

# Draft National Standards for Residential Centres for People with Disabilities



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

## Consultation Feedback Form

**October 2012**

Your views are very important to us. We would like to hear what you think about the draft Standards. Your comments will be considered and will inform the development of the final National Standards.

The *Draft National Standards for Residential Centres for People with Disabilities* contain Standards and features. You can comment on one or all of them, or you may wish to make general comments. When commenting on a specific Standard or feature, it would help us if you tell us the reference number of the Standard (e.g. Standard 2.3) or feature (e.g. Feature 2.3.1) that you are commenting on.

**The closing date for consultation is 5pm on 21 November 2012**

**You can email or post a completed form to us. You can also complete and submit your feedback on [www.hiqa.ie](http://www.hiqa.ie).**

## About you

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<b>Date:</b>	21 November 2012

<b>Are you commenting on behalf of your organisation or in a personal capacity?</b>	<b>Organisation</b> <input checked="" type="checkbox"/> <b>Personal</b> <input type="checkbox"/>
<b>Organisation:</b> (Please include name of organisation if making this submission on behalf of your organisation)	Inclusive Research Network

## General feedback questions

The consultation document presents for public consultation proposed new *Draft National Standards for Residential Centres for People with Disabilities*. The Standards are intended to provide a roadmap for the provision of safe and effective residential services for children and adults with disabilities.

We would like to hear your views on the use of these draft Standards as part of an overall strategy to drive safe and effective residential services in Ireland and we would like to find out what you think of the Standards, for example:

- Do you think that all the areas you consider important are covered?
- Are the Standards and features clear and easy to understand?

## Content of Standards

### Layout and design

Please note that these are draft Standards for consultation. The final document will contain colour and images where suitable.

### Question 1: Is the language used clear?

#### *Please comment*

Overall it was felt to be difficult to give a clear response as there were varied needs of the IRN network members.

It was suggested that a list of terminology would be very helpful to explain the terms/ language HIQA should explore different ways of communication e.g. more pictures, symbols, braille for people who have sight issues, etc.

People need support to understand the pictures/symbols and have someone to explain what they mean. The IRN members propose that an integrated document is also produced with the easy to read, the simple text and the main text in one document. This would be a useful tool for support people to explain the standards.

The IRN members felt that HIQA could have come and explained it to people with intellectual disabilities how they will measure the standards.

It was strongly felt that every person with an intellectual disability should have a version of the standards suitable to their wishes, e.g. easy to read, DVD, etc.

The IRN members had particular difficulties in understanding the term “residential centre” and what did this mean, did it mean community house, group home and if so this was not clear to them. They also expressed concern at an approach that was based on a centre rather than an individual’s life. They felt that many aspects of the standards related to other areas of their life.

The IRN members were disappointed to see that the language has changed from the 2009 standards which talk about ‘individuals’ and instead here the standards talk about ‘people with disabilities’. We feel this categorises people with disabilities as different from other individuals.

The IRN members recommend that the final standards use the phrase ‘individuals’ or ‘individuals who use the services’ instead of ‘people with disabilities’.

In the plain English version, while the font is appropriate the language is complicated by including long sentences with multiple ideas and words that are difficult to understand (e.g., legalistic language, passive voice).

The IRN members suggest more visuals, explanations and examples are needed to help understand the meaning of the standards and how they will work in reality. This could include to developing a DVD with information on the final standards recorded in collaboration with people with intellectual disability using role play and specific concrete examples to explain the standards

**Question 2:** Is the layout of the Standards clear, easy to follow and easy to understand?

*Please comment*

See Question 1 above.

**Question 3:** Do you feel that the order and structure of the Standards is logical for residential services for people with disabilities?

*Please comment*

Some people did not fully understand this question. The language is not easy, would be better to use simple words.

### **Residential services – people with disabilities**

Safe and effective residential services are person-centred; effective; safe; promote health and development; have good leadership, governance and management; make good use of resources; have staff with the required skills, experience and competencies; and make good use of information.

**Question 4:** Do you feel that the Standards will drive improvement in residential services for people with disabilities?

*Please comment*

What kind of residential centres? Does it apply to group homes?

Overall, most people felt the standards would improve services by highlighting the faults in the services and by giving people goals to reach. They also felt that having a standard would make sure that things didn't slip. The funding would need to be available in order to drive improvement. It is also about attitude, if the right attitude is there that will help the drive for improvement.

Do the standards understand the importance of the support staff relationship with the person? We are concerned that this may be missing and wish to highlight the complexity involved. The IRN members propose that the person chooses the type of working relationship they have with support staff. The relationship with the support staff is very important for people and when they have staff leave for another job that there should be support for the person to manage the change of staff. It's a trust issue.

However some people expressed a concern that if their community house closed down they would have nowhere to live. They were therefore unsure what say they would have in this process and it caused them to question if the standards were a good thing if they were happy living where they were, for example what happened with some of the nursing homes. IRN members were also concerned about making sure that money was available to improve a community group home rather than close it

The IRN members were concerned about the need for the standards to look at what is actually happening in the persons home. There is concern that the standards will lead to a lot more paperwork. Going in to measure what is happening means lots of paperwork, every house is being asked to provide evidence of what is going on. Support staff are having to go on training – this is all to get ready for standards, support staff are on the computer and in the office doing paperwork and not able to spend as much time with the people they support. In some areas everything has to be recorded so each person has to carry around a book which records what they do each day – does this actually improve people’s lives? This also leads to a person’s right to privacy being violated because everything is being recorded.

How will HIQA measure do people feel they have the right to privacy? Privacy is very important to people – they want to be able to lock their door and have the key.

The IRN members said that the availability of support staff should not interfere with people having access to their home, for example when houses close at certain times like certain times of the day and holiday. Support staff have to be available for when you want to access your own home.

## Comprehensiveness

These Standards apply to residential services provided by private, public and voluntary bodies.

**Question 5:** Do you feel that all the important areas have been covered or are there any areas that should be included or excluded?

*Please comment*

Talking to people who are not living in a residential setting at the moment they said that the most important things that they would want to maintain if they had to move into a residential setting were:

- Privacy
- Choice
- Connection with family, friends and community

The IRN members are not sure if the standards properly address these areas especially the area of community involvement and relationships.

Some of the important areas that were highlighted are:

Involvement of people with intellectual disability in the recruitment of support staff. It was strongly felt that people should be involved in interviewing and choosing their support staff.

People wanted support staff to be able to listen and support them in their choices

Individual Person Centred Plans can be really useful but they cannot be too rigid. Each person should have a copy of their plan. It would be a good thing if this was checked.

The standards need to look at how people want to move forward in their life towards independence and living independently. This did not seem to be a strong element of the standards although it is part of the Disability Policy Review and the UN Convention on the Right to Choose where and with whom to live.

What about family involvement in conflict? If the family wanted something for the individual that the individual did not want how do we resolve this conflict?

What is good support? The IRN members suggest that HIQA come and talk to us about what is good support? Our group could tell HIQA about the research we are planning. It was suggested that the IRN and HIQA would link up and develop the recommendations together.

Is there a staff protection standard? If this is going to work there needs to be protection for everybody – individuals, support staff, etc. Support staff understanding and respecting a person's decisions. There is safety for the support staff in supporting a person to take certain risks, not always having to consult and ask staff can you do something. IRN members were concerned that the impact of the standards could lead to restrictive support rather than improving their lives.

People want flexible support staff but they cannot be available on call at all times, maybe have an explanation around flexibility. Support Staff contracts need to be developed around when they are needed. Is it around responsibility? It's about building a relationship and knowing the flexibility of that person.

## Applicability

These Standards are intended to be used in day-to-day practice to encourage consistent residential services in Ireland.

**Question 6:** Do you think these Standards are applicable to residential services for people with disabilities?

*Please comment*

Yes the standards are useful to make sure that people are supported well in their lives, please see previous comment re residential centres.

The word "consistent" raised concerns around it being too regimented. For example we had a discussion on what the term consistent meant in the context of: ***Is there milk in the fridge and how would this be interpreted in the standards?*** Whose responsibility would this be in a community house/ group home/"residential centre" and how would the standards apply. We all run out of milk at times on our own homes. Would it be assumed as staff responsibility or would it be understood as a shared responsibility within the house or an agreed responsibility?

Different houses have different practices – lesson is to learn best practice and then deliver that out. Give people the most home like situation, home should reflect the personalities of the people that live there not the support staff.

Person having the most power – but how do you measure that? Control & Power – that is the test that they should be using for the standards.

A very strong concern was around personal finance and having control over your own money and being consulted about charges, etc. People felt it was very important to know about financial charges being put on people's money in order to have power over your money. In most houses the money is locked away and the staff control the money. Some people are not allowed to have their own bank card. People generally do not know how much money they have in the bank or post office, they are given an allowance each day/week. Also not very obvious about what is a charge, what is a contribution? People need good support to have control over their money.

People have no information about the money coming into the service to support them and are not being consulted about how the money is being spent and the fact that it pays for the staff that support the person.

Value for Money Review Report – best value for the money that is given to services for each person. But the staff supporting the person also would need to know about the money each person is assigned in order to explain it to the person.

More choice

### Accessibility of Standards

It is intended that these Standards will be frequently referenced by residential services for people with disabilities.

**Question 7:** What do you think would be the most useful format for the Standards: hardcopy, electronic, audio, easy to read, symbols, Braille?

*Please comment*

See Question 1 above. It was strongly felt that all of the above formats should be available to people

Use of lamh and other means of communication to explain standards to people who use these forms of communication

The group also felt it would be good if there was someone from HIQA who would come talk to individuals who use the services about the standards.

A very good example of making information accessible is on the referenced link <http://www.idstilda.tcd.ie/>

Is there a place where it could be explained verbally?

IRN members were concerned about the absence of discussion with them on the standards.



## Specific feedback questions

In this section please provide your comments on the Standards and / or features. Two boxes are provided for your feedback: one is for your feedback on the Standards for children; one is for your feedback on the Standards for adults. Please complete either of the boxes, or, if you have comments on both the adults' and children's, please feel free to complete both boxes.

Please consider the following questions as part of your review:

- Is the language used in the Standards and features easy to understand?
- Can these Standards and features be applied within residential services?

### Theme 1: Child-centred services/Person-centred services

*Comments about Children's Standards. Please include Standard / feature number*

The IRN members are concerned at Children's and Adults Standards being together. We think the Children's Standards should be part of the General Children's Standards. Children need to be supervised and looked after. Adults with intellectual disability should not be treated the same as children – the standards should be separate.

*Comments about Adults' Standards. Please include Standard / feature number*

Standard 1.3.4: We felt that people should have an active say in all decisions about the service they receive. It is important that the standards mention the difference between being informed of changes and being involved in decision making regarding changes.

Standard 1.4.5: In relation to intimate relationships we were glad to see it mentioned in these standards but think that more needs to be said.....

e.g. people need support to build confidence, have a place to meet, education

Most importantly people need opportunities to have private space for intimacy with a partner where they live if they want this.

The 8 themes cover relevant areas.

However, it is not clear how control and decision-making is covered in the standards in terms of facilitation as well as assessment. Further clarity is needed on assessment of person-centred services and what are acceptable person-centred practices. There is empirical evidence that indicates that even if services have individual service plans and operate under "person-centred" directed principles, the person for whom the services are provided does not make decisions about them. We suggest we call them "person directed" principles instead.

What information do adults with disabilities have access to? What are the mechanisms to facilitate decision-making and how are they evaluated according to these standards? These need further clarification.

Training and recruitment of staff supporting people with intellectual disability should be influenced by the people with whom they are going to work. This could be also developed at the national level by groups of people with intellectual disability that could participate in developing guidelines for recruitment of support staff, participate in the recruitment, and training of support staff (for example, the Inclusive Research Network). For example, people with disabilities could participate in the recruitment process and training of staff. There are excellent best practice examples by the Galway Research into Action used in the Brothers of Charity Galway.

## Theme 2: Effective Services

*Comments about Children's Standards. Please include Standard / feature number*

*Comments about Adults' Standards. Please include Standard / feature number*

Yes I feel it is good we must remember that it is their "home" and all their needs are met

Standard 2.1.1: Everyone agreed that the first person to talk to about the person centred plan is the individual.

However, people thought the standards should also mention that where the individual can't speak for themselves support staff should talk to family, friends, old neighbours, social workers etc about what they know that can help develop the best plan for the person.

Standard 2.3: While everyone agreed that people should have a choice about where they live and the house that they move into, people also felt the standards should talk about the rights of the people already living in the house and what they think of the new admission.....people should be given notice if someone new is moving in, should have a chance to meet them in advance and should be able to discuss the admission before a final decision is reached.

People with intellectual disability decide how to make their house homely, for example decisions about decoration are made by all the people living in the same place.

Management of own medication is encouraged and people are trained and supported to manage their own medication.

Services should be accountable to people supported, for example house meetings and other accountability structures.

People should be part of the decision making process on use of resources to better achieve outcomes.

### **Theme 3: Safe Services**

*Comments about Children's Standards. Please include Standard / feature number*

*Comments about Adults' Standards. Please include Standard / feature number*

Standard 3.1: The group felt that where people need support with intimate care they should have a choice where at all possible in who provides this support.

People need sex education and stay safe programmes.

## Theme 4: Health and Development

*Comments about Children's Standards. Please include Standard / feature number*

*Comments about Adults' Standards. Please include Standard / feature number*

Standard 4.3: The group felt that where people can't take their own medication they should be included in taking their medication as much as possible and given explanations about the medication they take.

Also, the IRN members felt that not everyone on medication needs a nurse working in their home so they did not think that a nurse should have to administer all medication. Through other advocacy meetings we know that people with nursing care in the house pay a higher rate than those without nursing home and so putting in extra nursing support where it is not needed will cost individuals who use the services more.

Management of own medication is encouraged and people are trained and supported to manage their own medication.

People felt why was health & plans being put together? There is a danger of keeping people healthy as opposed to having a PCP about your life.

## **Theme 5: Leadership, Governance and Management**

*Comments about Children's Standards. Please include Standard / feature number*

*Comments about Adults' Standards. Please include Standard / feature number*

What information do adults with disabilities have access to? What are the mechanisms to facilitate decision-making and how are they evaluated according to these standards? These need further clarification.

## Theme 6: Use of Resources

*Comments about Children's Standards. Please include Standard / feature number*

*Comments about Adults' Standards. Please include Standard / feature number*

Standard 6.1: Individuals who use services should be involved in decisions about how resources are used. People in the group felt this is especially important when decisions about cuts are being made – people are usually told about what cuts are being made but not involved in the decision about what services are most important and what should be cut.

People also felt that it is important to note that people need different support at different times in their lives – sometimes people go through a hard time and need extra support for a little while. The standards should require the flexible use of resources to support this.

What information do adults with disabilities have access to? What are the mechanisms to facilitate decision-making and how are they evaluated according to these standards? These need further clarification.

People should be part of the decision making process on use of resources to better achieve outcomes.

## **Theme 7: Workforce**

*Comments about Children's Standards. Please include Standard / feature number*

*Comments about Adults' Standards. Please include Standard / feature number*

People in the group felt those individuals who use the service should be involved in staff selection (Standard 7.1) and also in staff appraisal (Standard 7.3). They felt that the best people to evaluate the support that staff provides are the people receiving that support.



## **Theme 8: Use of Information**

*Comments about Children's Standards. Please include Standard / feature number*

*Comments about Adults' Standards. Please include Standard / feature number*

People felt that privacy was very important and are concerned that the standards might increase the risk to privacy with the additional paperwork requirements.

**Are there any other general comments you would like to make? Please feel free to use additional space or continue on a separate page.**

**People need to choose who they live with.**

All people are equal

People being involved in decisions about their supports, services. But what does this actually mean? There should be changes after people have been involved towards having meaningful involvement leading to outcomes. HIQA should be able to trace the changes.

There needs to be more examples about what the standards will actually mean in peoples day to day lives.

The IRN members felt that there should be more reference to family and friends and according to the persons choice.

Not everyone with a disability (any disability) needs " Care" The word support should be used instead

What about taking some risks? Everyone takes risks everyday. Everyone makes mistakes and this is normal.

Do people who are non-verbal get their rights?

Individual Plans should come at the top with Quality of Life

The IRN Members had particular difficulties in understanding the term residential centre and what did this mean, did it mean community house, group home and if so this was not clear to them. They also expressed concern at an approach that was based on a centre rather than an individual's life. They felt that many aspects of the standards related to other areas of their life.

## **Thank you for taking the time to give us your views on the *Draft National Standards for Residential Centres for People with Disabilities***

Please return your form to us either by email or post.



You can download a feedback form at [www.hiqa.ie](http://www.hiqa.ie) and email the completed form to [consultation@hiqa.ie](mailto:consultation@hiqa.ie).



You can print off a feedback form and post the completed form to:

Health Information and Quality Authority,  
National Standards for Residential Centres –  
People with Disabilities,  
George's Court,  
George's Lane,  
Smithfield,  
Dublin 7



If you have any questions on this document, you can contact the consultation team by calling (01) 8147634.

**Please return your form to us either by email or post before 5pm on  
21 November 2012**

Please note that the Authority is subject to the Freedom of Information (FOI) Acts and the statutory Code of Practice regarding FOI.

Following the consultation, we will publish a paper summarising the responses received. For that reason, it would be helpful if you could explain to us if you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances.