

**Submission on HIQA's
Draft National Standards
for Residential Centres
for People with
Disabilities**

November 2012

Submission of the Irish Human Rights Commission to the Health Information and Quality Authority on the Draft National Standards for Residential Centres for People with Disabilities

1. Introduction

The Irish Human Rights Commission (IHRC) has a statutory remit under the Human Rights Commission Act, 2000 to endeavour to ensure that the human rights of all persons in the State are fully realised and protected. The IHRC seeks to ensure that Irish law and practice reflects best international practice in the area of human rights. To this end its functions include, keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of human rights, and making such recommendations to the Government as it deems appropriate in relation to the measures the IHRC considers should be taken to strengthen, protect and uphold human rights in the State.

In the present instance, the Health Information and Quality Authority (HIQA) has requested commentary on its Draft National Standards for Residential Centres for People with Disabilities (draft HIQA Standards). The IHRC welcomes the publication of the draft HIQA Standards, which set out a number of important principles in great clarity and detail. The IHRC's comments on the draft Standards narrowly focus on the Draft Standards on Children. The commentary made on these Standards should, unless child-specific, also be taken as recommended for inclusion in the standards on adults. In the main the Standards address and uphold international and human rights standards. The present submission seeks to identify discrete areas where the standards may be strengthened.

2. International Standards

Three international instruments are of primary relevance to the draft HIQA Standards. These are the UN Convention on the Rights of Persons with Disabilities (CRPD), which Ireland signed on 30 March 2007, but has not yet ratified, the UN Convention on the Rights of the Child (CRC) and the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), both ratified by the State.

The application of these international standards to persons with intellectual disabilities in a day care, residential and respite centre was considered by the IHRC in its 2010 Enquiry report entitled *Report on the Human Rights Issues Arising from the Operation of a Residential and Day Care Centre for Persons with a Severe to Profound Intellectual Disability*. The recommendations of that enquiry inform this submission, in particular the deficits in residential centres for persons with disabilities identified and the accountability mechanisms recommended, including HIQA oversight. In this regard, the IHRC has since early 2010 called on the State to commence the relevant provisions of the Health Act 2007.

3. Introduction to Standards

The Introduction section includes reference to the rights of the person which underpin the standards which is very much welcomed. This section could be strengthened by explicitly stating that the purpose of the Standards includes ensuring that residents of centres benefit from the rights set out in the CRPD. The inclusion of this reference in the Standards would allow for the Standards to be informed by the developing international interpretation of the rights in the CRPD by the UN Committee on the Rights of Persons with Disabilities.

4. Principles informing the Draft National Standards for Children with Disabilities and Principles informing the Draft National Standards for Adults with Disabilities

These sections (p.7) could benefit from the inclusion of a statement that the principles are also to promote the active participation of all residents and that in addition the principles are also designed to promote advocacy for those residents – whether children or adults – who have an intellectual disability. Such inclusions will, it is submitted, harmonise with the principle of promoting integration with the community and social networks.

5. Standards

While appreciating the point made (pp 10-11) that not all Standards will be regulatory and are designed to lead to continuous improvement, the IHRC would suggest that if the standards are established pursuant to the requirements of the CRPD, those standards should be binding on service providers. This would assist in clarifying the obligations that flow from such standards (being standards rather than mere recommendations) and assist HIQA in its regulatory and compliance role.

6. Standards for Children:

Theme 1 – Child-centred Services

This theme correctly identifies a child-centred approach to standards as being central to service delivery. This picks up on the key themes of both the CRC and the CRPD.

We recommend that a new paragraph be inserted after paragraph three to state that residential centres are not places of detention and that accordingly children have the right of freedom of movement within and from the residential centre. Therefore locked doors, restriction to certain rooms (apart from other bedrooms), curfews etc. should be avoided unless the organisation's risk policy identifies certain areas as unsafe, or an individual care plan identifies restrictions on movement as necessary given the age and vulnerability of the child.

This recommendation is made to impress on residential care workers that the residential centre is the child's home and not a place where their movements

should be excessively controlled as in an institution; that while children who are resident may not be allowed at certain times of day or night to leave the home for safety, homework or other care plan reasons, the presumption is that they are to be treated like other children living at home during the week and at weekends in order to respect the rights in the CRC and CRPD including the rights to rest and leisure, to engage in play and recreational activities and to participate freely in cultural life and the arts (Article 31 of the CRC).

Standard 1.1

The emphasis on human rights and equality is welcomed and could be slightly strengthened.

Thus in 1.1.1 there could also be reference to the rights of children as enshrined in other human rights conventions (this would cover the European Convention on Human Rights whose observance is now a statutory duty under the European Convention on Human Rights Act 2003 and the International Covenant on Economic, Social and Cultural Rights ratified by the State (which includes provisions on the rights of the child and persons with disabilities to health, education etc.).

Further, the equality grounds enumerated in paragraph 1.1.2 could be extended to include civil status and family status which are also set out in the Equal Status Acts 2000- 2011. Further, it could include "other status" which is a requirement of international human rights standards.

Otherwise Standard 1 is well crafted and places the child at the centre of decision making.

Theme 2 Effective Services

One of the main recommendations of the IHRC's 2010 enquiry report was that disability services for persons in day care, residential and respite centres should be re-framed from a top-down global costing basis to a system based on individualised assessments informing service needs in a community living model. Under this proposal, the Day Services component should be informed by individualised need assessments and that a person centred outcome programme for the individuals concerned would be put in place and monitored. It was recommended that such a system would inform a national average costings mechanism as recommended in the report.

To be successfully rolled out, it was suggested that a communication model between service providers and the families of individuals with a severe to profound intellectual disability in such residential centres should be put in place.

In this regard Standard 2 is very much to be welcomed with its emphasis on personal plans for children drawn up in consultation with children and their families, reviewed and modified at least annually with the appointment of a key worker.

While this Standard reads well, the IHRC would draw attention to its experience when conducting the above mentioned enquiry. While most care plans (for the adult residents) were properly set out and recorded with the consultation of families involved, any dependence on budget rendered many of the planned outcomes unfeasible. This conditionality of outcomes meant that, faced with funding cuts and State failure to provide adequate core service funding, the charity involved did not have the means of delivering on the personal plan outcomes for many of the individuals. Thus while a daily walk around the centre may have been feasible, a trip to town at the weekend may not where cost (bus service, available staff, cost of activities in town) may have proved prohibitive.

Thus the IHRC would recommend that further thought be given to how this Standard might be met as otherwise successive year on year personal plans for a child may inevitably be reduced from the person's needs to a situation corresponding to the ability of the service provider to provide the need.

Clearly the link with funding based on needs is key but also key is the ability to provide a service which meets the child's actual well-being, health, education and psycho-social needs (before discussing civil and political rights).

Allied with the above, the IHRC would recommend that reference to an individual advocate's involvement in devising the personal plan should be included. As the key worker is usually an employee of the centre, the advocate should be a personal advocate of the child (which could be the child's parent(s) or relative), and would provide an independent input into the planning.

Specifically the IHRC recommends that Standard 2.1.7 be amended to insert in the content of each child's personal plan reference to the commitment to realise (progressively¹) the child's needs and aspirations.

Theme 3: Safe Services

This important standard could be strengthened by including reference to protection from all forms of physical or mental violence, injury, negligent treatment, maltreatment or exploitation.

In this regard, Article 19(1) of the CRC provides "States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from **all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation**, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child" (emphasis added).

¹ See the requirement of "progressive realisation of rights" enshrined in the International Covenant on Economic, Social and Cultural Rights.

Theme 4: Health and Development

This theme is welcome with its emphasis on health and development (Article 6 of the CRC) enhanced through provision of accessible services based on need, early intervention and narrowing the gap in health outcome.

The IHRC recommends that a clear statement be inserted on the child's enjoyment of available, accessible, acceptable and quality healthcare ("the AAAAQs") as required under Article 12 of the International Covenant on Economic, Social and Cultural Rights. The AAAAQs seek to address the social determinants of health and focus on guarding against discrimination and narrowing the health outcomes between groups such as persons with disabilities and the general population.

Specifically in relation to Standard 4.3.1, the IHRC recommends the insertion of the words "and which emphasise the consent of the child (or their guardian)" after the reference to best practice guidelines. No doubt the guidelines will have consent as a core principle but asserting this fundamental human rights point separately is recommended.

Theme 5: Leadership, Governance and Management

This theme refers to governance in residential centres. The IHRC again refers back to the main recommendation of its Enquiry report and recommends that this concern as to funding protocols in service agreements for management of budgets be addressed. The "cascade down" effect of budget allocation from central government, through the HSE to private service providers does not involve assessment of the needs or aspirations of the child or adult with disabilities. To do this a "bottom up" approach would be required. While this is recognised to be a matter beyond the remit of HIQA, nonetheless HIQA's remit to supervise, monitor and enforce quality National Standards will, it is submitted, be put at risk unless governance issues are addressed in this section.

In an attempt to introduce the concept of smart "bottom up" planning, budgeting and ensuring services reach the individuals in centres, the IHRC recommends the insertion of a new paragraph under Theme 5 to read:

"Effective leadership and management is exercised by negotiating funding protocols and agreements based on the assessed needs and aspirations of the children resident in the centre as informed by their personal plans".

One of the matters raised during the IHRC's enquiry was the fact that the need to divert the charity's resources to high-risk individuals resident in the centre through a "wrap-around" 24/7 service to meet, *inter alia*, health and safety protocols, resulted in reduced funding for other services (including individual plans). To mitigate such situations arising it is recommended that the following be inserted below Standard 5.2.24:

“Risk management protocols will ensure that resources to address immediate risks (such as a risk of harm to other residents) are managed in such a manner as to ensure that the services for residents needs and aspirations do not fall below a minimum identified “floor” of services which would offend the basic dignity, respect and rights owing to all the residents of the centre”.

7. Standards for Adults

Due to resource constraints, the IHRC is unable to provide commentary on these Standards. Its recommendations on the aforementioned Child Standards are, unless child-specific, also recommended for inclusion in the standards on adults.

8. Conclusion

The IHRC welcomes these draft National Standards for Residential Centres for People with Disabilities. In order to ensure the State’s full compliance with the relevant international human rights instruments, the above recommendations have been made to strengthen the Standards to ensure the utmost protection of the rights of the child/young person and the IHRC is hopeful that they will assist in the further development of these welcome standards.

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