Citizens Information Board
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Draft National Standards for Residential Centres for People with Disabilities

Submission by the Citizens Information Board

1. Introduction

The Citizens Information Board (CIB) welcomes the opportunity to make a submission on the Draft National Standards for Residential Centres for People with Disabilities. This is further to our 2008 Submission on the previous Draft Standards. The CIB has direct and ongoing experience of the difficulties and challenges faced by people with disabilities from its involvement in delivering the National Advocacy Service (NAS). The NAS provides independent, representative advocacy for vulnerable people with disabilities, including those in residential centres.

The CIB welcomes these revised Draft National Standards as another important milestone in addressing many of the issues that have been identified over the years in relation to people with disabilities in long-term residential settings. The Board also welcomes the fact that, while making specific provisions for children, the Draft Standards integrate provisions for adults and for children in the one document. This is important given that many service providers deliver services to both adults and children.

This submission restates the CIB view that, while provision for and implementation of minimum standards is a crucial component in ensuring that care and support is of the best quality possible, the primary focus in residential services should be on maximising choice and promoting social inclusion for people whose actual home is the residential centre. Standards should thus focus on supporting choice, control, and participation as well as on managing vulnerability, risk and dependency.

The finalisation of these standards will help to ensure a much needed stronger support system for people with disabilities in residential centres and their implementation will supplement the various initiatives taken to date under the National Disability Strategy. Putting these standards on a statutory footing with provision for registration and mandatory inspection will be crucial.

This submission contains four sections. Firstly, some general observations are made on the document with particular reference to the requirements of a rights approach as well as the role of advocates. The second section makes comments and suggestions on the Introductory Section in the document. Comments are made on specific standards and provisions for adults next and, finally, some general comments are made on the standards and provisions for children.

2. General Comments

The changes in relation to terminology and lay-out from the previous Standards document provide a more extensive listing of standards components. The replacement of the 7 sections by 8 themes is helpful. However, what is less clear is the merit of replacing the term ‘criteria’ with that of ‘features'. While the implied emphasis is on different ways on how the centre may meet each Standard, it would probably be more effective to make this much more explicit for service providers, e.g., how do staff know whether or not the centre is meeting a specific Standard. Also, there would be merit in including more cross-referencing between different standards and ‘features’. This would assist both centre staff and managers in navigating their way through what by its nature a very complex document.

While putting the resident rather than the service provider at the centre is a key implied underlying principle of the Standards, there is little evidence of the voice of residents coming through the document. There is also the question as to whether the resources available are commensurate with the implementation of an extensive set of standards. This suggests a need for some system of prioritisation over and above what will be required by regulation. Otherwise, there may be a danger that many of the Standards will be dependent on how each service provider prioritises the implementation within their own tight budgetary requirements. This would significantly undermine the concept of uniform national standards. Ideally, there is a need for more work on developing a system of auditing by service providers in relation to how well they are meeting each ‘feature’ of each Standard. This raises significant logistical and resource questions.

An important question arises as to the extent the voice of residents has been captured and reflected in the Standards document. This is particularly relevant in respect of those with whom there is typically relatively little consultation, i.e., those with more profound or severe disabilities.

The Standards is a relatively lengthy document. A question arises as to whether the standards relating to matters such as ‘management’, ‘use of resources’ and ‘record-keeping’ might be better set out as a separate inclusive section to cover both adults and children.

The Standards are extensive and cover a wide range of daily living, organisational and administrative matters and this is very welcome. However, there are some gaps. Overall, there would appear to be insufficient attention given to people with reduced/ lack of capacity and how their participation can be optimised in terms of core concepts such as choice and individual planning and the safeguards required to ensure that their needs are fully met. Neither is there enough emphasis on people with deteriorating conditions such as age-related dementia. Provisions for end-of-life care lack sufficient detail.

There is no standard relating to what charges in residential services cover (referred to in the legislation as 'charges for in-patient services'), what constitutes 'extras' and what the responsibility of the resident is in this regard. This is a particularly important area given the increased budgetary pressure on all service providers.

There is a need for a Standard around managing conflict– whether between residents, between a resident and staff, resident and family members and about options for appeal where a resident or his/her family disagrees with management decisions, e.g., in respect of where or with whom a person is to live.

A Rights Approach

The Standards document makes a number of references to rights in relation to both children and adults. These include the promotion and upholding of equal rights of children and adults with disabilities in accordance with the provisions of the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child as well as the rights enshrined in Irish law. The need for residents to be well informed of their rights and supported in exercising their rights is stated as is the need to facilitate residents in accessing advocacy services, legal representation and court personnel, where appropriate.

The Standards fall short, however, in that there is little reference to the more proactive aspects of rights provisions. These include social inclusion, capability development, maximising individual potential, access to leisure and cultural activities, equality of status and due recognition as citizens. These are significant omissions in the Standards. The primary emphasis in the Standards may, therefore, be on a safeguarding and protectionist approach which, though essential, is limited in that it fails to give due cognisance to factors such as capacity building and enhancing participation in mainstream community living.

The Standards make no reference to the role and operation of Rights Committees which have been established by a number of service providers in keeping with the Personal Outcomes model of service delivery used.

The Role of Advocates

The Standards reflect a general acknowledgement that people with a disability in residential services are vulnerable, not only because of their needs, but also because historically the system of service provision has tended to be based on a dependency model rather than on an approach that maximizes choice and independence. There are multiple references in the Standards to the role of advocacy and the need to make provision for residents to have access to independent advocates *(1.5.4,* 1.6, 1.6.4 and 1.7.3 in relation to children and 1.5.5, 1.6, 1.6.3, 1.6.5 and 1.7.3 in relation to adults).

Clearly, there would need to be a significant increase in the number of advocates if the provision of advocacy as implied in the Standards were to happen. The 2011 National Intellectual Disability Database shows that there were 8,214 people with an intellectual disability in receipt of full-time residential services.[1] There were 823 people registered on the 2011 National Physical and Sensory Database as availing of residential services.

In some cases the Standards provide for an advocate to assist people to communicate. While such assistance is sometimes necessary, it may not need to be done by an advocate. It is clear that access to independent advocacy services for people in residential services needs to be strengthened. It is also necessary that the role be clarified. Since there is a significant resource issue here, there is a need for further exploration as to how the advocacy support role for people with disabilities in residential settings might be developed and a need for a number of models to be put in place.

Standards should make reference to other forms of advocacy both within the residential service and external to the service. Features should include rights review and/or resident representative committees and engagement with other external advocacy supports, such as Parents and Friends or volunteer groups. Where serious issues arise for an individual, advocates from the National Advocacy Service could be called in to address them.

The finalisation of the standards provides a good opportunity for service providers to consider how access to advocacy support for people in residential services can be strengthened and enhanced to ensure that every person is supported according to his/her needs.

3. Comments on the Introductory Section

Page 8: There is a need for a clearer statement as to what constitutes a designated centre for purposes of the Standards and about what type of services and what type of occupancy are covered by the Standards and the accommodation that would be subject to inspection by HIQA.

Are all stand-alone houses or clusters of houses managed by one service provider to be included? This is particularly important in ensuring that there is an appropriate distinction between people who manage and have responsibility for their own homes, whether ‘supported community living’ or other independent living accommodation, and accommodation managed by a service provider. There is a need for greater clarity as to how and whether the standards apply in situations where people have

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[1] It should be noted that almost two-thirds of those with intellectual disabilities (17,916 individuals) lived at home with parents, relatives, or foster parents. This figure does not take account of those in the mild intellectual disability category living at home/independently without supports or services.

their own tenancies which is a growing trend in keeping with the concept of independent living in the community.

Pages 9 -10: While the themes as set out are broad -ranging, they do not give sufficient cognisance to how the voice of the residents is to be respected and channelled which is a core component of the UN Convention on the Rights of Persons with Disabilities. Also, the themes do not include any reference to enhancing and supporting a caring, nurturing and supportive home environment for residents. This is a significant omission.

Page 11: There is a need for much greater clarity as to what are the 'regulations' and the 'regulatory standards' referred to and whether these have been developed and, if so, where they are to be found. Service providers need clarity in this area and should have an opportunity to comment on the regulations before they are finalised. Otherwise, there may be a real danger of default and consequent closure or a system where centres are allowed to continue to operate even though they do not comply with the regulations.

3. Comments on the Adult Section

Page 62: The term 'Each person' is not appropriate in 2.5 in that not all people with disabilities may need respite services.

Standard 1.1

There should be more reference in this Standard to the provision of respectful support to people who have limited capacity to make decisions and an additional feature should be included accordingly.

Page 66: 1.1.2 should be amended to: 'take responsibility for their own financial affairs **with assistance as necessary'**.

Standard 1.2

There is a need for some reference as to how necessary hygiene standards are to be maintained where there is a divergence of view between staff and residents.

Page 67: 1.2.1 should be amended since 'expressed permission' will not be possible in all cases. A key question here is how this is to be dealt with where a person cannot communicate an opinion verbally or otherwise.

Page 69:

1.3.2 The meaning here is not clear and requires some re-wording.

1.3.4 **"where they wish"** should be added

1.3.7 There needs to be an acknowledgement that some people may wish to do so but may not be able because of functional or other difficulties.

Page 71: 1.4.4 It would be useful to specify, e.g., phone, computer and Skype

1.4.5 “**where this is their wish”** needs to be added here.

Page 72/Standard 1.5

Reference should be made to “a number of formats” so that people can choose how they want to access information. There should also be provision for a person to nominate a representative to deal with information on his/her behalf if s/he does not wish to engage with it directly.

1.5.5: There is a danger that the role of the advocate may be seen as just one of facilitating communication – this function can be carried out by other people, e.g., key support workers or relatives. The broader role of the advocate needs to be understood by service providers.

Page 73/*Standard 1.6*

There is a need for some reference to situations where there is a conflict of view between staff and the individual and provision for residents to query centre decisions affecting them.

1.6.3: This is probably not necessary here as it is stating the obvious and not meaningful as a ‘feature’.

Page 74/*Standard 1.7*

The Complaints system as set out is very focused on procedures from a service provider perspective. What is more important is what a resident who has a complaint should do and who s/he should contact. Many people in residential centres say may feel they cannot complain directly because they are too dependent on staff. In particular, there is probably little likelihood of children with significant disabilities being able to engage in the type of complaints procedure set out.
Two options would help:

(a) A Designated Person in the centre to whom complaints could be made on a confidential basis.

(b) A Complaints Adjudicator within HIQA with his/her name and contact phone number displayed prominently in every centre. (Such a mechanism would also be beneficial to relatives and advocates).

In any case, there is a clear need for a user-friendly mechanism to enable residents to have easy access to ways of reporting a concern to an outside agency.

Page 75/Theme 2: Effective Services

Some reference should be made to the need for service providers to ensure that there is continuity of staffing/key support person for each individual given the fact that staff changes arising from retirement, people changing jobs and people taking maternity and other leave, may have a negative impact on some individuals if planning is not made for some transitions.

Page 76

2.1.3 “**Where a person cannot express wishes, the views of significant others about their preferences should be taken into account”** should be added as an additional ‘feature’.

The reference to end-of-life care needs to be stronger. When it comes to end-of-life care, the needs of people with disabilities are no different to those of the general population. This means that the person has choices, receives end-of-life care that is appropriate to his/her needs and wishes, and that every effort is made to optimise his/her quality of life by providing the best possible care to the end. The Standards should seek to ensure that there is access to high quality end-of-life care.

Page 77

2.1.8 Provision should be made here for situations where a person is unable to engage as distinct from declining to engage.

2.1.9 This ‘feature’ would be better located as 2.1.1

Page 79

2.2.14 This ‘feature’ should have higher priority in the list. Also, there should be a separate ‘feature’ on heating – lack of sufficient heat is a common complaint to NAS advocates

2.2.16 and 2.2.17 might be more appropriately located under Theme 5, *Leadership, Governance and Management*.

Standard 2.3

There appears to be insufficient attention given to: (a) the situation of residents who are reluctant to move; (b) those who feel that they have no alternative but to live in the centre; and (c) those who may wish to leave but for whom this option causes concerns for their safety and well-being.

Page 82/Standard 2.4

Standard 2.4 focuses on young adults. However, there is a need to cater for the requirements of all transitions – transitions can be out of congregated settings; to hospital, to nursing homes or dementia services. This is particularly important if the recommendations of the *Time to Move On* Report are to be implemented.

Also, some reference needs to be made in this Standard to the need for a key support staff person to support the person during and after the transition.

Page 83

2.5.5 should be put first and 2.5.1 appears to be somewhat superfluous.

There should also be some reference to the need for contact between centre staff, family and other support staff in the community.

Page 84/Theme 3: Safe Services

It would be more accurate to refer to people ‘participating in’ rather than ‘making’ decisions as this would be inclusive of all persons and closer to the actual reality.

Pages 85-86/Standard 3.1

More prominence might be given to the role of the Designated Person referred to in 3.1.12 and, specifically, as to how other staff should liaise with the Designated Person. This should be linked in with the provision in 3.1.2 relating to ‘the duty of each staff member to report any past or current concerns’….’

3.1.4 There is an assumption here that this is possible for all individuals which may not be the case.

3.1.13-3.1.17

These ‘features’, as stated, might imply that residents have freedom to spend their money without due reference to their obligations to pay for charges and services.

There are no provisions under this Standard for a person who cannot manage his/her money fully or partially and has no representative to assist him/her in this process.

There is no ‘’feature’ dealing with what should be done in instances of abuse of one resident by another.

Page 88/Standard 3.2

There is no provision for seeking alternative solutions where the centre is unable to manage a person’s negative behaviour. Neither do there appear to be guidelines for dealing with situations where the person does not agree to an intervention in respect of managing his/her behaviour.

Page 92/Standard 3.4

The definition of an ‘adverse event’ should be more comprehensive and should include self-harm, harm to another resident or staff member or serious damage to furnishings or the building.

Page 94/Standard 4.1

4.1.4 might be better placed first in the list of ‘features’.

Reference should also be made to the residents having the option of visiting doctors/dentists externally where possible.

Page 95/Standard 4.2

Provision should be made to deal with situations where a person refuses necessary treatment or intervention.

Page 96/Standard 4.3

There is a need for more clarity around what medication and in what circumstance a person may self- administer and how the decisions about this should be made.

Page 104/Standard 5.4

There is a marked absence of provision for how payments from residents are agreed and managed. This is particularly significant because of the current situation in Section 39 funded centres where charges are levied on a ‘voluntary’ basis.

Page 107Theme 7-Workforce

The roles and skills required to carry out the important key supporter worker for each individual resident should be referred to in Theme 7 and additional ‘features’ included to reflect this.

5. Comments on the Children’s Section

The specific comments made on the Standards and provisions in relation to Adults apply equally to the section on Children.

The children’s section is comprehensive and an important component of the Standards. However, the language and concepts very much reflect those of the Adults’ Standards and, therefore, cannot be said to be truly child-centred.

There is insufficient emphasis on the role of the family and the balance to be achieved between the voice of the child, the voice of parents/guardians and the voice of those *in loco parentis.* While consultation is necessary and important, decisions about the best interests of the child clearly cannot be the total responsibility of children or young persons under 18. This needs to be stated explicitly.

There is a very strong need for each child to have a key worker whose role is to facilitate the voice of the child, to engage an independent advocate where necessary, to facilitate access to appropriate communications technology and to ensure that the child’s capacity for choice, decision-making and consent is maximised.

More is also required on how linkages with schools are to be applied, particularly in the context of the strong emphasis on an inclusive and integrated approach to educating children with disabilities stated in the UN Convention on the Rights of the Child and in subsequent reports by the UN Committee on the Rights of the Child.

6. Conclusion

The Standards are an important milestone. Their implementation will no doubt present major logistical and resource challenges and will require ongoing capacity development by each service provider. In this regard, it should be stated explicitly that responsibility for implementing the *National Standards for Residential Centres for People with Disabilities* lies firmly with service providers and their staff. The Standards alone will not bring about change; they are, however, a foundation on which change can be built. The Standards offer a context within which a rights approach can be consolidated, thus ensuring a stronger person-centred approach which should result in a more responsive and respectful care and support system for individual residents.