently the required policies should be reviewed.
- A number of organisations were guided by the HSE policy on Community Infection Control (Infection Control 2011) however HIQA would not accept this Policy and instructed registered providers to have a site specific policy in place. However, in other instances organisations are expected to have adopted a single national HSE policy e.g. the Safeguarding Vulnerable Adult's policy. From a service management perspective having

multiple policies in operation within a single service is not at all effective or implementable.

General comment:

- Earlier submissions to the NDA detail Federation member organisations concerns in relation to the requirement to register new designated centres before residents move into them and the serious difficulties caused by this requirement (refer to Housing submission documents).
- We need to avoid a scenario where there is an assumption that completion of the regulatory/inspection process is the outcome i.e. if you undertake a specific action you will reach compliance and meet the regulations. Rather we need to ensure that implementation of the regulations will lead to better outcomes and quality of life for each individual supported.

(6) Views on HIQA's communication & information process relating to registration & inspection:

➤ **The following general comments relate to the HIQA communication and information process:**

- From the date of receiving the registration pack there was a huge volume of information to be gathered within a very short timeframe e.g. getting 2 written references, verification of staff member's employment history, etc. There needs to be more time allowed for same.
- The changing format of forms (e.g. the garda vetting form) mid-process caused confusion for some agencies.
- In relation to the notifications/updates issued by HIQA these need to reach service providers in a timely manner. When information / new forms are uploaded to HIQA's website this should be notified to agencies.
- The tone of written communication from HIQA can be quite formal however when following up with a call to HIQA's offices the approach is more understanding and helpful.
- HIQA questionnaires to be completed by people supported were not in an easy-to-read format and there was nowhere on the form to identify if the person received support to complete same.
- Information issued by HIQA should be clear and accessible – HIQA need to produce their reports in an easy to read format.
- A very short time frame between receipt of questionnaires for people being supported and their families / relatives and the date of the inspection – difficult to have questionnaires circulated and returned on time.
- HIQA communication is not always issued to the same person in the organisation but sending it via email and post is very helpful.

➤ **What is good practice regarding the information and communication provided by HIQA / what worked well?**

- HIQA guidance documents are very useful and should be disseminated throughout organisations.
- Further guidance documents would be useful e.g. fire safety, preparing an annual report on quality and safety.

(7) Overall impact to date of the introduction of HIQA regulation and inspection of residential services for adults and children with disabilities

➤ The following section aims to provide an overview of the main impact areas arising from the

introduction of the HIQA regulation and inspection process:

- There is an increased focus on resident's rights, equity, addressing complaints and treating people with dignity and respect, which will enhance individuals overall quality of life. In some cases there has been an increased focus in the HIQA reports on basic human rights.
- The regulations have helped to create some impetus to move towards the implementation of the congregated settings report but equally there are re-institutionalised practices being promoted where the value of ordinary lives is diluted.
- The process of external inspection is powerful - the introduction of the statutory regulations has made services more accountable and has identified areas of poor practice that services are forced to address.
- There have been considerable additional budgetary pressures on organisations e.g. relating to buildings, registration fees, etc. A recent National Federation survey on the costs associated with the registration / inspection process and the implementation of the actions arising from HIQA inspection reports has indicated that the costs amount to approximately €25 million (2014/5).
- There is an increased pressure on staff members due to additional administrative demands and this in many cases has the negative result of reducing the amount of time that PIC's have to engage in front line activities and to directly engage with those supported or to engage in initiatives that support policy implementation e.g. congregated settings.
- It is easier to identify performance issues as a result of the inspection process.
- The regulations have prompted some necessary changes in relation to buildings which required action around fire protection etc.
- The regulations have in some cases reduced registered providers' flexibility to respond to emergencies but on the other hand it has forced services to plan ahead for emergencies.
- The regulations as they currently stand are not disability informed and discourage risk taking – rather they promote a 'safety culture' which has been an unintended consequence. This risk adverse culture inhibits innovation in the implementation of innovative national disability policy. The focus shouldn't be on 'what is the best organisation?' as this is not the same as what is best for the person with a disability. In effect a service could be fully compliant with the regulations but would it be the best place to receive a service? This is a major dilemma and is symptomatic of the assumption that a focus on process will lead to desired outcomes (which underlies the regulations / HIQA approach).
- The absence of capacity and consent legislation disadvantages people with disability.
- Advocacy supports services need to be strengthened and made more readily available/accessible.
- As HIQA reports are published online there is another body of work emerging for registered providers in responding to the media. The emphasis within the media sometimes lacks balance highlighting only areas of non-compliance. This places increased pressures on organisations to respond to the media when all efforts should be focused on addressing the issues arising within reports and moving services forward.

(8) Suggestions for promoting good practice amongst service providers / what works well?

- The National Federation's Quality and Standards Sub-Committee is positive and assists organisations in promoting good practice.
- **What makes one Centre stand out more from another?**
 - Having an internal Quality Committee in place within an organisation which meets regularly and disseminates information to all staff members.

- The level of leadership within an organisation – from top management right throughout the organisation.
- The level of understanding and confidence of the PIC's within the organisation – this can be affected by the level of training and support provided to support them in their role.
- Effective training and enhanced staff understanding of what organisations are seeking to achieve as a result of the registration and inspection process. An understanding that the overall aim is not solely about securing registration and good reports from the inspection process but that it is at all times about ensuring that individual's in receipt of services get the best quality service and life possible.
- Where good links have been developed with the local community and there are real linkages to supports and services outside of those provided by the organisation.
- Where compliance leads to positive outcomes and high satisfaction levels for residents, families and staff members.

(9) Feedback on HIQA Providers Forum

- The Providers Forum has been a useful communication forum where the issues that are raised by organisations are highlighted and discussed. However, HIQA has been unable to effectively respond to many of the issues raised as they continually refer to the 'regulations' which they are required to adhere to and have little scope to adapt the regulations to a situation. (An example of this is in relation to the registration of new buildings, difficulties of renting accommodation, securing emergency accommodation, etc.)
- The Forum has been very useful around the development of guidance documents and additional guidance documents would be welcome.
- HIQA should develop more easy-to-read documents (forms / reports) for residents and their families.
- The Forum has also been useful in informing a better understanding of the difference between supports provided to persons with a disability by voluntary organisations and those relating to the nursing home environment.
- The Forum provides the opportunity to raise issues in relation to the overall HIQA registration and inspection processes and to provide feedback in relation to how these can be streamlined. It also facilitates organisations to provide feedback on the practical elements of inspections and how these can be improved.

'The HIQA/Provider Forum is an example of a putative yet significant effort to remain engaged and to share learning. This could be profitably be seen as a potential foundation for a forum for Responsive Regulation as described in the NESC review of Quality and Standards in Human Services in Ireland' (quote from National Federation member organisation).

(10) Is overall legislation adequate to address issues of non-compliance?

- HIQA has a powerful set of consequences in its armoury when required and no organisation wants to be seen as a poor or failing provider.
- It is difficult to measure this at this early stage - there is insufficient evidence at present.
- Other key pieces of legislation need to be addressed in order to support the implementation of the regulations e.g. consent and capacity legislation, advocacy, fire regulations, are key.

(11) Any other issues or comments

- The experience of external inspection and accountability has been a challenge one which has resulted in both positive and negative experiences for registered providers.
- The concern is that so much effort and time is expended on seemingly trivial issues. As was outlined earlier there is no sense among providers that being fully compliant with the 18 outcomes is a guarantee that people have a good life. There has to be opportunity to take stock of the positives and the negatives and show that we are learning both as providers and regulators. It is certain that both have much to learn.

In summary:

'It is of course an exceptionally complex business to introduce a regulatory system into a previously unregulated environment and resembles the task of building a ship while simultaneously venturing forth upon the high seas. However as we all must travel in this ship in order to reach a common destination it would be wise to ensure that we take time to reflect on what is being learned. We welcome the NDA review and hope it can provide significant assistance in supporting this sectoral learning.' (Quote from National Federation member organisation).