

# **WHAT NOW... WHERE NEXT?**

## **PART C**

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**HOW THINGS MIGHT BE — WHAT  
YOU SHOULD EXPECT FROM  
RESIDENTIAL SERVICES**

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# WHAT YOU SHOULD EXPECT FROM RESIDENTIAL SERVICES?

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In recent years HIQA (Health Information Quality Authority, see Appendix 3) prepared standards for residential care for adults with disabilities called *National Quality Standards: Residential Services for People with Disabilities*. At present, they are not mandatory. That is, service providers are not required by law to adhere to them. However, they are an example of what you might reasonably expect from a residential centre. They consist of nineteen standards which must be adhered to. Each standard has a number of criteria which must be met exactly as stated in the Standards or in some other satisfactory way. The decision as to what "other way" is satisfactory will be made by the inspectors when they begin inspections.

The information below is based on the HIQA standards. It concentrates on certain areas of the Standards, in particular, those areas which would most apply to people with intellectual disability and/or autism. While we list the 19 Standards without their criteria in Appendix 3, to get the full picture you should look at the full Standards document at [www.npsa.ie](http://www.npsa.ie).

In the Standards they refer to the person with a disability as the "individual". In the case of someone who might have limited capacity to make decisions for themselves the word

individual can be interpreted as his/her parents, other family members or carers. Throughout this document, when we refer to the "individual" or your "family member" it should be interpreted in that way.

## WHAT YOU SHOULD EXPECT FROM RESIDENTIAL SERVICES? - IN BRIEF

Below we give a brief overview of what you should expect from your family member's residential service. In Section B we'll go into more detail.

**When your family member gets a residential placement you should expect certain things from the service provider:**

### 1. **First you should expect documentation.**

That is, the first thing you should expect is to be given a folder or a booklet which describes what services the provider supplies. This should enable you to be clear about what your son or daughter is being offered. This document should list the terms and conditions of the placement. It should deal with your family member's

accommodation rights, how the service handles complaints and how it handles behaviour issues.

## 2. Health Issues

Your family member should be encouraged to live a healthy lifestyle. Service users should be encouraged to eat a balanced diet. You should expect the staff to encourage activities that involve healthy and enjoyable exercise. Also, the staff should be conscious that your family member has the right to attend a GP of his/her choice and to have regular medical checkups.

## 3. Staff issues

If a service user is to be happy in his/her home it is important to have committed staff. You should expect all staff to be properly trained, to be clear about their duties, to communicate with all the service users and to be supervised properly. Also, you should expect the staff to work with you in a positive way to ensure your family member's happiness.

## 4. Activities and involvement of your family member

Your family member should be encouraged to be part of society in every way possible. He/she should be encouraged to pursue educational opportunities, be members of clubs, go to social events and take as many social roles as possible. Your family member should also be encouraged to be an

active citizen, observe his/her religious beliefs and travel in and outside this country.

## 5. Caring for your family member's money

NOTE: Standard 7 of the HIQA Standards deals with the individual's money. It states that "*Each individual exercises control over personal finances and is protected from financial abuse and exploitation*". It is worth remembering, the "individual", depending on the circumstances, can mean the individual's family.

The individual has the right to control his/her own finances. For most people reading this it seems very simple. That is, if the individual lacks the capacity to control their own finances then the parents or the siblings will assist. However, it must be borne in mind that, in some cases, as the individual gets older, his/her parents die and his/her siblings are also getting old. So who helps the person to control their own finances? The Standards clearly state in this case, and other cases, the individual must be facilitated to access an independent advocate of his/her choice.

## 6. Personal Plan

Standard 8 of the HIQA Standards deals with the individual's Personal Plan. This section is disappointing in so far as the terms Person Centred or Person Centred Planning are not used. However, it is clear that the personal plan must be comprehensive.

## WHAT YOU SHOULD EXPECT FROM RESIDENTIAL SERVICES? - IN DETAIL

Below we give a more detailed list of what you should expect from your family member's residential service. The section numbers correspond with those above.

### 1. First you should expect documentation.

According to the HIQA Standards this documentation should include the following:

- i. The terms and conditions of your family member's placement should be stated clearly:
  - a. There should be a clear statement whether any charges are applied for services, what the charges cover and whether particular supports are only available on payment of extra charges.
  - b. It should say clearly what the service provider is agreeing to provide.
  - c. It should also state the rights, obligations and liability of your family member, where relevant.
  - d. It should confirm that your family member has a right:
    - to enjoy the security of a permanent home and not be required to leave against his/her wishes unless there are compelling reasons for the move. It should be made clear what a "compelling reason" might be, this might be illustrated with examples.

However, such examples might not cover every case.

- If, in the opinion of the service provider, there were "compelling reasons", it should state that you and your family member would be consulted in advance of such a move and should expect to be in a position to negotiate an alternative appropriate placement.
  - This section would also apply to your family member being asked to leave on a temporary basis for the convenience of staff.
- ii. There should be a statement that:
    - your family member should have a bedroom to him/herself unless he/she wishes to share;
    - your family member should be allowed to stay in the residential service if not well enough to go out, unless he/she chooses otherwise.
  - iii. There should be a complaints procedure/policy:

This policy should make it clear that there is a culture of openness and transparency that welcomes feedback, the raising of issues and the making of suggestions and complaints by individuals. It should be clear that such complaints are seen by the service provider as a valuable source of

information and would be used to make improvements in the service provided.

iv. Special Note – Behaviour Issues:

It should be clear that staff are trained to understand behaviour that indicates an issue of concern or complaint that your family member cannot communicate by other means. Such messages should receive the same positive response as issues of concern and complaints raised by other means. This means that if your family member exhibited challenging behaviour you could expect the service to understand that such behaviour is a form of communication. You should also expect that the service would do everything possible to understand the reason for such negative communication and try to put a programme in place to address the issues causing the behaviour.

**While the documentation mentioned above is most important for your family member HIQA Standards covers a wide range of other areas:**

## 2. Health Issues

- i. Your family member should be encouraged by the service provider to access appropriate health information and education, both within the residential service and in the local community, in all areas relevant to his/her life including:
  - diet and nutrition
  - recreation, interests and activities

- smoking, alcohol and other drug consumption
- exercise and physical activity
- sexual relationships and sexual health.

- ii. This positive attitude towards health should be reflected in the activities that take place and also in the approach to diet. In other words, you should expect that your family member would be encouraged to take regular exercise and to eat a healthy diet. You should be surprised if they are given a lot of “fast food” or if they take no exercise other than walking to and from the mini-bus door.
- iii. Your family member should be registered with and facilitated to attend the general practitioner of his/her choice.
- iv. Your family member’s medical, dental and other health needs should be assessed at least annually, or more frequently, in accordance with his/her needs and wishes.

## 3. Staff issues

- i. Job descriptions for staff who provide support to individuals should state the requirement that staff establish and maintain relationships with their customers that are based on respect and equality and that promote their independence.
- ii. All staff should:
  - communicate effectively with your family member

- listen and respond to your family member
  - make information accessible to your family member.
- iii. The service provider should try to ensure that the support given is consistent and that good relationships always exist. They must do this by:
- Having clear strategies for the retention of staff,
  - Management should ensure there is sufficient staffing levels to avoid excessive use of casual, short-term, temporary and agency workers.
- iv. All staff should receive appropriate and regular supervision.
- v. Staff should be trained when they start work with your family member's place of residence. There should also be continuing training and an annual appraisal programme to ensure that those working with individuals retain competence in all areas including:
- meeting the changing support needs of your family member
  - fulfilling the aims and philosophies of the service provider organisation
  - understanding and adhering to the policies and procedures of the service provider organisation and those of their professional or regulatory body
  - understanding their personal and professional responsibility for the safety and welfare of your family members.
- vi. Staff should work in partnership with you to promote the safety and well being of

your family member, this must be in accordance with the wishes of your family member.

- vii. Staff should consult with you and other members of the family, with the informed consent of your family member, in order to learn how best to support him/her to manage his/her behaviour.
- viii. The person-in-charge should have the responsibility to ensure that your family member is informed of day-to-day arrangements in the residential services, such as, which staff are on duty and whether any arrangements are subject to change.

#### **4. Activities and involvement of your family member**

- i. Your family member should be facilitated and encouraged, where he/she so wishes, to:
- express his/her views and opinions;
  - access community-based facilities. That might be, for example, join clubs, go to social events, go to the cinema etc.;
  - observe his/her religious beliefs and practices;
  - take responsibility for his/her own financial affairs (see 5 below);
- ii. Individuals of all ages should be encouraged and facilitated to pursue educational opportunities, meaningful activity or employment that suits their needs and preferences.
- iii. Your family member should be encouraged and supported to become, or

to continue to be, an equal and active citizen through involvement in community groups and activities, in accordance with his/her wishes

- iv. Your family member should have opportunities and support to participate in individual and/or communal recreational activities within the residential service and in the community, either with, or independent of, others living in the house.
- v. Your family member should be able to avail of opportunities to travel inside and outside the country.
- vi. Your family member should be facilitated to maintain social roles occupied prior to admission and should be encouraged to develop other social roles. (see Part B on Social Roles)

## 5. Caring for your family member's money

- i. The individual should have easy access to personal monies and should spend it in accordance with his/her wishes.
- ii. The individual has the right to control their own finances.
- iii. Where the individual requires assistance to manage his/her financial affairs, he/she can nominate the person to be entrusted with this responsibility. That person must keep an account of all monies spent. It's worth noting that if the person nominated is a member of staff, he/ she must account to the person-in-charge as well as the

individual (again, "individual" means the family if the individual has not the ability to manage his/her own money).

- iv. The individual should be able to avail of facilities for the safe storage of his/her money and valuables.
- v. Records and receipts of possessions handed over for, or withdrawn from, safekeeping should be kept up to date.

NOTE: See below for how an individual's money should be spent.

## 6. Personal Plan

The individual's personal plan should outline his/her wishes and aspirations and the support to be provided to realise his/her personal goals.

The personal plan:

- i. Should take account of the individual's assessment of his/her abilities, skills and needs (again, in the case of "individuals" with intellectual disability and/or autism, the parents should be consulted)
- ii. Should be carried out with appropriate professional assistance, if required and requested by the individual
- iii. There should be one single complete plan. For that reason it should also take into account any formal assessment carried out on the individual's behalf under the Disability Act 2005 or otherwise, and other specific plans such as health plans, risk

- management plans, intimate support plans, in order to ensure that there is a single integrated plan.
- iv. The plan should outline the services and supports to be provided to the individual to achieve a good quality of life and to assist him/her to realise his/her goals including:
- health services
  - education, life-long learning and employment support services
  - social services
  - transport services
  - assistive devices and technologies.
- vi. The personal plan should take account of, and record, the individual's wishes in relation to where he/she wants to live and with whom. This is quite a radical concept at the present time where many people regard getting any residential placement as being an achievement. This introduces the idea of people having choices in their accommodation.
- vii. There should be a key worker appointed whose primary responsibilities are to assist the individual, in accordance with his/her wishes, in developing his/her personal plan and to oversee its implementation. The interesting thing about this clause is that it refers to the fact that the key worker should be "chosen by the individual". This is a big change from what most people would be used to.
- viii. The key worker must ensure that the planning process is conducted in a manner that ensures the maximum participation of the individual.
- ix. The individual should retain possession of his/her personal plan. Its content should be shared with support staff, other professionals, relatives and friends in accordance with the individual's interests, wishes and informed consent.
- x. The individual's personal plan should be developed at the earliest opportunity, if possible, before admission to the residential service, and should influence the agreement reached with the service provider.
- xi. The individual's personal plan should be reviewed at least every six months to reflect changes in circumstances and preferences.
- xii. The individual should participate in the review of his/her plan and decide on any changes to it, with advice and assistance of other participants, if required.