

## **Submission on Draft Interim Standards for New Directions, Services and Supports for People with Disabilities**

***October 2014***

### **Introduction**

The Citizens Information Board (CIB) welcomes the opportunity to make a submission on the Draft Interim Standards for New Directions, Services and Supports for People with Disabilities. Through its involvement in delivering advocacy services through mainstream provision and the National Advocacy Service (NAS)<sup>1</sup>, the CIB has experience of the difficulties and challenges faced by people with disabilities seeking to access supports to enable them to live independently in the community. The NAS has first-hand experience in supporting people with disabilities to make decisions to have their voices heard and their rights met.

These Draft Interim Standards are another important milestone in developing a more inclusive and mainstreaming approach to meeting the needs of people with disabilities. We welcome the inclusion of advocacy in the New Directions Draft Standards which explicitly acknowledges the important role of advocacy in supporting people. However, such references assume an ability to meet the demand within current funding which needs further detailed consideration.

The Submission contains two sections. Firstly, some general contextual observations are made which are considered relevant to the development and implementation of the Standards. The second section makes comments and suggestions in response to specific consultation questions.

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<sup>1</sup>The NAS provides an independent, confidential and free, representative advocacy service that works to ensure that when life decisions are made, due consideration is given to the will and preference of people with disabilities and that their rights are safeguarded. The NAS operates on the principle that people with disabilities: make decisions about their lives; are listened to and consulted by their families and those who provide their services; access the supports they need to enable them to live their life and enjoy meaningful participation in family, work and leisure; enjoy the benefits of participation in and contribution to their local communities.

## **General Considerations**

### ***Factors Relevant to the Standards***

Provision for and implementation of minimum standards is a crucial component in promoting equality and social inclusion. However, the Standards will only bring about required change if other factors are kept to the forefront of policy development. The following have been identified by the CIB as such factors:

- There is a need to develop more inclusive linkages generally between specialist disability services and generic services – this is particularly important in relation to people with an intellectual disability;
- The mainstreaming focus of the Draft Interim Standards is very welcome and reflects a necessary understanding of people with disabilities as an integral part of our community and all our social structures.
- Individual plans and related goal-setting must be realistic, specific and delivered and monitored in such a way as to ensure that they are meaningful in a practical way for individuals;
- Provision needs to be made for proactive consultation with people with more severe forms of intellectual disability who are likely to require multiple communication supports in order to voice their needs and aspirations;
- The focus on the needs of people as individuals which has emerged strongly in recent years and which is very much reflected in the Standards has significant resource implications for service providers which presents challenges in an ongoing tight budgetary framework;
- Detailed consideration is required in respect of how the provisions of the Assisted Decision-making (Capacity) Bill in relation to supported decision-making will be reflected in the Standards when the legislation is enacted.

### ***Catering for the Diversity in the Population of People with Disabilities***

The population of people with disabilities is marked by diversity which is masked by the generic usage of the term 'people with disabilities'. Providing services and supports in a manner which caters for this diversity is a huge challenge. It is also the case that concepts such as choice and individual planning are much easier to apply in respect of some people than others. Thus, the Standards as set out will require considerable development to make them applicable to different groups with very different needs. While the Standards as outlined are understandably generic, much more is required to make them meaningful for those with very complex care and

support needs. This no doubt will be an ongoing project and in that regard, the present document is clearly an important beginning.

### ***Assessment of Needs and Individualised Supports***

A core provision of the Disability Act 2005 is the provision of an individual's right to an independent assessment of need for people with disabilities,<sup>2</sup> and a subsequent right to receive necessary social services on the basis of a service statement.<sup>3</sup> The Value for Money (VFM) Review (Department of Health 2012)<sup>4</sup> envisaged more effective methods of assessing need, allocating resources and monitoring resource use as well as the articulation of a set of realistic, meaningful and quantifiable objectives to achieve measurable outcomes and quality for service users at the most economically viable cost. The new policy approach around individualised supports has been identified as requiring an approach to needs assessment that is driven by the person and family (as appropriate) and one which covers the important domains in a person's life. (Expert Reference Group (ERG) on Disability Policy 2011<sup>5</sup>). The implementation of the Standards should be guided by the key characteristics of the individualised support concept which have been identified as:

- Determined by the person (in collaboration with their family/advocate as required and in consultation with an independent assessor) not the service provider or other 'experts';
- Directed by the person (with their family/advocate as required);
- Provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person and a 'natural' group activity, such as a team sport);
- Flexible and responsive, adapting to the person's changing needs and wishes;
- Encompassing a wide range of sources and types of support so that very specific needs and wishes can be met;
- Not limited by what a single service provider can provide
- Having a high degree of specificity

(Expert Reference Group (ERG) on Disability Policy 2011:15).

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<sup>2</sup> Sections 8–9, Disability Act 2005.

<sup>3</sup> *Ibid.* section 11.

<sup>4</sup> [http://www.dohc.ie/publications/VFM\\_Disability\\_Services\\_Programme\\_2012.html](http://www.dohc.ie/publications/VFM_Disability_Services_Programme_2012.html)

<sup>5</sup> Expert Reference Group (ERG) on Disability Policy (2011), *Report of Disability Policy Review*, [www.dohc.ie/publications/disability\\_policy\\_review.html](http://www.dohc.ie/publications/disability_policy_review.html)

The VFM Review states that all funding should be allocated on the basis of a standardised assessment of individual need, which should be linked to the resource allocation methodology. “Since it will not be feasible for all assessed needs to be met in full by the HSE in the context of competing resources, the protocols for prioritising need, and deciding which needs are met and which are not, should be transparent, fair and equitable” (Department of Health 2012:176). This factor is centrally relevant to the implementation of these Standards.

Assessment is defined in the Standards document as “a process by which a person’s needs are evaluated and determined so that they can be addressed” (Glossary).

There is a need for more detail in the document as to how people’s choices, needs and abilities, wishes and aspirations are to be assessed, determined and prioritised - who is responsible for carrying out the assessment, for prioritising and reviewing needs and updating service statements accordingly.

We welcome the overall thrust of *New Directions* towards individualised supports. However, there is relatively little reference to individualisation in the Draft Standards which is indicative of a service focus rather than an individual focus. We consider that the essence of the Standards, despite the intention towards individualised supports, is not clear, creating the risk that the person seems to be encouraged to fit into the service available rather than the service being built around the person. We are concerned at the omission of the person's involvement in choosing their own staff. The implication is that services may continue with little change and may reinforce group provision. For example in Standard 1.7 – the focus is still on the "service" and not the provision of supports around the person to live the life of their choosing.

### ***A Rights Approach***

The Draft Interim Standards reflect a general acknowledgement that services and supports for people with disabilities should “promote and uphold the equal rights of adults with disabilities”. The document makes several references to the rights of people with disabilities, in particular, Standard 1.1 which states that “The rights and diversity of each person are respected and promoted”. The need for people to be well informed of their rights and supported in exercising their rights is stated as is the need to facilitate people in accessing advocacy services where required. While these are important provisions, there are a number of relevant considerations which need to be taken into account.

- Firstly, people with disabilities are part of a wider community including, family, friends, service provider staff and wider social and friendship networks. Some people clearly require help in developing, enhancing and maintaining such networks;

- Secondly, many people frequently need assistance with maintaining and developing an appropriate social support infrastructure to enable them to assert their rights. This point may not be sufficiently well emphasised in the Standards.
- Thirdly, the need to ensure that people's will and preferences are at all times fully respected is crucial from a rights perspective – ascertaining the will and preferences of people with reduced capacity is, therefore a key consideration;
- The respective and complementary different support roles of independent advocates, family members/friends and service provider staff need to be stated explicitly.

## Addressing Specific Consultation Questions

### General Feedback Questions

#### 1. Is the language clear?

Overall, the language used in the document is relatively clear. What is less clear, however, is how service providers are to assess whether or not they are compliant in respect of many of the specific features.

The use of terminology throughout related to person-centredness and responding to the needs and wishes of individuals, while welcome, runs the risk of losing its essential meaning through over-use. Also, more detailed consideration is required as to what the terminology means for people with different types of disabilities and for those who may have difficulty in communicating their needs, wishes and preferences.

We have concerns at the lack of detailed description of good *Person Centred Planning* practice as it is generally acknowledged that there are significant variations in how it is practiced.<sup>6</sup> *Person Centred Planning* can vary from selecting from a prescriptive service options menu approach to the detailed practice reinforced in the Genio Endeavour for Excellence and Enabling Excellence programmes which focuses on the person's interests and abilities using the Discovery approaches within a Socially Valued Role framework. We consider this is a priority area for attention, the key cornerstone to ensure that the standards have the potential to impact on the lives of people who use support services.

Ideally, there should be more reference to outcomes in relation to specific Standards and Features – in other words how service providers can assess whether or not they are compliant. This is particularly important in the absence to date of regular inspections as is the case in respect of HIQA National Quality Standards for Residential Services,

There are also questions about how the standards will be monitored and compliance will be evidenced, for example, what measures will be in place to dig below the surface of what is presented. There is a general vagueness around how standards are deemed to be met. This could lead to different interpretations of standards and inconsistent monitoring of standards. We propose that further clarification of how the standards should be met is required to ensure consistent interpretation and validation.

#### 2. Is the layout easy to follow?

The use of a thematic framework (7 themes and related standards) with stated features under each standard is helpful. However, while the Features set out the various ways in which services are expected to comply with a Standard and while

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<sup>6</sup> John O'Brien, the originator of *Person Centred Planning* has acknowledged that the implementation of it has not in general followed his intention on what this means in practice.

the document sets out what a service user can expect under each Standard, there might be a more specific focus on how service providers would know whether or not they were compliant with a particular Standard.

Also, it would be useful if more cross-referencing between different standards and 'features' could be included. This would assist service provider managers and staff in navigating their way through what by its nature is a very complex document.

Of particular importance will be ensuring that the Standards Document is accessible to all people with disabilities.

*3. Are the order and structure of the Draft Interim Standards logical for services and supports for adults with disabilities?*

Some cross-referencing between the Introductory Section (Summary of the Draft Interim Standards) to the relevant detailed Standards would be helpful with cross-referencing to relevant page numbers.

*4. These Draft Interim Standards will apply to services and supports for adults with disabilities, funded by the HSE. Have all important areas been covered and are there any areas that should be (a) included or (b) excluded?*

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 significant support needs and how their participation can be optimised in terms of core concepts such as choice and individual planning and the actions required to ensure that their needs are fully met.

While putting the individual rather than the service provider at the centre is a key underlying principle of the Standards, it is not clear how the concept of giving voice to people with a severe intellectual disability is to be implemented in practice.

While the provisions of the Assisted Decision-making (Capacity) Bill 2013 have not yet been finalised, it is clear that they will have a significant bearing on the process of decision-making by people with reduced capacity. In particular, the Standards need to reflect the emphasis in the proposed legislation on taking account of people's will and preferences. Therefore, a synthesis of the core provisions for supported decision-making in the Bill should be included together with some provisions for how these are to be implemented.

*5. Are these Draft Interim Standards relevant to services and supports for adults with disabilities?*

The Draft Interim Standards are most applicable to services and supports for adults with disabilities and provide an important and necessary framework for the provision

of support in accordance with individuals' needs, preferences and aspirations. However, their full implementation is likely to be very resource intensive and, for that reason, some further prioritisation may be required and a phased compliance implementation programme put in place.

### ***Specific Feedback on Themes 1 to 3***

#### *Theme 1: Individualised Services and Supports*

An additional Feature 1.1.5 should be included:

*“Each individual is provided with accessible information about his/her civil and social rights and entitlements and is supported in understanding his/her rights.”*

Standard 1.3 – There is a need for a clear statement about whom, and in what circumstances, there is a right to access to information about individuals – this is crucial from a rights perspective and particularly for people who may have difficulty in giving consent.

Standard 1.3.4: We propose that further clarity is required in this standard as to how the referral process will take place, at what stage an advocate will become involved and what type of service or response might be most appropriate e.g. Citizens Information Service (CIS), National Advocacy Service, Peer Advocacy, Self-Advocacy etc.

*Standard 1.3.8:* We propose that the standards should outline the responsibility of key workers and managers to access advocacy on behalf of people using the service. The Standard should also stipulate a requirement for services to cooperate with advocates at all levels of working.

*Standard 1.4:* We welcome that the "right of each person to make decisions is respected and supports are provided to facilitate decision-making, including access to advocacy services."

However, the heading may lead people to assume that the advocate's role involves decision making. As this is not the case we would advise that advocacy be separated from decision making in this standard.

Standard 1.4.1: The standard should also outline how the person's views are recorded as well as being sought by staff.

Standard 1.4.3; *New Directions* should support people to make decisions in the first instance but where there is uncertainty or when avenues for supporting decision making have been exhausted, people should be supported to access advocacy services. When involved in supporting decision making, advocacy services should be facilitated to access the people they work with and they should be provided with all relevant information to enable them to make effective representation.



Standard 1.4.4: Services should ensure that the advocacy and information services they support people to access are appropriate to the needs of each individual.

Standard 1.4.5. There is scope for the standard to include the need for the service to engage with the advocate and to be receptive to the advocacy process. We suggest that this standard should be expanded to contain an obligation on the Service to respond appropriately to advocacy services accessed by people. As currently written the standard would seek advocacy to be accessed but may not ensure that advocates are included in relevant meetings.

The HSE have included a section on access to advocacy and NAS in their Service Level Agreement with all services for people with disabilities. The HSE acknowledges the role of NAS for people with disabilities in providing independent representation to people with disabilities who use HSE funded services. This requires services to facilitate NAS advocates to access its premises/houses at reasonable hours; assist advocates to make private appointments with its service-users, facilitate its staff to cooperate with the advocate(s); make available to the advocate files or FOI documents relating to the person receiving advocacy, where this is requested; and accept the advocate as representing the person at case-conferences and multi-disciplinary meetings, where appropriate. Services should be accountable for the engagement and involvement of advocates and this should be measured.

We are concerned at the lack of reference to work throughout the document which reinforces a life of leisure for adults and not the normative focus on employment. For example in Standard 1.5 work is not mentioned.

Standard 1.4.6. We propose that Self-Advocacy should be defined in the Glossary.

Standard 1.6 places the focus on the person coming into the community as a person with a disability and not on the person coming to the community possibly in a role *based on the persons strengths and interests.* The levels of participation in the community is vague throughout this standard. For example in the heading it says that “each person is supported to use local community facilities” where it could say that each person is supported to interact with the people in their community in a meaningful way using local community facilities.

While we agree that Standards should be in line with a person’s choices and abilities, needs should not be a barrier. The following Standards should be available to people regardless of need, i.e., the need should be adequately supported: 1.6 – 1.7 – 2.5 – 2.6 – 2.7 – 2.9 – 2.10

Standard 1.7 is particularly important. Given the widely reported difficulty people with an intellectual disability have in making transitions into mainstream community living and related services, further Features as to how people should be supported in this regard would be useful.

Standard 1.9.7: Further clarity is required in this standard as to how the referral process will take place, at what stage an advocate will become involved and what type of service or response might be most appropriate e.g. Citizens Information Service, National Advocacy Service, Peer Advocacy, Self-Advocacy etc. The role of staff in supporting people to make complaints or concerns should not be superseded by relying on this standard. However, it may be appropriate to have independent advocacy services accessed at an early stage depending on the nature of the complaint. This standard should also refer to the obligation on the Service to respond appropriately to advocacy services when they are supporting people to make a complaint.

### *Theme 2: Effective Services and Supports*

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 such transitions.

An additional Feature is suggested for inclusion under Standard 2.6 as follows;

*“Appropriate supports, including, for example, independent advocates and friendship circles, are available for people to enable them to maximise opportunities in the community”.*

Under Standard 2.13 (The effectiveness of services), the identification of a more detailed set of outcomes would be useful (which could be included in an Appendix).

Many of the Standards in Theme 2 are dependent on a person's needs' which could result in high support needs denying people access to education (2.9 & 2.10), restricting the development of social roles (2.6) and limiting the person in finding means of self-expression (2.7). If the word 'needs' was removed these standards would have far greater potential for benefiting the people who are often left out of day service activities due to high support needs. In Standard 2.1 – it seems that the service provider is determining choice.

Standard 2.1.4. We suggest that the words "take account" are open to interpretation and could allow a service to be only receptive of the person's wishes without taking action to support their preferences.

Standard 2.4.2. We suggest that there is a role for services to facilitate people's access to mainstream services without overseeing the process. For example, people should be free to access grievance counselling etc. without the need for a referral to a psychologist and to be free to partake in ordinary life experiences without being shielded by the service.

Standard 2.6 needs more development on Socially Valued Roles and what this means, based on the key interests of the person.

### *Theme 3: Safe Services and Supports*

There is a need to include reference to the use of appropriate assistive communications technology and the involvement of an advocate to ensure that the voice and perspectives of more vulnerable people are facilitated.

We suggest a revision of this section which places a focus on supports for people to protect themselves towards building supports in their own support network. At the 2011 NDA conference, Dr. Hoong Sin reinforced the environmental context of vulnerability rather than the individual context. In researching abuse of people with disabilities, he reports that risk is not simply due to disability or characteristics of the person, but that vulnerability is situational. Essentially, the best response to address vulnerability is the same as for any other citizen. People need to be informed; make decisions that help them feel in control and thereby increase their competence, confidence and safety. Promoting protection through empowerment in this way, ensures people are supported as much or as little as needed, and are seen as individuals in their own unique situation, capable, and with full rights and entitlements to citizenship. Dr. Hoong Sin advises against protectionist, (disabled people are vulnerable) or deficiency (disabled people are lacking) approaches and recommends rights based approaches with more structured and explicit processes for managing risk. He acknowledges that this is a balancing act, involving rights and risks that must involve people with disabilities themselves. Ultimately, rights promotion and protection from abuse are multifaceted in nature and require a complex response.<sup>7</sup>

We propose that this section focuses on the suitability or unsuitability of the environment in which the person is spending time, the relationships in their life and if their needs are being met.

Standard 3.1. There is a total absence of information on how to protect oneself.

Standard 3.2: Behaviour as a form of communication is both positive and negative by nature. Standard 3.2 and its features could unintentionally limit a person's ability to communicate by discouraging behaviours that are judged as negative. Standard 3.2 potentially makes the person the problem and removes the focus from environmental

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<sup>7</sup> Janet Klees has also written on the focus of keeping people safe which adopts a relational focus.

and social influences. The last phrase of 3.2 concretises this point - “If your behaviour makes it difficult for you to benefit from the services and supports, specialist support is provided to understand and if possible, to help you to change your behaviour”

*Standard 3.2.8.* We suggest that the standard needs to outline who will monitor and evaluate the plan.

## **Specific Feedback on Themes 4 to 7**

### *Theme 4: Leadership, Governance and Management*

There should be a requirement to have the views/perspectives of families/friends, representatives and independent advocates included in reviews of individual plans.

Standard 4.2 We suggest that a demonstration of implementation would be useful.

### *Theme 5: Responsive Workforce*

Some reference should be made to a requirement for specialist training in relation to supported decision-making, ascertaining people’s will and preferences and ascertaining people’s views on living options in the future when their parents are no longer around.

Standard 5.2.3. It is positive to see recommendations for services to have strategies for the retention of staff.

### *Theme 6: Use of Resources*

Some Guidance should be provided on how available resources should be used to prioritise the most important Standards.

Standard 6.1 should allow for and encourage individualised funding for people using day services.

## **Appendices**

The Glossary of Terms references the terms Advocate. *It can be undertaken by people themselves, by their friends and relations, by peers and those who have had similar experiences, and/or by independent trained volunteers and professionals.*

We suggest that this is amended to read ‘and/or by independent trained volunteer and paid advocates’.

## **Overview**

The Draft Interim Standards are an important milestone and offer a valuable impetus to implementing the vision set out in *New Directions* which emphasizes the need for

supports to be individualised and outcomes-focused to enable adults with a disability to live in their community, in accordance with their own wishes. 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 Draft Interim Standards for New Directions, Services and Supports 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 an approach which should result in a more responsive and integrated support system for individuals.

Notwithstanding the many references to a person-centred approach throughout the document, it may be the case that the Draft Interim Standards have not fully taken into account the perspectives of people with disabilities, their families and representatives. The latter may well be different to those of service providers and those charged with developing and implementing quality standards. Since people with disabilities, their relatives/friends, staff and management will be looking at the Standards from different perspectives, there is a need to ensure that they are developed and implemented in a holistic and integrated manner taking into account all of those perspectives.

It would be useful for the Standards to be more explicit on the different types of advocacy supports available in order to ensure that access to advocacy and information is the best possible.

Catering for the diversity of the population of people with disabilities is a central consideration and one which requires further consideration if the Standards are to be fully meaningful for *all* adults with disabilities.