

Themes and Standards Quotes

Public Consultation on the Draft Interim Standards for New
Directions, Services and Supports for Adults with Disabilities

Please note this document contains only quotes that were explicitly identified by respondents as connected to specific Themes, Standards or Features. The primary report includes a broader range of data from across stakeholders.

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Theme 1: Individualised Services and Supports

General Comments

Is there anything else you want to say about this book? From this booklet individuals felt they did not get 1:1 or lack off due to staff shortages. The majority of time do not be involved in deciding who they work with both service user x staff. Do not get enough support provided to them in transitions from one service to another. Sub039

Theme 1: Individualised Services and Supports: In theory yes, but how to see how they can be implemented Sub032

I feel many of the areas relating to person centred planning and supports for service users to live their individual lives to the fullest are in operation and active. Staff are receiving training in Person centred planning and Advocacy. There are a number of Advocacy Groups that educate service users in the areas of Rights and New Directions Initiative. Staff teams link with MDT supports to ensure that service users receive individual holistic care regarding their day service, respite etc. Sub069

I don't see how this is possible for many people (Clients/Users) as from my experience they will seldom be capable of making a well informed decision. Sub073

How is a personal plan correctly assembled, as in many cases it will not be possible for the person to have a meaningful input from their perspective especially as this is so important as it outlines the services and supports to be provided to achieve the goals. This may only be possible with relevant input from Parent /Carer Sub073

(Service Provider Name), (Area Name) are already using personal outcomes measures to try to achieve individualised supports and services. This is very relevant and most important that this theme is included. The people we support have voiced strong opinions regarding choices in the service they receive. Sub077

Some people commented that having a Person Centred Plan is a good way to make sure that services are individualised and that many of these standards can be met through using the PCP process. Sub096

The standards included are well thought out but the word 'choice', which appears in most standards, needs to be carefully managed because in our personal experience choices that were offered to our daughter were declined by her because she did not understand the significance of them. We were not informed at the time what the choices were. In other words, parents and carers should be informed on a continual basis what programmes etc. are likely to be offered, so that provider and parent(s) can work together with the individual concerned in order to enhance his/her life skills and choices. It is only be working together that the best support possible is offered to people with intellectual disabilities. Sub103

Is the layout easy to follow? Too many standards in Theme 1 & 2 Sub109

Theme 1: The word “Individualised” was difficult for some people to understand. Although the meaning is explained underneath we suggest putting the word Individualised before “It is about providing support one person at a time” as is done with the word “Effective” in Theme 2. Sub109

Good Layout; Easy to understand; Writing is a good size; It is good that it mentions Person Centred; Some words were not understood like ‘Advocacy’; There was a lot of information to take in in this part. Sub107

Are the order and structure of the Draft Interim Standards logical for services and supports for adults with disabilities? The Introduction and Part 1 is quite repetitive and long. However the layout is easy to follow. Sub107

The standards are comprehensive and detailed and take into consideration all aspect of the service user’s life. Cover everything. Many of the family members were happy to see supports available to their children and felt many of these standards were already in place in the services in (Service Provider Name). Sub107

General discussion took place in our feedback group in relation to concerns in situations where an individuals choice of service activity cannot be met due to the risk they may potentially pose to other service users in a particular setting. The issue of rights and personal choice versus risk may need to be developed a bit more in the standard. Sub110

Theme 1: No mention of how all supports are to be assessed and who makes the decision on what level of support is deemed appropriate. Sub141

*Extra staff must always be on hand to support both Client and Staff. Sub142

Theme 1: Individualised Services and Supports: Part 3 page 24 I don’t feel people have a right to choose appropriate risks. This would be in contradiction to duty of care. Sub208

Theme 1: Individualised Services and Supports: My daughter is unable to make decisions - so most of this is n/a. She attends a wonderful centre here in (Area Name). Sub215

The Family is not mentioned in the easy read and this needs to be added- circle of support. Sub226

See my comments above about the role of the community who are to play a major part in implementing the standards. For those service users living a distance from everyone there is a danger of them becoming more isolated. Carers will have to play an even greater role in their son/daughters life. The reality is the service user will probably spend a much larger portion of their day at home. Sub239

1. Where is funding and resourcing coming from to meet the provision of these new services? While much of what is outlined reads well in theory, it needs concrete

financial support and a solid structure to make it a success. Also, will availability of service depend on geographic location? Sub249

Would an allowance be given to those availing of this service? Like the way RT are giving a training allowance Sub253

Inclusion in Ones Community – Could community be where they work rather than where they live? Sub253

Theme 1: Individualised Services and Supports: The standards and features under Theme 1 are on pages 16 to 30 in the Draft Interim Standards. On-going with continual development within our Day Service. Sub254

Theme 1: Individualised Services and Supports:. General feedback on Theme 1 was positive. Staff are concerned about the practicality of carrying out all of the work involved due to the lack of resources (staff, facilities) as a result of constraints on budgets. Sub263

Theme 1 – general descriptor: Where there are communication issues the person's representative should be collaborated with- This should be changed to give examples of who this would be and should include advocate or family member. Sub266

Theme 1: Individualised Services and Supports: As my child is 15 years old and still within the Special Need School I'm NOT in a position to give an honest answer as I cannot base your proposals against reality. My main focus is to try and simulate a conversation about meaningful employment opportunities for our young adults in the private sector (with government supports) Sub269

Standard 1.1

Is there anything else you want to say about this book? From this booklet individuals felt they did not get 1:1 or lack off due to staff shortages. The majority of time do not be involved in deciding who they work with both service user staff Do not get enough support provided to them in transitions from one service to another. Sub039

Standard 1.1: Yes if they understand what it means. Sub081

1.1 the rights of each person are respected; 1.3 choices 1.4 decision making; 1.5 personal plan; 1.6 support in local area; 1.7 chance to try new things; 1.8 goals & dreams. We work with each service user to adhere to all of the above. Each service user has their own consultations every year on their choices of activities and personal supports are in place to assist service users achieve their life choices. Sub113

1.1 standard - the rights of each person are respected. Sub213

1.1 Rights – Agreed [a definition and estimated cost of “advocate service” would be helpful]. Sub242

The majority of the Service Users in the focus group felt that Standard 1.1 and 1.2 were most important in relation to rights and dignity (68.9%). Sub245

Following from the previous, standards are usually much more prescriptive in language, identifying roles and responsibilities and describing the actions expected to ensure compliance with the referenced policy. For example, Standard 1.1 states that 'The rights and diversity of each person are respected and promoted'. This is an essential requirement. However, a standards document should specify how this will be achieved. It should identify the role within the service provider with responsibility for ensuring the compliance with the standard, how and how frequently adherence to the standard will be measured, what documentation requirements are necessary and the governance and oversight structure. I would reiterate this comment for the majority of standards in the document. Sub289

Reference is made to the UN Convention on the Rights of Persons with Disabilities in Standard 1.1 As the Convention is internationally renowned as having a transformative effect on the lives of persons with disabilities it is disappointing that the complete repertoire of rights which are afforded to persons with disabilities are not fully utilised within the interim standards. It is recommended that Articles 1 and 3 and 5 of the UNCRPD should form an integral part of Standard 1.1. Sub291

Standard 1.1: Agree with this standard – every person has the right to be treated with respect and dignity at all times. It may prove difficult to support an individual with severe to profound intellectual disability (ID) to access advocacy services. Sub297

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. Sub353

Standard 1.1 - The Rights and diversity of each person are respected and promoted. This Standard clearly states that the rights of people using disability services are enshrined in the UN Convention on the Rights of People with Disabilities and in Irish

Law. It is important to note that as the UNCRPD has not yet been ratified in Ireland; Irish people with disabilities are not yet in a position to assert their rights under this International Convention. In the what this means for you section of Standard 1.1, the person's rights seem to have been interpreted only in connection with the service that they receive rather than as a citizen of Ireland. The need to recognise and deliver on the rights of people with disabilities is fundamental to the effective implementation of New Directions. It is essential that all sectors of the community, including service providers, respect the rights of people with disabilities accessing supports in the community. Sub355

Standard 1.1 (all upcoming quotes from Sub355)

"It is important as this Standard assists with promoting person-centred services for service users focusing on choices"

"Service users feel this is a very important Standard and that everyone should get 1:1 support when needed and that everyone has different needs / backgrounds / cultures and these are to be respected"

"This is a really important Standard. And while the service caters for a wide variety of people it's not a case of 'one size fits all'. Everyone is an individual, and even people with the same 'condition/disability' will have aspects which are unique and specific to them, so it's important that the rights of the individual are always respected and the differences between individuals are acknowledged and catered for. The rights of each person can be respected, provided that resources are not exhausted and staff are not over used on individuals"

"It is important that people respect that we are different and have individual ideas and views and just because we have disabilities doesn't mean we all think the same"

"We agree with this Standard as it is important to help everyone with their individual development. It is also highly important that everyone is respected and that we support one another. We must accept each other's differences and have a mutual respect"

" People feel this is the main Standard and it is important for service users to be listened to"

(end quotes from Sub355)

'I want to have someone to talk to, to find out about my rights' (Standard 1.1). Sub367

The consensus of the group expressed that a visual planner of what staff are working in the day services would help as they expressed that they found it hard to distinguish who was SU's and who was staff. A handover was needed with SU's of the plan of the day was not happening and this should happen. Sub368

a) The Standards are developed as a fixed set of norms that all people with disabilities attending a day service are expected to conform to. It is a major concern that the Standards are regimented without considering the individual needs of the person supported, beyond the label that they have. To assume that, on the whole, the Standards can apply to those with a mild Intellectual Disability as well as those with severe autism seems counteractive to the core principles of individuality of the standards. As Standard 1.1 states 'the rights and diversity of each person are respected and promoted' though this seems almost conflicting with the assumption that active citizenship and community involvement must be pursued. The community represents a huge threat to the people on the autism spectrum due to high social expectations, environmental stressors and sensory overload. The fact that community inclusion is a core principle seems unfair to those supported. Sub369

Standard 1.1 - The Rights and diversity of each person are respected and promoted. This standard clearly states that the rights of people using disability services are enshrined in the UN Convention on the Rights of People with Disabilities and in Irish Law. In one focus group, learners stated, "It [the Standard] is really important because it treats everyone equally and accepts everyone is different and unique. It's important because not everyone's the same. It's the most important standard in the charter". Another group highlighted the fact that there are a "lot of different people with different personalities in RT and this means that everyone has to be looked at as an individual". Sub370

In the what this means for you section of Standard 1.1, the person's rights seem to be have been interpreted only in connection with the service that they receive rather than as a citizen of Ireland. The need to recognise and deliver on the rights of people with disabilities is fundamental to the effective implementation of New Directions. It is essential that all sectors of the community, including service providers, respect the rights of people with disabilities accessing supports in the community. Sub370

Feature 1.1.1

Relatively easy to provide this information but very difficult to access mainstream services. Sub297

1.1.1 The Irish Government have still not ratified the UN convention on the Rights of People with disabilities so rights for people with disabilities are not fully enshrined in Irish Law. Sub372

2. Is the layout easy to follow? The layout is quite clear, however it was felt that at times the document was over professionalised. Simplifying the layout of the standards by not using 1.1.1 and 2.1.2 etc would make the document clearer. Because of the length of the document all families present felt the feedback time was too short for proper consideration to be given to each item. The strongly felt that the time period was unrealistic and more would prepare individual feedback if a longer time frame was given. Sub379

Feature 1.1.2

Service providers have detailed information about community facilities and activities and actively network with community based organisations. Linkages should also be made with the Community Department of the relevant Local Authority and with the Local Community Development Committee structures. Sub344

1.1.2. From the features of this Standard, it is not clear who is responsible for informing the person about their rights or supporting them to understand those rights. Supporting people to exercise their rights is the responsibility of many different stakeholders in the community. Within the service, service providers are responsible for ensuring that the person is treated with dignity and respect and that they are supported to understand their rights while they receiving supports from the service provider; however, human rights-based education is also the responsibility of education providers, etc. It is also important to note that there are many rights which are enshrined under the UNCRPD which are not available to people with disabilities for example, equal recognition before the law, the right to engage in a sexual relationship and to found a family, the right to marry, the right to take part in a jury and the right to vote. Where these rights are not available under law, guidance is required for the service provider to enable the individual to exercise their rights under the UNCRPD. Sub355

1.1.2. From the features of this Standard, it is not clear who is responsible for informing the person about their rights or supporting them to understand those rights. Supporting people to exercise their rights is the responsibility of many different stakeholders in the community. Within the service, service providers are responsible for ensuring that the person is treated with dignity and respect and that they are supported to understand their rights while they receiving supports from the service provider; however, human rights-based education is also the responsibility of other stakeholders in ten community, while the fulfilments of people's rights is the responsibility of all stakeholders. It is also important to note that there are many rights which are enshrined under the UNCRPD which are not available to people with disabilities for example, equal recognition before the law, the right to engage in a sexual relationship and to found a family, the right to marry, the right to take part in a jury and the right to vote. Where these rights are not available under law, guidance is required for the service provider to enable the individual to exercise their rights under the UNCRPD. One learner highlighted the need for responsibilities as well as rights saying "the rights of the person need to be respected unless they infringe on the personal safety of others" Sub370

Feature 1.1.3

1.1.3 Service providers are committed to treating everyone they support with dignity and respect and to promoting equality and ensuring that the person is respected in relation to their unique characteristics. However, New Directions envisions far greater involvement in the local community, accessing both public and private amenities where such respect cannot always be guaranteed from the provider of the service e.g. local bowling alley or its customers. It is important that the Standards

recognise that greater community involvement could lead to a reduced ability to safeguard individuals against disrespect and discrimination. Sub355

1.1.3 Service providers are committed to treating everyone they support with dignity and respect and to promoting equality and ensuring that the person is respected in relation to their unique characteristics. However, New Directions envisions far greater involvement in the local community, accessing both public and private amenities where such respect cannot always be guaranteed both by the provider of the service, for example, local bowling alley or its customers. It is important that the standards recognise that greater community involvement could lead to a reduced ability to safeguard individuals against disrespect and discrimination. Learners in our consultation commented on their need to feel safe in the community and how they feel safer in the centre than in the community where they have, at times, been subjected to stigma and discrimination. Learners in our focus group suggested that respect for the individual cultures of people should also be included in the Standards. One learner said “I liked the concern for the protection of students against bullying, prejudice and the desire to create a safe place to be in” Sub370

Feature 1.1.4

1.1.4 A requirement to ensure that each person is facilitated to access advocacy services or an advocate of their choice is welcome. Consideration should be given to the best ways to support people to access an advocate. In the glossary, the definition of advocacy includes support by family and friends. In some cases family and friends may not be the most appropriate advocates because of the issue being discussed and in these cases a more independent advocate should be sought and should be available. There are many different sources of advocacy both in services and in the community and all should be accessed to positive effect for the person. Sub355

Standard 1.1.4: This standard could include the possibility of participation in an independent peer advocacy group/network. Sub367

1.1.4 A requirement to ensure that each person is facilitated to access advocacy services or an advocate of their choice is welcome. Consideration should be given to the best ways to support people to access an advocate. In the glossary, the definition of advocacy includes support by family and friends. In some cases family and friends may not be the most appropriate advocates because of the issue being discussed. Learners in our consultation highlighted that sometimes they don't want family involved and they want to be consulted before they are. A more independent advocate should be sought and should be available in these cases and where necessary. There are many different sources of advocacy both in services and in the community and all should be accessed to positive effect for the person. Sub370

1.1.4: Some services believe that staff can advocate for the person who uses the service, and they may not recognise the potential conflict of interest. There is an opportunity to be clearer here or in the glossary. Sub424

Proposed Features 1.1.5 – 1.1.7

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.” Sub353

1.1.5 Each person is supported to live their life free from discrimination on the basis of disability ensuring that each person has equal and effective legal defence against acts of discrimination. Discrimination as defined in the Convention “means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including the denial of reasonable accommodation. Sub291

1.1.6 Each person is recognised as persons who are ‘equal before and under the law’ and are also entitled to ‘equal protection and equal benefit of the law.’ Sub291

1.1.7 Each person is afforded an equal opportunity to achieve their goals and needs through such substantive equality measures as reasonable accommodation which means the “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.” Sub291

Standard 1.2

Standard 1.2 photo	<p>Privacy</p> <p>They did not like the photo that went with the standard talking about privacy, privacy is more than knocking on bathroom or bedroom doors, it should include confidentiality around personal information, meetings and personal issues.</p> <p>People felt that this should be a given, but isn't always – people wondered if inspection of day services would mean more things written down about them ...and staff spending more time on paperwork. Sub093</p>
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Standard 1.2 the picture for “People respect your rights to make choices” is a little confusing some people felt that it related to a person being thought letters-suggestion to change picture to make it clearer that it relates to choice. Sub109

1.2 choices good. Sub222

The majority of the Service Users in the focus group felt that Standard 1.1 and 1.2 were most important in relation to rights and dignity (68.9%). Sub245

Standard 1.2 says that every person's privacy and dignity is respected. People respect your right to make choices. Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? Important. We agree with the standard, the person should be able to make the same choices without be forced or pressurised by others. Standard is reasonable and should be enforced quite well. Yes people have the right to make choices, but if they don't know, they could get support. Sub278

Standard 1.2: Agree with this standard – especially protecting people's personal information and only using it to provide better services for the individuals. Sub297

Standard 1.2 The dignity, privacy and autonomy of each person are respected and promoted. This Standard and its features are welcome. However, there may be a need to place greater emphasis on the individual in the language used. For example 1.2.2 states that staff understand the individual needs of people with disabilities. It would be better if staff understood the needs of the individual with a disability rather than understanding the needs of the group. Sub355

Standard 1.2 9 (following quotes from Sub355)

"All service users have the right to make choices and this is especially important when promoting individualised services. It is important to respect choices"

"It's vital that a person's privacy and dignity is respected and that they can make their own choices regarding their care and treatments provided. The service caters for adults and encourages individuals to feel part of the decision-making processes regarding their care, exercise programmes and participation in social activities etc".

"Extremely important that everyone's privacy and dignity is respected. Everyone has different needs / issues and problems and these all need to be respected on a 1:1 basis. All people should respect each other's choices".

"You have to make your own choices; if you tried something and didn't like it, you can change".

"A person's privacy and dignity must be respected as this is a basic human right, absolutely important".

"The service users found this Standard very important and would not wish to change anything about this. The service users feel respected and feel they have the support from staff and the support needs they need to make new choices".

"It's expensive to live now, will I have to pay more money?"

(end of quotes from Sub355)

An individual planner was suggested to learn how to operate some medium to high risk machinery. SU's felt that they are capable of using some machines but are not afforded the opportunity due to H&S as pointed out by TL's. Sub368

Standard 1.2 The dignity, privacy and autonomy of each person are respected and promoted. Learners felt that this Standard is very important because all information should be private and learners should need to give permission for someone to see their confidential information. Sub370

1.2 "Welcome and like that privacy and dignity is promoted and respected" (Ref; Easy to read Standards 1-3). Sub372

Feature 1.2.1

No results

Feature 1.2.2

Standard 1.2.2 staff understand the needs of people – surely this should include developing relationships with the person and their support systems, this would include family members. Sub266

Standard 1.2 The dignity, privacy and autonomy of each person are respected and promoted . This Standard and its features are welcome. However, there may be a need to place greater emphasis on the individual in the language used. For example 1.2.2 states that staff understand the individual needs of people with disabilities. It would be better if staff understood the needs of the individual with a disability rather than understanding the needs of the group. Sub355

Standard 1.2.2 staff understand the needs of people – surely this should include developing relationships with the person and their support systems, this would include family members. Sub378

Standard 1.2.2 staff understand the needs of people – surely this should include developing relationships with the person and their support systems, this would include family members. This would be an ideal place to start to acknowledge the important role of parents and other family members. Sub379

Feature 1.3.8 relates to the maintenance of personal information and may therefore be more appropriately placed under Standard 1.2, Feature 1.2.3 rather than have features relating to data protection included in both Standards. Sub355

Feature 1.3.8 relates to the maintenance of personal information and may therefore be more appropriately placed under Feature 1.2.3 rather than have features relating to data protection included in both Standards. Sub370

1.2.3: If the sector is regulated at a future date, information may need to be available to regulators. How will reviewers of standards monitor this if implemented? Will the permission of the person who uses the service be required prior to a potential review of the person's records? Sub424

Standard 1.3

Standard 1.3 requires amendment to include amendment to Standard 2.2 above:
Sub004

I don't see how this is possible for many people (Clients/Users) as from my experience they will seldom be capable of making a well informed decision. Sub073

In relation to standard.1.3&1.4 we all agree the consultation process with service users needs monitoring to ensure that all service providers are facilitating this.
Sub094

1.3/1.4 For ID people ability to understand and make decisions is grossly and dangerously over stated. Sub095

Standard 1.3: some people recommended that it is also important to give information regularly (more than once) to help people understand and remember it. Sub096

Standard 1:3 I am aware of clients that are not allowed to use the in house e-mail system because the company feels it would inherit a liability. They equally will not allow an e-mail account to be set up for cyber bullying purposes. Sub097

1.1 the rights of each person are respected; 1.3 choices 1.4 decision making; 1.5 personal plan; 1.6 support in local area; 1.7 chance to try new things; 1.8 goals & dreams. We work with each service user to adhere to all of the above. Each service user has their own consultations every year on their choices of activities and personal supports are in place to assist service users achieve their life choices.
Sub113

1.3 It is also important to mention people support plan and how we need to get the balance between peoples needs + wants. Sub226

Theme 1: individualised services and supports: (1.3) please explain what format a copy of interim standards will take for a person with severe or profound disability?
Sub232

1.3 Info - Agreed [No recognition of impaired understanding is included + see 1.1 Most of our trainees will be unable to understand or relate to these standards & just giving them a copy is grossly inadequate. Many have difficulty in making choices and communicating their preferences] Sub242

The majority of the Service Users in the focus group felt that Standard 1.1 and 1.2 were most important in relation to rights and dignity (68.9%). Standard 1.3 and 1.4 scored the next most important. (58.6%) Sub245

Standard 1.3 states that each person has access to information some people are unable to comprehend what is being said to them and it is not service user friendly.
Sub262

Standard 1.3 says that every person can make their own choices. People are given information to help them to make choices. Information is given in a way that people can understand. Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? It's important and we agree. It needs to include the following at the end: 'once they don't harm you or anyone' Standard is essential. Information provided must be in a clear and accessible manner to all forms of ability so that people can be confident with the choices they make. You could explain more to them. Sub278

Std 1.3 It is felt that this reflects the above outlined requirements of Article 3 and 5 however it is recommended that those persons who avail of services should be informed that those measures outlined in Standards 1.3 are a legal entitlement as required by the UNCRPD. Sub291

Furthermore it is advised that in addition to features 1.3.1 to 1.3.8 that each person in making an informed decisions / plans is supported to examine the nature of a particular plan/service, the potential benefits of a plan/service, the potential drawbacks of a plan/service and alternative choices to the plan or service. Std 1.3 this is the way forward as 'Service Users' will have control and choice around their own life. For some Service Users, this transition may present a challenge as routine and structure are an important and sometimes essential part of their life. So being mindful of this would be important. Sub291

The right of people with mental disabilities to make their own choices may not always be in their best interests. If Service User Name was given the choice to stay at home or go to work he would very happily stay at home (standard 1.3). Sub302

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. Sub353

Following quotes are from Sub355

"This Standard is essential as all individuals require the information about choices they choose. It is important to identify different communication tools e.g. PECS focus on the tools that are required for each individual. Makes well-informed plans and choices".

"Information is mainly given orally, generally in a face-to-face situation. This is good as it means the individual can ask questions there and then, and this means that there should be no confusion or ambiguity, and everyone knows what's involved. You cannot make a broad statement like this without emphasising that people's choices cannot interfere with other people's choices or way of life"

"People have a right to information so they can make the choice that suits them"

“Some people need support to get this information and this support should be given to them”

“Language should be used that the person listening understands. Sometimes hard to understand language is being used in forms, etc. Plain and simple language needs to be used”.

“This Standard is extremely important as there has to be a focus on clarity of communication. Information has to be given in a way that can be understood by everyone, regardless of disability or difficulty”.

“We feel that our families should be encouraged to allow us to make our own choices even if they disagree with them”

“The service users feel the information that they were given is understandable and they have the staff support if needed to make new choices within their day service. Very important in a service”

“To be given enough information to make the right choice is important from the service users perspective, using different ways to communicate; pictures, words, creativity, discussion is a huge help. Very important in a service”

We are given choice but information shared can be made easier and delivered in a way that people understand.

(End of quotes from Sub355)

What did you not like in this book? ‘I don’t have a computer’ (Standard 1.3). ‘I need some help to read information’ (Standard 1.3). ‘I need lots of time to think and understand the standards. October 17th is too soon.’ ‘I want to know where my money goes to? I’d like to be more involved in my funding’ (Standard 1.3) ‘I need opportunities and experiences in order to make informed choices’ (Standard 1.3)
Sub367

Some SU’s feel that a structured time table is needed as they don’t know what they’re doing throughout the day. There is lack of information to make choices. A coffee morning once a week was suggested. All SU’s felt that this would be excellent to find out what is going on and for social interaction pleasure. Sub368

Standard 1.3 Each person has access to information to enable them to make well-informed plans and choices, provided in a format that is accessible to their information and communication needs. The features of this Standard provide strong safeguards for the person in terms of ensuring that they have access to information about the services available to them in a format that suits their needs. Our learners said “this standard is essential. Information must be provided in a clear and accessible manner to all forms of ability so that people can be confident with the choices they make”. Others said “Sometimes learners are restricted in doing what they want to do because of staff numbers. This Standard is important because individual timetables work for some learners”. However, in the context of New Directions it may be

appropriate to use more active language in relation to ensuring the person is central to the service provided. Sub370

I.3 While everyone agreed that choice is important, families expressed concern that sometimes a particular choice may not be able to be supported for one reason or another. Sub381

Feature 1.3.1

Std I.3 It is felt that this reflects the above outlined requirements of Article 3 and 5 however it is recommended that those persons who avail of services should be informed that those measures outlined in Standards I.3 are a legal entitlement as required by the UNCRPD. Furthermore it is advised that in addition to features I.3.1 to I.3.8 that each person in making an informed decisions / plans is supported to examine the nature of a particular plan/service, the potential benefits of a plan/service, the potential drawbacks of a plan/service and alternative choices to the plan or service. Sub291

Feature I.3.1 states that information is provided about both specialist and mainstream services and opportunities. A definition of what is meant by specialist and mainstream should be included in the glossary. Sub355

Feature 1.3.2

I.3.2 Assistance and support must be provided to all staff and client of the service. This will make communication in the community work successfully. *Extra staff must always be on hand to support both Client and Staff. Sub142

Feature 1.3.3

No data

Feature 1.3.4

Standard I.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. Sub353

Feature I.3.4 provides information about accessing advocacy services. This Standard could also benefit from reference to the role that families play in the circle of support for the person, where this is their choice, and the importance of the person having support in the planning process. Sub355

Standard I.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, National Advocacy Service, Peer Advocacy, Self-Advocacy etc. Sub374

Feature 1.3.5

I:3:5 – Communication with regard to Interim Standards: We have facilitating the communication of Interim Standards to our service user group using both Easy Read and Narrated Video. However given their level of disability (severe to profound Intellectual disability) it is extremely difficult to communicate such information. As with all other areas of service provision it is most important to involve advocate/family in all aspects of this process. Sub106

Standard 1.3.5 each person is provided with an accessible copy of the standards – these need to be developed more as the standards are far more wide ranging than the easy to read version covers. In addition audio or visual versions should be made available. Sub266

1.3.5 Communication with regard to Interim Standards: We have facilitating the communication of Interim Standards to our service user group using both Easy Read and Narrated Video. However, communication needs to be basic and graphic to explain and feedback as it is extremely difficult to communicate such information given the service users level of disability. As with all other areas of service provision it is most important to involve advocate / family in all aspects of this process. Sub342

Feature 1.3.5 provides that each person is provided with an accessible copy of the Interim Standards and time is spent by staff explaining the Standards to each person. The following change is proposed to the text of this feature “each person is provided with a copy of the Interim Standards in a format and language he/she can easily understand and time is spent by staff explaining the Standards to each person”. Sub355

Clarification is also required in relation to how Feature 1.3.5 will work in practice – is it proposed that services will be required to get each person to sign off or formally acknowledge that they have received a copy of the Interim Standards and that they were explained to them. Sub355

Standard 1.3.5 each person is provided with an accessible copy of the standards – these need to be developed more as the standards are far more wide ranging than the easy to read version covers. In addition audio or visual versions should be made available of the full standards including all seven themes. Sub359

Feature 1.3.5 provides that each person is provided with an accessible copy of the Interim Standards and time is spent by staff explaining the standards to each person. The following change is proposed to the text of this feature “each person is provided with a copy of the Interim Standards in a format and language he/she can easily understand and time is spent by staff explaining the standards to each person”. Sub370

When the Interim Standards are implemented, it would be appropriate for the HSE to provide a range of different formats of the Standards to support service providers to provide this information. At the Information Sessions held throughout the country, a video or audio version of the Interim Standards was particularly

highlighted by service providers, families and people with disabilities. The audio version provided during the consultation was useful. Sub370

Standard 1.3.5 each person is provided with an accessible copy of the standards – these need to be developed more as the standards are far more wide ranging than the easy to read version covers. In addition audio or visual versions should be made available

Standard 1.3.5 each person is provided with an accessible copy of the standards – these need to be developed more as the standards are far more wide ranging than the easy to read version covers. Will a braille version be made available? Sub379

Standard 1.3.5 each person is provided with an accessible copy of the standards – these need to be developed more as the standards are far more wide ranging than the easy to read version covers. In addition audio or visual versions should be made available of the full standards including all seven themes. Sub380

Feature 1.3.6

The features of this Standard provide strong safeguards for the person in terms of ensuring that they have access to information about the services available to them in a format that suits their needs. However, in the context of New Directions it may be appropriate to use more active language in relation to ensuring the person is central to the service provided. For example, Feature 1.3.6 states that each person is informed and consulted about the developments in the service. This feature could be strengthened through the inclusion of the following changes “each person is informed and consulted and play an active role in decisions made about developments in the service that they personally receive”. Sub355

However, in the context of New Directions it may be appropriate to use more active language in relation to ensuring the person is central to the service provided. For example, Feature 1.3.6 states that each person is informed and consulted about the developments in the service. This feature could be strengthened through the inclusion of the following changes “each person is informed and consulted and plays an active role in decisions made about developments in the service that they personally receive”. Sub370

Feature 1.3.7

No data

Feature 1.3.8

1.3.8 A number of services may have individual service user information which is sensitive in nature e.g. forensic reports and information which could potentially be harmful to the individual in a number of cases- some concern raised over this- caution required. Sub110

1.3.8 In a small number of individual cases where client information is very sensitive in nature, e.g. forensic psychology reports, where potentially this information could be harmful to the client or family/advocate. Sub283

Std 1.3 It is felt that this reflects the above outlined requirements of Article 3 and 5 however it is recommended that those persons who avail of services should be informed that those measures outlined in Standards 1.3 are a legal entitlement as required by the UNCRPD. Furthermore it is advised that in addition to features 1.3.1 to 1.3.8 that each person in making an informed decisions / plans is supported to examine the nature of a particular plan/service, the potential benefits of a plan/service, the potential drawbacks of a plan/service and alternative choices to the plan or service. Sub291

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. Sub353

Feature 1.3.8 relates to the maintenance of personal information and may therefore be more appropriately placed under Standard 1.2, Feature 1.2.3 rather than have features relating to data protection included in both Standards. Sub355

Feature 1.3.8 relates to the maintenance of personal information and may therefore be more appropriately placed under Feature 1.2.3 rather than have features relating to data protection included in both Standards. Sub370

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 the services cooperation with advocates at all levels of working. Sub374

Standard 1.4

Standard 1.4_AI: Where the right of a person to make decisions cannot be vindicated due to their level of intellectual disability. Where profound impact on communication abilities by way of speech, writing and other forms of communication exists, an advocacy group composing of volunteer family members, members of staff or people interested in the general welfare of that person from the wider community, should be set up, to represent that persons needs on an ongoing basis. A focus of that group should be the maintenance of records on meetings of the group. Sub004

The Draft Interim Standards provides no obligations on the service provider to satisfy the residential needs of clients. Nor does it state the minimum requirements that accomodation should fulfill. Nor does it state the capital funding required to satisfy these needs. Nor does it provide an obligation on the service provider to gather publicly available data on the numbers of residential units required or capital requirements of same. It does not estimate numbers on a per capita or county or borough or council basis. Nor does it set out sanctions in regard to breaches of contract. Sub004

In relation to standard.1.3&1.4 we all agree the consultation process with service users needs monitoring to ensure that all service providers are facilitating this. Sub094

1.3/1.4 For ID people ability to understand and make decisions is grossly and dangerously over stated. Sub095

Standard 1.4: some people felt that they don't always have the right to make choices and they wondered about this standard. Sometimes families, staff and other people get involved in making decisions. Sub096

Standard 1.4 the word "Decision" is a little confusing we suggest its changed to something easier. Sub109

1.1 the rights of each person are respected; 1.3 choices 1.4 decision making; 1.5 personal plan; 1.6 support in local area; 1.7 chance to try new things; 1.8 goals & dreams. We work with each service user to adhere to all of the above. Each service user has their own consultations every year on their choices of activities and personal supports are in place to assist service users achieve their life choices. Sub113

1.4 Consulted Agreed [Guidance on measuring capacity is needed together with cost implications]. Sub242

The majority of the Service Users in the focus group felt that Standard 1.1 and 1.2 were most important in relation to rights and dignity (68.9%). Standard 1.3 and 1.4 scored the next most important. (58.6%) Sub245

Standard 1.4 says that each person has the right to make decisions. This right has to be respected. If people need support to make a decision, they should be given the right support. The right support can include using advocacy services. Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? It's important. We agree with the standard and it should be respected. It's the same as the last standard. The person themselves should make the final decision, but should have all the support and advocacy they need to help them make the final decision. Sub278

Std 1.4 There is no mention in the interim standards of the rights of persons with disabilities within both domestic and international human rights law to have recognised formal assistance and support agreements to make their own decisions. This is an opportunity to amalgamate the rights afforded by the standards and bolster them. Sub291

Standard 1.4: Agree with the principle of the Standard. Sub297

1.4 : This standard reinforce the choices - the right to make choices, this is completed in a way each client understands through pictures, short words. Sub348

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. Sub348

Standard 1.4 The right of each person to make decisions is respected and supports are provided to facilitate decision-making, including access to advocacy supports. Would it be possible to combine the features of this Standard and the previous Standard 1.3 as both cover similar issues and the features of Standard 1.4 would give far greater strength to Standard 1.3? Sub355

Standard 1.4 (quotes from Sub355)

"This Standard is very important as everyone has the right to choice and to make their own decisions. Ensure all information is given before so as an informed decision can be made and then it is important for us to provide the support required for individuals to make decisions."

"All service users have the right to make decisions for themselves and with support if necessary. The group feel that there should be more advocates available. Independent advocates possibly hired by the HSE who would be available to service users"

This is useful to know because sometimes the individual does not fully comprehend the full extent of a situation, and when barriers are encountered it's useful that access to support and the right to use 'advocacy services' to further their cause is really helpful. Each person has the right to make a decision – More education on the meaning of RIGHT. Very important, but not easy as there is not enough crossover between all services"

"We all have a right to make decisions about our lives and sometimes we need staff to support us in making decisions, giving us the right information needed to make the decisions"

"Yes I have the right to make decisions. Everyone should have rights and be treated the same. We should have the option to have rights in our own home/community. We need more information on advocacy"

"All were in agreement that this should be in place for all services, including access to advocacy groups/an advocate. "Help to speak up for yourself. Nobody can overpower your right to make your own decision"

"This is a basic human right that everyone is entitled to and must be encouraged to do so. It is important to have resources and services that can provide support to those individuals making decisions"

"We feel that our families should be encouraged to allow us to make decisions that affect our lives and not make these decisions for us"

“The service users explained how they are aware of the advocate services available and also spoke about (Service Provider Name) and additional supports available to them. Very important in a service.”

(end of quotes from Sub355)

SU's want more activities and choices . They felt like upcoming events were not communicated to them enough and more should be done to improve communication. Monthly News Letter to be more regular and in colour sent out to houses about events. Monthly planner in advance was suggested by SU's. Some SU's did not know they could avail of an advocate. Sub368

I.4 No reference made to capacity assessment, decision making support options e.g. the three types as set out in the assisted decision making (capacity Bill 2013) Assisted decision making, Co Decision making and Decision Making Representative. Sub372

Standard I.4: We welcome 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 advocates role involves decision making. As this is not the case we would advise that advocacy be separated from decision making in this standard. Sub374

I.4 All agreed with this standard, again a caution was expressed that decisions need to be "informed" in that people are made aware of the consequences of deciding one way or another. Sub381

I.4 Parents said that the Advocacy Services does not have the knowledge, expertise and experience for people with intellectual disabilities. Sub412

Feature 1.4.1

Standard I.4.1: The standard should also outline how the person's views are recorded as well as being sought by staff. Sub353

Feature I.4.1 is welcome as it recognises the central role that people should play in decisions that are made about their lives. Feature I.4.2 reiterates the centrality of the person's wishes and this is essential to drive truly person-centred services. Sub355

Feature I.4.1 is welcome as it recognises the central role that people should play in decisions that are made about their lives. Sub370

Standard I.4.1: The standard should also outline how the person's views are recorded as well as being sought by staff. Sub374

Feature 1.4.2

Feature I.4.1 is welcome as it recognises the central role that people should play in decisions that are made about their lives. Feature I.4.2 reiterates the centrality of the person's wishes and this is essential to drive truly person-centred services. Sub355

Feature 1.4.2 reiterates the centrality of the person's wishes and this is essential to drive truly person-centred services. Our learners said that "the person should be able to make the final decision, but should have all the support and advocacy they need to help them to make the decision". Another said it is "important to be able to make decisions rather than other people deciding about my future". Sub370

Feature 1.4.3

1.4.3. Presumed capacity. This is a tricky one – one can be capable of some activities but not have intellectual capacity as in the average IQ level. My son has great visual capacity and recognises people's cars no matter where he sees the car without the owner, even though he cannot read or write or understand numbers. He also has a great memory – we use photos and pictures with him. Sub100

Standard 1.4.3 who should make these decisions on behalf of a person if they cannot make them. There is no mention of families providing decision making supports. Sub266

Service users: Involve people from places that you live in. Families: 1.4.3 – based on the presumption of capability to decide. Sub291

Staff members: There is no mention of a standard assessment tool to ascertain the support needs of the people we support, surely this is essential in designing/developing services, and some national guidance on this would be welcomed. The involvement of a day service that promotes person centeredness should focus the majority of its efforts attempting to fulfil aspirations, needs & abilities. Skills teaching, in all its attributes should be directed solely to achieving goals, or elements of that particular goal. The assumption of capacity should always be present, regardless of any individual presentation. Individualised services & supports is rightfully theme 1 of the standards for New Directions, and in making the capacity issue clear from the onset, it puts to rest any argument in this respect, which could allow for blockages in service delivery. Sub291

1.4.3 the issue of capacity is automatically presumed regardless. The standards, needs to make absolutely clear what all other supports are, in respect to the standard 1.4.3, stating all other supports "should be exhausted". This should be streamlined, because if left to individual service providers, there may be too much of a variation, allowing for discrepancies within and between service providers nationally. Sub291

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. Sub353

In the absence of new capacity legislation, Feature 1.4.3 requires greater clarity. A presumption of capacity is valid; however, in many cases capacity to make a decision

requires that the person has the information required to make the decision and is supported to understand the consequences of that decision. The service provider, family members and the HSE all have a responsibility to ensure that the person has the information that they require to make a decision. The feature gives little guidance in relation to considering people's previous will and preferences and also to consulting family and friends about the person's wishes. The Assisted Decision-Making (Capacity) Bill 2013 is due for completion in coming months and when complete, service providers will play a role in ensuring that the person can access the relevant decision-making supports where their capacity is in doubt. In the absence of relevant capacity legislation, service providers can encounter difficulties when balancing a person's wishes with their needs. Sometimes someone might wish to undertake an activity in their lives but may need to develop a skill in order to assist them to become more independent in that area. Sub355

In the absence of new capacity legislation, Feature 1.4.3 requires greater clarity. A presumption of capacity is valid; however, in many cases capacity to make a decision requires that the person has the information required to make the decision and is supported to understand the consequences of that decision. The service provider, family members and the HSE all have a responsibility to ensure that the person has the information that they require to make a decision. The feature gives little guidance in relation to considering people's previous will and preferences and also to consulting family and friends about the person's wishes. The Assisted Decision-Making (Capacity) Bill 2013 is due for completion in coming months and when complete, service providers will play a role in ensuring that the person can access the relevant decision-making supports where their capacity is in doubt. Sub370

Standard 1.4.3; New Directions Services 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. Sub374

Standard 1.4.3 who should make these decisions on behalf of a person if they cannot make them. There is no mention of families providing decision making supports. Sub378

Standard 1.4.3 Each person is presumed to have capacity – This is good in principle but what happens in the case of someone who does not have the capacity to make decisions without assistance who should make these decisions on behalf of a person if they cannot make them. There is no mention of families providing decision making supports. There is a definite need for this standard to be clearer and less open to interpretation. Sub379

Feature 1.4.4

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.
Sub353

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.
Sub374

Feature 1.4.5

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. Sub353

Feature 1.4.5 Access to advocacy services is essential to enabling people to make independent decisions. As the model of service provision evolves to embody the principles of New Directions, there will be far greater choice for the person in their day-to-day activities. To ensure that their choices are genuine and not based on the requirements of the service or the wishes of their parents or family, advocacy supports, including developing a culture of advocacy within services will be essential. While some service providers such as (Service Provider Name) have invested in advocacy supports for their clients, many others will not have done so and provision will need to be made to allow capacity building for services in the area of advocacy.
Sub355

Feature 1.4.5 Access to advocacy services is essential to enabling people to make independent decisions. As the model of service provision evolves to embody the principles of New Directions there will be far greater choice for the person in their day-to-day activities. To ensure that their choices are genuine and not based on the requirements of the service or the wishes of their parents or family, advocacy supports, including developing a culture of advocacy within services will be essential. While some service providers such as (Service Provider Name) have invested in advocacy supports for their clients, many others will not have done so and provision will need to be made to enable capacity building for services in the area of advocacy.
Sub370

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. Advocates are sometimes blocked from attending relevant meetings currently. Services should be accountable for the engagement and involvement of advocates and this should be measured. Sub374

Feature 1.4.6

Standard 1.4.6. We propose that Self-Advocacy should be defined in the Glossary. Sub353

Feature 1.4.6: Self-advocacy according to the level of the person's ability should always be the primary focus. Everyone can self-advocate in some way whether it be deciding between two different activities or making bigger decisions. A small change is proposed to this feature "Self-advocacy is fully supported and facilitated, in line with each person's ability, needs and wishes". In the "what it means for you" section of this Standard, clarity is required in relation to the "service provider provides supports for self-advocacy". It may be more appropriate to say "the service provider supports you to speak up for yourself and play a central role in decisions that are made about your service" Sub355

Feature 1.4.6: Self-advocacy according to the level of the person's ability should always be the primary focus. Everyone can self-advocate in some way whether it be deciding between two different activities or making bigger decisions. A small change is proposed to this feature "Self-advocacy is fully supported and facilitated, in line with each person's ability, needs and wishes". In the "what it means for you" section of this Standard, clarity is required in relation to the "service provider provides supports for self-advocacy". It may be more appropriate to say "the service provider supports you to speak up for yourself and play a central role in decisions that are made about your service". In (Service Provider Name), learners can undertake a module to develop self-advocacy skills which supports them to develop their communication skills, make decisions and stand up for their rights. Similar training will be necessary in many services to encourage people to fully participate in a more personalised service. Sub370

Standard 1.4.6. We propose that Self-Advocacy should be defined in the Glossary. Sub374


Standard 1.4 requires amendment to include: 1.4.7 " Where profound impact on communication abilities by way of speech, writing and other forms of communication exists, an advocacy group composed of volunteer family members, members of staff or people interested in the general welfare of that person from the wider community, should be set up to represent that persons needs on an ongoing basis. A focus of that group should be the maintenance of records on meetings of the group. " Sub004

Standard 1.5

Standard 1.5: The group felt that the plan should reflect on the individual as a whole and not just focus on their day service, but on respite service and all services that the individual receives. The group also felt that this plan should follow the service user when they attend each service. Sub007

Regarding standard 1.5: Inspectors should check if accessible versions of Person plans are available to all who need them. Sub066

How is a personal plan correctly assembled, as in many cases it will not be possible for the person to have a meaningful input from their perspective especially as this is so important as it outlines the services and supports to be provided to achieve the goals. This may only be possible with relevant input from Parent /Carer. Sub073

	<p>Service users agreed that they should be involved in all planning meetings about them “ nothing about us without us” Sub093</p>
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1.1 the rights of each person are respected; 1.3 choices 1.4 decision making; 1.5 personal plan; 1.6 support in local area; 1.7 chance to try new things; 1.8 goals & dreams. We work with each service user to adhere to all of the above. Each service user has their own consultations every year on their choices of activities and personal supports are in place to assist service users achieve their life choices. Sub113

Part 3 page 24 I don't feel people have a right to choose appropriate risks. This would be in contradiction to duty of care. Sub208

1.5 PCP - Agreed [It is impractical to allow service users select KW – compare teachers etc. A guide/definition of declining to develop PCP would be helpful] Sub242

To whom it may concern, Thank you for giving us the opportunity to comment on the plans for new and updated services for clients. My brothers and I (and our late mother) are grateful to the (Service Provider Name) (and its many guises and name changes) over the last 40 years. Our brother Service User Name, based in Location Name has been one of the clients since then.

I understand that you are updating and creating new standard operating procedures and protocols but I'm guessing that some of these procedures are already in place and that you wish to formalise them? Or is it all something new? We love the idea of involving the clients in more social events, perhaps in the evenings and at weekends. Our main concern with our brother is that he can be quite isolated outside of work hours. He is quite independant but a bit of a loner and we are often worried that he feels lonely as he lives alone. Most of his friends seem to live too far away to see them regularly. So it would be nice to know that there would be a couple of social events that he could go to without him having to think and stress about organising it himself. I would also like to know if each client will be assessed individually again?.... to see if they are getting enough out of life and indeed if life is getting enough out of them? We were a bit concerned about his general motivation. eg. getting himself up in the morning and getting out and having a purpose. Sub247

Standard 1.5 This standard says that each person has a personal plan that says what supports they will have to help them live a good life. A personal plan says what you want in life and the supports to help make this happen. Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? Agree. It's important to provide a structure and a routine with a goal oriented approach. True. Everyone needs a plan. Sub278

The language used however contains vocabulary and concepts which are not relevant to service users everyday lives and which were difficult for service users to visualise and understand e.g. "statement of purpose", "standard 1.5" Sub285

Standard 1.5: Day service provision does not usually take responsibility for people's health issues – parents do. Sub297

Is there anything else you want to say about this book? I think the standards are good but in the current climat I don't see how the standards will change my life, as there is a shortage of staff/ people to assist me go to places I want to go. No funding to move into a home that meets my needs, is more accessible for me as I use a wheelchair and has fewer people. Sub313

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. Sub353

Also the objective of this Standard should underpin Standard 1.5 which provides for the development of a personal plan which should be based on progression and on achieving goals and aspirations. The Standard seems to focus very much on learning rather than on achievement in all areas of a person's lives. Sub355

Standard 1.5 [quotes from Sub355]

"This Standard is vital to each individual in order to ensure that staff provide the correct support to meet each individual's needs. A personal plan is unique to every one individual and it is important as it sets out what the person wants in life".

"Very important to have a personal plan but there needs to be clarity as to whether it's a long term plan / short term plan etc".

"A 'personal plan' is important because sometimes the condition/disability can be overwhelming and a plan can help the individual to see a bigger picture with attainable goals (hopefully) to increase their enjoyment and quality of life. Change this Standard to "enable them to live as full a life as possible".

"It is important to us to have a Personal plan so that we can plan for our future and plan outcome so we can reach our goals in life. We think this Standard is very important. However to reach outcomes will the support be available e.g. staff, transport, finance".

"Is it what we want, or need, or both and who decides?".

“All were in agreement that everyone should have a person centred plan. They were happy with this Standard; felt that it was a “good thing”. People linked their person centred plan with “learning skills”; “learn things for life”; “improve health”; “where you want to be and how to get there”

“The service users feel they get a lot of support around personal goals from their circle of support. Very important that this is encouraged within a service”

“It doesn’t talk about reviews”

[End of quotes from Sub355]

‘I would like to make a newspaper to put a picture of me on it, and make the newspaper all about me, ie. The things I’d like to do’ (Standard 1.5). ‘I live at home with my parents. I’d like the standards to work with/for my parents and me’ (Standard 1.5 and 2.1). Sub367

In one of our family focus groups, a family member said that “personal plans should be kept very simple and reinforced every day”. One learner welcomed the flexible approach to individualised services provided for in the document saying, “It seems to consider a flexible approach for the student as to what is most interesting for himself /herself”. (Service Provider Name) learners have their personal plan reviewed regularly. Families are invited to come if the learner wants them to and sometimes this can work well; however not every person wants their family there though and this is respected. Families also welcomed the requirement in the Standards for the personal plan to support the person to build friendships because they believe that having family and friends involved in a person’s life is essential to building their confidence. Also the objective of this Standard should underpin Standard 1.5 which provides for the development of a personal plan which should be based on progression and on achieving goals and aspirations. Sub370

1.5 No reference to NDA standards on person centred planning. 1.5 Currently each person has a PCP and audited under HIQA Standards for residential services for people with disabilities. Clarity needed on whether a person should have one PCP or should they have a separate one for their day service. The ideal for the person is that they have a plan for a good life. Sub372

We are concerned at the lack of reference to work thought out 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. Sub374

Standard 1.5 Personal plans –how are these going to be funded, if an individual requires ongoing supports will funding be made available. In the move towards more community based activities who will fund individuals accessing these, particularly for individuals who are unable to secure paid work which assist in funding activities. If an individual chooses to stay at home will supports be provided for this when needed? A particular concern was that if an individual chose to stay at home then families would be expected to provide the required supports to facilitate this. Sub379

I.5 - Before this standard can be implemented there need to be a process whereby all government departments have a common plan. At present this is not happening so the service users cannot attain this standard. Families feel this standard is aspirational rather than possible. Resources are not sufficient for what the person chooses. Sub412

Feature 1.5.1

No data

Feature 1.5.2

I.5.2. Active citizenship. How can people be helped when it comes to voting? This is surely the most active form of citizenship. The new system of photos on the ballot paper helps. What else? Sub100

I.5.2 for maximising independence Sub210

(Service Provider Name) Staff: I.5.2: To access Education and employment is a very meaningful outcome for our clients, however many of our mainstream educational institutions are not wheelchair accessible or disability friendly. Education on disability awareness is vital for these partnerships to be effective. Sub279

I.5.2: Active Citizenship: While active citizenship would be very worthwhile for our clients, it is also a concern due to the physical and cognitive challenges that exist for our clients, some clients will need PA support in accessing community facilities/groups and clubs. There is no funding for this, therefore how will service providers meet this need. Many of the local community buildings are again not accessible; the standards need to be more realistic as to what can actually be provided on the ground. Sub279

I.5.2: To access transport services: Our current rural transport system is ineffective; many areas only have one bus service per day which are mostly not wheelchair accessible. Private transport services are costly and unaffordable for our clients and service providers. Again increased resources to meet this support are not included. Links also need to be made with public and private transport bodies. There is no information or direction on how to activate this support. Sub279

I.5.2: (Clients)-- To access transport services: Transport is an area that caused the group concern in relation to the lack of services in the rural areas. Important for the standards to highlight this. Sub279

I.5.2: To access assistive technologies: We agree that this is a very necessary support; however some direction is required to include information and links. Sub279

I.5.2 lack of assistive technology Sub291

Agree with remainder of I.5.2. Agree but sometimes difficult to support an individual who is part of a bigger group. Not always easy to get everyone's agreement when it comes to risk-taking. Sub297

Feature 1.5.2 details the services and supports that should be outlined in the personal plan. It is important that this list is not perceived as definitive and that flexibility is available to enable the service provider to meet individual need. All of the supports listed may not be required by the person, or indeed possible for the person based on the services available locally. The following amendment is proposed to the introductory paragraph of this feature: Each person has a personal plan that outlines the services and supports that they need to achieve a good quality of life and to realise their goals, which may or may not include the following supports: A definition of 'transitions' is required in the glossary to the Standards. Sub355

Feature 1.5.2 refers to the contents of a personal plan. A further addition to this plan would be support to access suitable supported or independent living accommodation and support to access relevant social welfare entitlements, in partnership with relevant statutory agencies. Sub370

1.5.2 To access transport services – non existent in rural areas , limited accessible of transport services who will advocate for these? The person, their family or service provider can't be the only partner in this. Sub372

Feature 1.5.3

Feature 1.5.3 requires greater clarification of the definition of 'their life stage' and what elements of their life are taken into account when determining a person's life stage. Sub355

Feature 1.5.4

1.5.4. ", and has a copy of their personal plan" should be changed to ". The person has ownership of their personal plan, while the service provider keeps a copy of it." Sub343

1.5.4. ", and has a copy of their personal plan" should be changed to ". The person has ownership of their personal plan, while the service provider keeps a copy of it." Sub365

Feature 1.5.5

No data

Feature 1.5.6

1.5.6. Positive risk-taking. What exactly does that entail? Is a staff member watching covertly or are they on their own? (I am relating all this to my son who has a moderate learning disability with very little speech and no understanding of numbers but has good communication skills and good health. Very active. Age 34.). Sub100

Standard 1.5.6 what is positive risk taking – either provide a definition or remove the phrase. Sub266

1.5.6 This is a very relevant & important standard within New Directions, the need to promote progression for an individual is indicative to positive risk taking. Positive

risk taking is absolutely a priority and the standard I.5.6. should go even further to promote a culture of “positive risk taking” within service delivery. Sub291

Feature I.5.6 states that risk assessment and positive risk taking should underpin the delivery of each person’s personal plan. In general, positive risk taking needs further consideration throughout the Draft Interim Standards as services need to become accomplished in managing positive risk if the objectives of New Directions are to be fully realised. In addition, risk assessments are based on acknowledged history and known risks. Stating that risk assessments and positive risk taking underpin delivery of a person’s personal plan sends a message that the service will be more formal and involve further assessments and red tape before someone can make a decision or take an action. People with disabilities in our services pointed this out about the draft saying that it sounded more formal and more involved in people’s lives that has previously been the case. Concern was expressed regarding staff being over-concerned with trying to manage all aspects of a person’s life for fear they make a bad decision for themselves. This is echoed in staff feedback – responsibility must be limited to the agreed supports and should not be all encompassing. Positive risk taking requires the support of the whole community and training should be made available to relevant stakeholders. Sub355

Families: Specifically, the Standards should require service providers to engage with families in relation to positive risk taking to ensure they understand that necessary precautions are being taken but that some risk must be tolerated in the delivery person-centred services which are designed to maximise independence. In one of (Service Provider Name) family focus groups, families stated that there had been a great deal of progress in the supports that their family member receives but that often they felt that they were being asked to come to terms with their family member achieving a greater level of independence without having time to get used to the idea. One parent said that (Service Provider Name) treats her child like an adult but that she had always treated them as a child and it was taking time for her to understand and feel comfortable about her child’s new found independence. This was particularly the case for older parents of older adult children. Sub355

Special and mainstream schools: The traditional approach to supporting a child with a disability is to protect them more than a child without a disability. This is necessary and appropriate. However, it is important that children are encouraged to achieve their individual maximum level of independence in line with their age and abilities. Schools therefore require support with implementing positive risk taking. Sub355

Standard I.5.6 what is positive risk taking – a definition should be provided. Sub359

Standard I.5.6 what is positive risk taking – either provide a definition or remove the phrase. Sub378

Standard I.5.6 what is positive risk taking. Sub379

Standard I.5.6 what is positive risk taking – a definition should be provided. Sub380

Feature 1.5.7

1.5.7. "and/or their representatives" should be "and their family/representative".
Sub343

Feature 1.5.7 states that the person's family members and friends should participate in this planning process in line with the person's needs and wishes. Where it is the person's wish, it is important that the role of the family is specified. The Standard should make it clear that families have a shared responsibility in supporting the person towards their goals. Sub355

1.5.7. "and/or their representatives" should be "and their family/representative".
Sub365

Feature 1.5.8

Feature 1.5.8 could be amended to place greater emphasis on the role of the family, where it is in line with the person's needs and wishes. The following amendment is proposed: Feature 1.5.8 Families support the service provider and others to be involved in developing and supporting the person's personal plan. Sub355

a) Areas that should be included: 1. Working with families: The standards provide for families to be involved in support plan development (Standard 1.5.8 and 2.5.6), however there are times when a families well-intentioned fears or caution inhibit people from supported risk taking, pursuing opportunities or achievable goals, available to them, or making choices about the activities they'd like to pursue. This is particularly in the case of people living at home. Services would like to assist the person in setting their own goals, and the steps that are needed to achieve these goals and choices, but this is sometimes made more difficult by parents. A set of guidelines for parents to guide them through how to best support their adult with a disability would be very helpful. A set of guidelines for working with families would be useful to both people with a disability and their day service providers. Education and training for parents, in the skills to deal with challenging behaviour, supported risk taking, and managing independence may also alleviate this situation and be helpful for young adults who wish to become more independent and make their own choices. Sub367

a) Areas that should be included: 2. Rights, and access to support for romantic and sexual relationships. The Standard's only brief mention of sexuality and romantic relationships is in relation to health (Standard 2.8.2), however the standards should more explicitly advocate for the right of adults with a disability to explore and practice their sexuality and romantic feelings in a safe and supported environment. In particular, people who live with their families, may feel their privacy and dignity will be better preserved by asking for the support and advocacy of their day services in relation to romantic and sexual relationships. Comments from people with a disability: "I want the right to have a family." "I'd like to have a boyfriend (girlfriend) and maybe have a baby." Sub367

a) Areas that should be included: 3. Working with local communities. For adults with more profound disabilities, local community can be a place where they are not

treated as adults with autonomy, and freedom of thought. Many people experience neighbours and members of local community who will defer conversation to parents or support workers. These attitudes will take time to adjust and although those who are more able and interested will spend more time in local communities, some people will still chose to not undertake activities outside of the environments where they feel included and valued. Sub367

Feature 1.5.9

1.5.9 Service providers need to develop systems and tools that promote maximum participation within the review of personal care plans. Sub291

Feature 1.5.10

1.5.10 SMART goals, objectives & outcomes need to be subject to specific, accountability and responsibility within a team. The standard 1.5.10. needs to highlight key working or similar as a system & tool in achieving this. Key working that is prioritised into areas of responsibility that has clear outcomes for the individual. Sub291

1.5.10: It would be helpful to capture the difference between an activity and an outcome. For example, some people see 'going swimming' as the outcome whereas it is in fact an activity that is used to achieve an outcome such as 'losing weight', 'getting fit', 'making new friends' etc. The goal isn't 'going swimming twice per week'. It is 'losing a stone', 'being able to swim a length of the pool without stopping', 'meeting at least two new friends' etc. Sub424

Feature 1.5.11

1.5.11 Caution required on this, it may be open to manipulation. Strong evidence would need to be provided that a person declined. In a service where a large percentage of service users declined then questions should be asked. Sub110

1.5.11: If a person declines to engage in the planning process it may be due to their lack of insight or as a consequence of their disability/injury. It might be necessary to have a family member or advocate of their choice to be involved if this is the case. Also in some cases professionals and or multidisciplinary teams may need to make a decision that would be in the best interest of the client. Service providers, clients, family members, advocates need to work together in the planning process and safeguards need to be put in place to protect all involved. It is not possible to be all things to all people, we need to be realistic and ensure we do not set our clients up for failure. Sub279

1.5.11. "people and their representatives" should be "the person and their family/representative". Sub343


1.5.11. "people and their representatives" should be "the person and their family/representative". Sub365

Standard 1.6

1.6 Each person is supported to use their local community facilities--while alot of our service users have an active role in the community some feel that acceptance into some of the community is limited. Sub040

Regarding standard 1.6 Inspectors should check people's natural support networks and check what support is needed from services like (Service Provider Name) to develop these further. Sub066

1.6 would like to see more facilities for people with special needs like training programs. Sub078

	<p>When we spoke about people using their local community, it was said it had improved, the question was asked who will bring us. Ratio of Service Users to staff does not make this standard easy to achieve, unless a big group go and there are still issues around accessibility.</p> <p>Sub093</p>
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1.6 Central to the new thinking is the role of the community. Many parents/carers believe that this community accommodation is totally overestimated and out of touch with the reality of modern society and its structure and functioning..The high expectation of such community integration and involvement is one of the weakest aspects of New Directions. The real fear is that such an ambition is not achievable in the manner assumed in the new Standards and the parents/ carers will be left to fill the gap and pick up the pieces. There are no details of how to harness the community but again it just throws it at the service providers. Moving to mainstreaming from the service providers is vague and does not take into account cost and extra staff required .Mainstreaming will be achievable in part for some but for others very limited. Sub095

Yes the Standards are certainly relevant to the provision of Day services for adults with Disabilities. However we would like to note that many features within Standards 1.6, and 1.7 may be difficult to assess and/or achieve for adults with complex needs and/or a severe to profound intellectual disability. Sub106

1.1 the rights of each person are respected; 1.3 choices 1.4 decision making; 1.5 personal plan; 1.6 support in local area; 1.7 chance to try new things; 1.8 goals & dreams. We work with each service user to adhere to all of the above. Each service user has their own consultations every year on their choices of activities and personal supports are in place to assist service users achieve their life choices. Sub113

Standard 1.6 There is a common theme coming back to us from feedback that our service users feel they won't be accepted in the community and would like to know what plans are in place in relation to education the general public regarding those with disabilities. Sub141

1.6 Community- Agreed [The nature of ID precludes most from being pro-active]. Sub242

To whom it may concern

Thank you for giving us the opportunity to comment on the plans for new and updated services for clients. My brothers and I (and our late mother) are grateful to the (Service Provider Name) (and its many guises and name changes) over the last 40 years. Our brother, Persons Name based in (Area Name) has been one of the clients since then. I understand that you are updating and creating new standard operating procedures and protocols but I'm guessing that some of these procedures are already in place and that you wish to formalise them? Or is it all something new? We love the idea of involving the clients in more social events, perhaps in the evenings and at weekends. Our main concern with our brother is that he can be quite isolated outside of work hours. He is quite independant but a bit of a loner and we are often worried that he feels lonely as he lives alone. Most of his friends seem to live too far away to see them regularly. So it would be nice to know that there would be a couple of social events that he could go to without him having to think and stress about organising it himself. I would also like to know if each client will be assessed individually again?.... to see if they are getting enough out of life and indeed if life is getting enough out of them? We were a bit concerned about his general motivation. eg. getting himself up in the morning and getting out and having a purpose. Sub247

Where is funding and resourcing coming from to meet the provision of these new services? While much of what is outlined reads well in theory, it needs concrete financial support and a solid structure to make it a success. Also, will availability of service depend on geographic location? Sub249

Standard 1:6 - This needs more specific information, will support be readily available, who will support Service User. Sub252

Standard 1:6 - Available resources play a very large part in supporting this standard i.e. staff and transport. Willingness of local communities to take part due to lack of information and fear in certain cases. Sub252

2.6 – Social roles in community – a lot at night-time. Parents aging do not always want / or able to take on this role. Sub252

Inclusion in Ones Community – Could community be where they work rather than where they live? Sub253

Standard 1.6- this standards states that each person should be supported in their local area but does not address cases where the individual does not want to be supported in their local area. Sub261

Standard 1.6 – Community involvement may be a problem for a lot of people as these people are so used to mixing within their own group and this will pose problems. Sub270

Standard 1.6 This standard says that each person is supported to be in their local area and use everything that their area has to offer. People are supported to have relationships with other people in their local area. People can have supports to get to know people if they want. Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? Agree. It's important to keep the relationships that help each other. What does local mean? Can local apply to other communities outside one's own locality. Very important that supports are in place to help people develop relationships if they wish. Come out of your own area. Sub278

Standard 1.6: each person cannot access community services even with supports. This is not possible only in some cases; unfortunately the community has not always got the appropriate supports. A person centred approach is needed, evaluations, service users getting to know their community and what it has to offer is very important in a real way. Sub296

Standard 1.6: Who are the community leaders? Services need to network more with local community and develop relationships locally. This takes a lot of time and energy. Services are generally very behind in assistive technology need adequate resources to do so. How will this happen with cut-backs? Sub297

However, we would like to note that many features within standards 1.6, and 1.7 may be difficult to assess and / or achieve for adults with complex needs and / or a severe to profound intellectual disability. Sub342

1.6: This standard is good and the way forward, support for inclusion – this is good for all clients self esteem and independence been part of local community. Sub348

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 Sub353

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. Sub353

Standard 1.6: There are a number of areas of concern in the what it means for you section of this Standard: The first bullet point states “you are supported to take part in activities in the local community, as a member of that community” and suggests

that is the sole responsibility of the service provider to enable this outcome. It should be reworded to read: “You are supported by your service provider, family, friends or other natural community supports to take part in activities in the local community”. The second bullet includes the following “with support from staff if you need it” and should be reworded to reflect the fact that many people will support you in your activities as follows, “You choose the activities you want to take part in, with the support of staff or families, friends or other natural community supports”. Sub355

Fully community-based services may not suit every person with a disability who requires a day service. People with physical disabilities with high support needs feel secure in an environment like a day centre because they have all the resources they need to ensure they are comfortable during the day such as assisted bathrooms, hoists, profiling beds, assisted shower facilities and staff assistance. In the community many people with high support needs may not be able to access bathrooms if they need assistance to transfer. In resource centres dedicated to people with physical disabilities, some people get fatigued during the day or need a break from their wheelchair, and a hoist and profiling bed is available if needed. People with acquired physical disabilities are often older and have already had careers, raised families and have attended mainstream third level education courses and at their stage in life their needs and wants are different to people with disabilities who have not had as much life experience. Also accessibility to buildings in the community can be limited and needs to be considered, many wheelchair accessible bathrooms are too small for people with larger wheelchairs to use and some community buildings do not have facilities to evacuate a wheelchair user in the event of a fire. The easy read version of Standard 1.6 does not refer to the individual’s choices, needs and abilities and this would be important to include. Sub355

Standard 1.6 [quotes from Sub355]

“This Standard is important as it outlines the importance of inclusion within the local community and local area. As a service it is vital that we provide the support necessary for individuals to access community events and outings on a daily basis”.

“Our centre is very far from some people’s local area so they have little opportunity to access their own community as they are reliant on transport. Transport should be provided and as a Standard as without this people are excluded unless a family member has an accessible car. (Service Provider Name) clients have an outreach programme so they have access to their local community”.

“Some people don’t want to get involved in their communities so how will I be supported in the activities I want to do”

“This Standard needs to very much looked at on an individual basis. NO person should ever feel under pressure to stay in their own local area if they do not feel it is right for them. Some people have very limited resources in their own area and enjoy getting out of their local community to meet more people”

“This is a laudable Standard because having a disability/condition can be very isolating. However, it would depend on the individual (their environment, family support, community facilities, community groups, transport etc.) whether this is an achievable aspiration outside of the (Service Provider Name) facility”

“It is important for us be able to use whatever services are available in the community for us, to have relationships and to get to know people in our communities and to get help from our service if we want to do this”

“Why say ‘local area’? Its people’s choice, local area may not be the community you choose. Just because there is no choice about housing, the local area may not be the place you feel good or part of, or want to be in. There is no housing choice and this effects how people integrate and feel connected”

“Expected in our service, we are out in the community. All service users should have access to the community services we do. Even transport is so important in feeling involved and connected”

“It is very important. People in the community are very supported. The members feel very welcome”

“A focus on community inclusion helps work towards living a normal, fulfilled life and takes the focus away from feeling different”

“I like being able to get out more and involving my family and friends”

“Worries about how people could be perceived in the community without the same level of support”

[end quotes from Sub355]

Standard 1.6 there should be acknowledgement of the friendships that are accessed through services and peer groups that have developed over time. Sub359

‘I like going to the gym and playing football with my friends’ (Standard 1.6); ‘I’d like more friends’ (Standard 1.6); ‘I’m 39 and I’d like to have more fun’ (Standard 1.6); ‘I want to make new friends in my life now’ (Standard 1.6); ‘I need more fun in my life now that I’m in my 20s’ (Standard 1.6); ‘More work placements outside of (Service Provider Name) (Standard 1.6). Sub367

SU’s felt that lack of cars prohibit them from accessing there local community supports. Some SU’s felt that Service Provider staff should not be so stern when a SU gives another SU a hug. They suggested that a policy should be written up and followed by all staff. They expressed that positive touch is healthy and can make you feel good. Sub368

As above in relation to Community responsibility in allowing people with disability to avail of natural community supports. We should remove the language that attributes responsibility of family or service provider to provide specialised options (1.6) . Sub369

Standard 1.6 The success of New Directions is based on engagement by all stakeholders in the community in supporting and welcoming people with disabilities into community activities and amenities. While it is understood that this standard relates to the responsibilities of service providers, it is important that the role of other stakeholders is reflected also. In its current form, this Standard could be interpreted as placing all responsibility for community integration on the service provider, which would be unlikely to succeed from the outset. Sub370

1.6 Engagement with community leaders and community life need to be supported by National Government agencies not just the service provider, where is the role of the family? Aren't they best placed in their own community to forge natural supports for their family member? Sub372

Standard 1.6 places the focus on the person coming into community as a person with a disability and not on the person coming to community as a person, possibly in a role based on 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. Sub374

Standard 1.6 there is no mention of the role of family supports that are available. Sub378

Standard 1.6 there is no mention of the role of family supports that are available. Sub379

Standard 1.6 there should be acknowledgement of the friendships that are accessed through services and peer groups that have developed over time. Sub380

1.6 This standard is particularly important for service users. many commented on the importance of walking to work, meeting people in town and attending local clubs. This was well understood. Sub381

Standard 1.6 It would be useful to include a periodic review of how a person with a disability is engaging with the community. Sub392

1.6 This standard would be a challenge to achieve for some of the adults with severe autism, severe and profound intellectual disability who also have a physical disabilities. Sub412

Feature 1.6.1

General feedback on Theme I was positive. Staff are concerned about the practicality of carrying out all of the work involved due to the lack of resources (staff, facilities) as a result of constraints on budgets. Standard 1.6.1. This involves service providers and support staff becoming much more political and active in raising awareness about disability issues within the community. Support from other Government bodies and agencies is needed to assist in bringing about change as Service providers cannot do this in isolation. There needs to be joined up thinking

from Government so that the onus is on society / communities / employers etc to be more inclusive. Sub263

I.6.2 This is the key for successful community integration, the standards I.6.1. – I.6.2. highlights this absolute necessity. Community based organisations should be streamlined & a data base created, as to allow for awareness, access & participation. The difficulty in accessing community facilities is service providers do not know “what is actually out there”. A standard should be created as to put some responsibility on community organisations to submit their service. A data base should be created with governance from and within the implementation group or similar. Sub291

Feature I.6.1 The following amendment is proposed to this feature “In partnership with other stakeholders, service providers play their role in engaging with community leaders to raise awareness about disability and to facilitate inclusion in community life and education”. Improving attitudes to the inclusion of people with disabilities is the responsibility of many stakeholders within the community. In its most A National Survey of Public Attitudes to Disability in Ireland, the National Disability Authority identified a deterioration of attitudes to people with disabilities. There are many agencies charged with raising awareness of disability issues including the National Disability Authority, the Equality Authority and other government bodies. It is essential that this cross-agency approach is acknowledged within the services. When these Standards become regulation, it will be difficult for service providers to demonstrate how they have single-handedly changed the attitudes of people with disabilities. A definition of ‘community leaders’ should be included in the glossary which accompanies these Standards. Sub355

Feature I.6.1 The following amendment is proposed to this feature “In partnership with other stakeholders, service providers play their role in engaging with community leaders to raise awareness about disability and to facilitate inclusion in community life and education”. Improving attitudes to the inclusion of people with disabilities is the responsibility of many stakeholders within the community. In its National Survey of Public Attitudes to Disability in Ireland, the National Disability Authority identified a deterioration of attitudes to people with disabilities. There are many agencies charged with raising awareness of disability issues including the National Disability Authority, the Equality Authority and other government bodies. It is essential that this cross-agency approach is acknowledged within the services. When these standards become regulation, it will be difficult for service providers to demonstrate how they have single-handedly changed the attitudes of people with disabilities. Sub370

Feature 1.6.2

I.6.2 This is the key for successful community integration, the standards I.6.1. – I.6.2. highlights this absolute necessity. Community based organisations should be streamlined & a data base created, as to allow for awareness, access & participation. The difficulty in accessing community facilities is service providers do not know “what is actually out there”. A standard should be created as to put some

responsibility on community organisations to submit their service. A data base should be created with governance from and within the implementation group or similar. Sub291

Feature 1.6.2 should be amended to reflect the need for person-centred supports. While a service provider should be in a position to provide information about services available in the local community, the person should also be supported to identify the activities they would like to participate in or goals they wish to achieve and the service provider would work with them to help them to achieve that. Dependence on a list of local community activities may be an obstacle to truly person-centred outcomes. Sub355

Furthermore, individuals should be able to self-refer to community-based activities and these services should be able to accommodate the needs of all members of the population. A current lack of truly accessible community-based services is a real obstacle to the full implementation of New Directions and to the achievement of these Standards by service providers. Every stakeholder must play their role in creating a society that is more accessible to people with disabilities. Sub355

Further consideration should also be given to the need to “actively network with community-based organisations” as this may require a different staff skill set and competence to what staff were hired and trained to do. Resources may be required to provide training to staff to gain these skills. Sub355

Feature 1.6.2 should be amended to reflect the need for person-centred supports. While a service provider should be in a position to provide information about services available in the local community, the person should also be supported to identify the activities they would like to participate in or goals they wish to achieve and the service provider would work with them to help them to achieve that. Dependence on a list of local community activities may be an obstacle to truly person-centred outcomes. Sub370

Feature 1.6.3

1.6.3: To get to know own community and local people is very positive, however education around disability should be provided to the community. Sub279

1.6.3: The concern again is that the standards do not emphasise any training for the community in relation to disability and could the extra burdens on community resources have negative outcome for people with disability. Sub279

Feature 1.6.3 states that people are introduced to local services and actively supported to access them. This is an extremely important feature and will play a significant role in supporting people to increase their independence and access new opportunities. Access for people to community services is extremely important e.g. education opportunities in the day time, supported work services and housing services. However, the system doesn't currently work well as these community services can be limited due to demand, dependent on location and can seem exclusive due to cost. Sub355

Feature 1.6.4

1.6.4 local communities need to be informed of how services intend to move forward and have information. This might help them to adjust their thinking and perception of how they see services for people with disabilities. Sub291

Feature 1.6.4 requires that people are supported to get to know the community and local people and to build natural relationships in the community. The question of how this will be measured arises. Also, it is very difficult for service providers to support people to build natural relationships if families and the community are not also involved. Throughout this Standard the responsibility is placed on the service provider while the natural supports of the family and other community groups are not charged with any responsibility. Sub355

Feature 1.6.4 requires that people are supported to get to know the community and local people and to build natural relationships in the community. The question of how this will be measured arises. Also, it is very difficult for service providers to support people to build natural relationships if families and the community are not also involved. Throughout this standard the responsibility is placed on the service provider while the natural supports of the family and other community groups are not charged with any responsibility. Sub370

Feature 1.6.5

1.6.5. Participation in the community. A lot of what I read sounds airy-fairy – most people in the community are working and have families and are not in a position to get involved. Plus if there is involvement it is only for about an hour or so. What happens then? Sub100

1.6.5: Concerned with the terminology used i.e. developing friendships especially in the community could lead to clients having an expectation around developing relationships, we must be appropriate at all times, putting clients needs first. It may be more appropriate to use a different term such as developing partnerships/making connections. Very important to ensure all involved with this process are safe including the community at large. Sub279

Feature 1.6.5 could be further strengthened through the addition of the following amendment “In partnership with families, local stakeholders and other community groups, service providers are proactive in identifying and facilitating initiatives for participation in the wider community, development of friendships, involvement in local social, educational and professional networks. Sub355

Feature 1.6.5 could be further strengthened through the addition of the following amendment “In partnership with families, local stakeholders and other community groups, service providers are proactive in identifying and facilitating initiatives for participation in the wider community, developing friendships, involvement in local social, educational and professional networks. Sub370

Feature 1.6.6

Feature 1.6.6: Clarification is required in relation to the service providers' responsibility in relation to this Standard which requires the provision of supports to access assistive technology and communication aids. In some situations, such aids can be expensive and no funding is available for their purchase. Is it the responsibility of the service provider to fund this equipment or could such funding be undertaken in partnership with the person with a disability, his/her family as well as other funders in the community? Sub355

1.6.6: Accessing assistive technology very important and necessary – provision needs to be made for accessing assessments as a starting point and related costs need to be built in. Sub279

Feature 1.6.6: Clarification is required in relation to the service providers' responsibility in relation to this Standard which requires the provision of supports to access assistive technology and communication aids. In some situations, such aids can be expensive and no funding is available for their purchase. Is it the responsibility of the service provider to fund this equipment or could such funding be undertaken in partnership with the person with a disability, his/her family as well as other funders in the community? Sub355

There are a number of areas of concern in the what it means for you section of this Standard: The first bullet point states “you are supported to take part in activities in the local community, as a member of that community” and suggests that is the sole responsibility of the service provider to enable this outcome. It should be reworded to read: “You are supported by your service provider, family, friends or other natural community supports to take part in activities in the local community”. The second bullet includes the following “with support from staff if you need it” and should be reworded to reflect the fact that many people will support you in your activities as follows, “You choose the activities you want to take part in, with the support of staff or families, friends or other natural community supports”. Sub355

Fully community-based services may not suit every person with a disability who requires a day service. People with physical disabilities with high support needs feel secure in an environment like a day centre because they have all the resources they need to ensure they are comfortable during the day such as assisted bathrooms, hoists, profiling beds, assisted shower facilities and staff assistance. In the community many people with high support needs may not be able to access bathrooms if they need assistance to transfer. In resource centres dedicated to people with physical disabilities, some people get fatigued during the day or need a break from their wheelchair, and a hoist and profiling bed is available if needed. People with acquired physical disabilities are often older and have already had careers, raised families and have attended mainstream third level education courses and at their stage in life their needs and wants are different to people with disabilities who have not had as much life experience. Also accessibility to buildings in the community can be limited and needs to be considered, many wheelchair accessible bathrooms are too small for

people with larger wheelchairs to use and some community buildings do not have facilities to evacuate a wheelchair user in the event of a fire. Sub355

Feature 1.6.6: Clarification is required in relation to the service providers' responsibility under this standard which requires the provision of supports to access assistive technology and communication aids. In some situations, such aids can be expensive and no funding is available for their purchase. Is it the responsibility of the service provider to fund this equipment or could such funding be undertaken in partnership with the person with a disability, his/her family, as well as other funders in the community? Sub370

Many family members highlighted the impact of the lack of local community transport links in rural areas saying that this supports a level of dependence among people with disabilities as they access the community because they are always reliant on someone for a lift. In a focus group which took place in the (Area Name) concern was also expressed about transport "Transport is an issue here as there is not a lot of public transport in (Area Name). People go into the community a lot but this is more difficult at night time and weekend if there is no one available to drive them in. If there was better public transport this would be much easier". Sub370

1.6.6 Using the word 'Support' is aspirational surely it is a right ..to access assistive technology and communication aids. Rather this standard should promote an assessment of need and then HSE provide Financial supports for speech and language therapy input, assistive technology and communication aids as required. Sub372

Standard 1.7

Regarding Standard 1.7, recently my son transitioned from one service to another within the same organisation, the transition was very messy and unsettling for "the person" and caused huge stress on his family. Sub036

Standard 1:7 What happens if the person needs continuous supports. Who will fund this? Sub097

Yes the Standards are certainly relevant to the provision of Day services for adults with Disabilities. However we would like to note that many features within Standards 1.6, and 1.7 may be difficult to assess and/or achieve for adults with complex needs and/or a severe to profound intellectual disability. Sub106

1.1 the rights of each person are respected; 1.3 choices 1.4 decision making; 1.5 personal plan; 1.6 support in local area; 1.7 chance to try new things; 1.8 goals & dreams. We work with each service user to adhere to all of the above. Each service user has their own consultations every year on their choices of activities and personal supports are in place to assist service users achieve their life choices. Sub113

Is the layout easy to follow? (Standard 1.7) I find this hard to follow: My reason is transitionis saying that the Client is being cut away from its Support Provider. Does

this mean – they are no long attached to their day center or are now independent. Sub142

1.7 Transition – Agreed [a standardised transition passport will be required]. Sub242

Standard 1.7. There is concern about the acceptable length of time for a transition plan, will there be guidance on how long a transition can take or is this dependent on the person developing the plan. Sub266

Standard 1.7 Each person has the chance to try new things that they are interested in. When people are changing from one type of service to another, they are supported with the change. For example, if people used to go to a day centre and then they start going to a fitness class in the local gym, they get any support they need while they are getting used to the new class. Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? Happy. Important we agree on helping people. Important because people may not be able to adapt to a change or new environment without a proper support structure in place. They could get support. It's part of getting healthy and fit. Sub278

Standard 1.7: Not sure; there is much movement between services and day service places as limited due to funding. Sub297

However, we would like to note that many features within standards 1.6, and 1.7 may be difficult to assess and / or achieve for adults with complex needs and / or a severe to profound intellectual disability. Sub342

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. Sub353

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. Sub353

Standard 1.7 Each person is supported to make transitions between supports provided by specialist and mainstream services and tries new experiences on an ongoing basis, in line with their choices, needs and abilities. This requirement to support people to make transitions is welcome and is fundamental to the

achievement of New Directions. The features of the Standard focus on when a transition arises rather than on the need for services to be constantly supporting people to progress to the next stage whether that is outside of the disability services or in taking up a new activity within their disability service. Sub355

Everyone gets satisfaction from a sense of progress and people with disabilities should be supported to experience change in their lives. It is important to note that the potential for transition will be limited by local opportunities, particularly in rural areas where opportunities are not always available. Moreover, transitions between mainstream and specialised services will require changes in terms of admission and discharge policies and flexible funding provision will need to be put in place. Sub355

The what it means for you section, could be enhanced through the inclusion of a statement such as “you are supported to find new opportunities and to progressing to new activities throughout your life” This Standard also needs to include a statement that a service may not necessarily be a “service for life” and that transitions and the use of natural community supports are a fundamental part of the service and of the person’s person-centred plans. This section should also include the need to develop a support plan for people approaching 65 years of age who may have fewer natural community supports as their parents are aging as well. This transition plan will require the full support of all stakeholders including the HSE. The easy read version of Standard 1.7 does not refer to the individual’s choices, needs and abilities and this would be important to include. Sub355

Standard 1.7 [quotes from Sub355]

“This Standard is important as it recognises that each person has the ability and interest to do new things that they may choose too. As a service it is vital that we gather relevant information and plan accordingly to ensure that each individual can try something new as they wish and we put the support into place where needed”.

“This happens as much as possible depending on staffing levels as with wheelchairs, rollators we need 1:1 staffing for these activities. Toileting facilities in the community restrict a lot of clients as hoisting is necessary” (feedback from a physical and sensory service)

“Very important to get support with a change / trying new things. It gives a person great confidence when they know that they have support available to try something new”

“The more support the better. It’s very intimidating to be confronted with a new environment (e.g. many new people, lots of noise, unfamiliar venue, poorly designed disabled toilets, location of fire escapes etc.) and having support makes it not so stressful and daunting”

“This is an important Standard for us to have support going to other services and to have the chance to try new things in the community. This will help us to feel confident and to become independent and to someday attend by ourselves”

“We like to have support to try out different things, sometimes these supports will be only for a short while but some service users will need support long-term”

“This Standard is important to us so that we can all try new things and see if they suit us and be able to reach our goals. It is important that we are helped to see our dreams come true and things we do are recognised”

“Yes, we feel very supported transiting from one service to another/work/activities. (Service Provider Name) is very supportive and helpful”

“It is important that people feel part of their community and for people to discover their own talents and strengths. Some examples brought up were individuals finding new talents and strengths through the work done with creative writing and at our local gym. The group agreed that had these opportunities not been arranged, they would have never discovered what they were capable of”

[end of quotes from Sub355]

Standard 1.7. There is concern about the acceptable length of time for a transition plan, will there be guidance on how long a transition can take or is this dependent on the person developing the plan. What happens if supports cannot be reduced because of the specific needs of the individual? If the implementation of this is going to require additional funding where will this come from? Sub359

Standard 1.7. This standard is welcomed, but should also include reference to independent living. People with a disability and their families may need experiences, rather than information, to make a decision (or trust a decision) about whether a person has the skills required to live independently or in a community. These experiences of living independently, or in community, could be provided through respite facilities, workshops or trial living experiences. An experience-led process is being piloted by (Service Provider Name) in (Area Name) and (Area Name) through (Service Provider Name), an independent project co-ordinated by arts and architecture professionals in collaboration with individuals and communities. Service Provider Web Address - If this standard is to be effective, there should be an imperative for education providers, other day services and health care officials, to liaise with day services in making decisions about transitions (eg, to independent living, or from secondary education) so that the day service has adequate time to work with a person, provide information, explain the range of choices available and the associated factors. This would entail providing all appropriate information (respecting privacy and dignity, and with the permission of the person with a disability) to ensure that informed support can be provided. This is a very pertinent factor in the provision of HSE funding (ie to ensure adequate funding is allocated to meet a person's needs). Currently, information around transition ie. where a person is changing their living or day situation under direction of a social worker, public health nurse etc, is not passed between service providers and health care professionals and this inhibits primary day services from providing the full range of support that they can in line with best practices. Sub367

Standard 1.7 Each person is supported to make transitions between supports provided by specialist and mainstream services and tries new experiences on an ongoing basis, in line with their choices, needs and abilities. This requirement to support people to make transitions is welcome and is fundamental to the achievement of New Directions. The features of the Standard focus on when a transition arises rather than on the need for services to be constantly supporting people to progress to the next stage whether that be outside of the disability services or in taking up a new activity within their disability service. Everyone gets satisfaction from a sense of progress and people with disabilities should be supported to experience change in their lives. It is important to note that the potential for transition will be limited by local opportunities, particularly in rural areas where opportunities are not always available. The what it means for you section, could be enhanced through the inclusion of a statement such as “you are supported to find new opportunities and to progressing to new activities throughout your life”. Sub370

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. Sub374

Standard 1.7. There is concern about the acceptable length of time for a transition plan, will there be guidance on how long a transition can take or is this dependent on the person developing the plan. Sub378

Standard 1.7. There is concern about the acceptable length of time for a transition plan, will there be guidance on how long a transition can take or is this dependent on the person developing the plan. What happens in the case where a person continues to require supports because of their specific needs after transitions have been completed – where will the funding for this come from. Sub379

Standard 1.7. There is concern about the acceptable length of time for a transition plan, will there be guidance on how long a transition can take or is this dependent on the person developing the plan. What happens if supports cannot be reduced because of the specific needs of the individual? If the implementation of this is going to require additional funding where will this come from? Sub380

1.7 People agreed with this standard. Some people expressed concern for the need to be realistic and consider resources. Sub381

1.7 It was felt that this standard was not realistic – once you move you have moved and there is little possibility or choice in terms of different service options. Until individual funding is available for each person it will be challenging to direct the focus around one person rather than groups. The concern with individual funding is that the type of service a person will be able to buy will be limited unless there is an increase in the budget. Families stated their family member is not able to cope with mainstream services. They will always need a lot of support and they questioned how receptive the general population are to people accessing and using community resources and supports. Sub412

Feature 1.7.1

1.7.1 Service providers develop a transition plan in conjunction with the person around the key issues for that person during the transition. Transition Plan from School setting to Day Service should be the first Transition Plan drafted for a school leaver. This should be a follow on from the Integrated Education Plan (IEP under the EPSON Act). This would ensure continuation of training and personal development from 18 into early adulthood. Continuation of objectives and goals will ensure smooth transition. This standard must be amended to reflect changing objectives for both schools and service providers and the HSE. (Service Provider Name) would assist with the wording of this standard. We note that the (Service Provider Name) were part of the publication 'Post-School Education and Training Information on Options for Adults and School Leavers with Disabilities – New Directions' was referenced on page 56 of that publication. Bring the two together now – and put in a Standard for School Leavers. Sub344

Feature 1.7.2

No data

Feature 1.7.3

No data

Feature 1.7.4

No data

Feature 1.7.5

No data

Standard 1.8

Regarding standard 1.8 Inspectors should check all progress made on each service users' goals and dreams. Sub066

1.1 the rights of each person are respected; 1.3 choices 1.4 decision making; 1.5 personal plan; 1.6 support in local area; 1.7 chance to try new things; 1.8 goals & dreams. We work with each service user to adhere to all of the above. Each service user has their own consultations every year on their choices of activities and personal supports are in place to assist service users achieve their life choices. Sub113

Standard 1:8 - Extra resources to be made available to achieving goals. In I.D. services specific Service Users may and will require more support / Finance. Sub252

Areas that should have been included: There should have been information about Relationships/Sexuality. Sub261

Standard 1.8 should be explained further. Sub261

Standard 1.8 Again no mention of the role of families. Sub266

Standard 1.8 Each person moves forward with their goals and dreams. You are supported to work towards your personal goals in all aspects of your life. You are encouraged and supported to try out new experiences. Your achievements are recognised, where appropriate . Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? Happy and agree. Very good standard to live by. Moral encouragement is important to help motivate the person and it's important to help recognise the achievements of the person. Important that people develop their skills and talents. It's important to try out new experiences. Sub278

Standard 1.8: Agree with this Standard in general often very difficult to have developmental progression within day services where there are new learning experiences. Can see it happening at present from school to RT living centre or other training opportunities – this is easier for those with mod/mild ID more difficult for others. No formal accreditation in the majority of current day services. How can this be achieved for everyone? It is fine to have these standards but who is going to support service providers to achieve these? Sub297

Standard 1.8: Each person makes progress towards achieving their goals and aspirations The objective of this Standard and its underpinning features could be combined with Standard 1.7 and this would provide a far stronger Standard. Also the objective of this Standard should underpin Standard 1.5 which provides for the development of a personal plan which should be based on progression and on achieving goals and aspirations. The Standard seems to focus very much on learning rather than on achievement in all areas of a person's lives. Sub355

Standard 1.8 [quotes from Sub355]

“This is also an important Standard as it is vital that people not only achieve their goals and dreams but once they are achieved to move forward with them or maybe even a new goal. This is necessary for individuals to progress in life and for us to provide the support for them to do so”.

“Everybody likes to feel appreciated and encouraged (whether it's by doing rehab to make their own personal situation better, or by contributing to the (Service Provider Name) service through helping others in the centre and in that way contributing in an 'active' way to their own rehab). It's good to get opportunities for new experiences and chances to develop physically and mentally. Who knows what might be in the future for the individual if they can see that the condition/disability does not have to mean that they are designed to a life of monotony. No change – just more education on resources, budgets and expectancies”

“We feel it is important to be recognised or thanked for our achievements/things we do. We feel that the community needs to be educated more on what we do in our day services and that we like being integrated into our local community”

“We are very proud of ourselves when we achieve something or help out in the community, be it big or small, this makes us feel good about ourselves”

“Some of us have been in services for over 30 years. We have developed good skills and have things in our lives that feel good. Where is maintaining this included”

“Stability is important to all people, for a few of us in particular this is related to our mental well being and should be included and recognised as positive”

“Choice should be respected in relation to knowing when people feel good that they can be supported to maintain and enjoy the lives they choose for themselves”

“Yes, we feel very encouraged and supported to achieve goals and dreams. New experiences are welcomed in (Service Provider Name)”

“All were in agreement that this was important. Examples given of support in relation to the Standard included people doing courses such as the leaving certificate and literacy courses. People felt that this should be available to “everybody”

“Having this Standard in place allows us to feel recognised as an individual within a group. Recognition enhances confidence and helps build self-esteem. Support to move forward with dreams and goals enables people to reach their full potential”

“Personal goals are good but sometimes transport is a real problem. We cannot attend things if public transport is not available

Standard 1.8: Each person makes progress towards achieving their goals and aspirations. The objective of this standard and its underpinning features could be combined with Standard 1.7 and this would provide a far stronger Standard. Also the objective of this Standard should underpin Standard 1.5 which provides for the development of a personal plan which should be based on progression and on achieving goals and aspirations. Sub370

Standard 1.8 Again no mention of the role of families. Sub378

Standard 1.8 Again no mention of the role of families. Sub379

1.8 Families were anxious that they are consulted around their family members dreams and goals, and that the necessary resources would be available. Sub381

Feature 1.8.1

No data

Feature 1.8.2

Feature 1.8.2 requires that each person is encouraged and supported to try new experiences and to do new things in their life on an ongoing basis. This should be in line with the person’s goals and wishes outlined in the person-centred plan. At times a person’s wishes for the future may not be possible but staff must be enabled to think innovatively to bring people closer to their goals. For example, in one (Service Provider Name) service, one client identified that he would like to learn to drive.

There were challenges for the young man in relation to gaining a drivers licence but in order to give him a sense of achievement in this goal area, a driver training programme was arranged with a local motor racing track and this gave the individual the opportunity to try out driving in a safe and managed environment. Families recognised the need for realistic goals. One family member commented, “Choice, control of life and integration into life is great but the reality of the situation is that their choice might to be a top model but it’s not going to happen. It has to be realistic”. Sub355

Feature 1.8.3

1.8.3 Formal accreditation (mainstream) may only be available to those in the mild range of ID. Clarity is required in relation to “less formal but structured”. Sub342

1.8.3 There is a lack of clarity in relation to this feature and the reference to ‘less formal but structured’ accreditation. What does this mean in practice? What does this mean for people who do not have formal day services but are taking part in sessional / skills / activation activities? Sub352

Feature 1.8.3 should be considered carefully. Many people currently using Day Services may not be in a position to achieve formal accreditation such as that provided by FETAC. One of the principle objectives of a person-centred plan is to support the individual towards having "a good life" for which formal accreditation may not be available. It is important that these Standards recognise the value of real life achievements such as making new friends, learning how to travel independently, moving into a new home, gaining work experience, learning to cook and to manage money. An emphasis on formal accreditation may move people away from learning these skills towards more formal learning. Sub355

Feature 1.8.3 should be considered carefully. (Service Provider Name) provides a wide range of FETAC award and many people in Rehabilitative Training achieve FETAC accreditation with (Service Provider Name)’s personalised support. However, in addition learners focus on other areas of their lives. It is important that these standards recognise the value of real life achievements such as making new friends, learning how to travel independently, moving into a new home, gaining work experience, learning to cook and to manage money. A sole emphasis on formal accreditation may move people away from learning these skills towards more formal learning. In our consultation learners, highlighted the importance of award ceremonies in recognising their achievements. Sub370

1.8.3 Need for supports and capacity building to local education and training boards. Sub372

Standard 1.9

Standard 1.9 requires amendment to include: 1.9.9 "Other means" referred to in 1.9.8 should include reference to amendment 1.4.7 above. To facilitate communication an advocacy group should appoint a liaison person from within the group to communicate between staff and group. Complaints and concerns should be written and noted by signature of each member of advocacy group and member/s of staff

dealing with the matter. An ongoing file should be kept as record of how the matter is dealt with. Sub004

Regarding Standard 1.9 Inspectors should check if each service has an adequate complaints process. Sub066

Standard 1:9 Numerous independent advocates will be required to ensure complaints are addressed. Maybe every organisation would have their specialised officer taken from the ranks of service user. Sub097

1.9 Our service users are aware of our Customer Complaints policy. We also have a contact service in place, where service users can apply to be linked with a trained member of staff to work through a task or tasks. Sub113

1.9 people listen & act quickly. Sub222

1.9 Complaints – Agreed [Advocacy Services – see 1.1] Sub242

Standard 1.9 People listen to you when you have a complaint or if you are worried about something. If you have a complaint or if you are worried about something, people will do something about it quickly. You will be respected and supported at all times. Sub278

Can you tell us what you think about this standard? Do you think this is important or do you think it should change at all? Agree. Important to help other people and respect them. Sometimes we aren't listened to, so this should be made compulsory and things like the wrap program should be implemented into the course in some way. Standard is essential. Being listened to will help the person feel valued and confident to speak up for themselves. More courage is given to the person when their opinion is listened to and valued. Sub278

Standard 1.9: Makes sense to have a complaints procedure in which all staff, families, and those who use services are aware of. Any complaints/concerns need to be dealt with in a timely and open manner. Information on complaints procedure needs to be in an accessible format. Sub297

Standard 1.9: [quotes from Sub355]

“This is a very important Standard within a service as everyone should feel supported in their environment at all times”.

“It's important that an individual can have their voice heard if they are unhappy or not comfortable with a situation and that their complaint will be taken seriously and dealt with effectively and quickly. Very important do not make promises that you cannot keep / more education for staff. I'd expect this to be the norm”

“This Standard is important to us and we think this Standard should stay 100%. It is important that we are listened to if we are worried about something. Respect is important too”

“This is important to us to have a voice and feel that people are listening especially when we have a complaint”

“It is also important that we get feedback on the progress of the complaint and how it is dealt with”

“Timeframe reassures people and works”

“Yes the people here feel very respected and supported. The centre does act quickly when a problem arises”

“All service users are aware of the steps in place for complaints and to talk to staff with concerns. There is a complaints folder, staff are always on hand to speak to, family members and other programmes are running throughout the year to help give people the tools to speak about any issues.

“How will I get transport to get around. Will I have to pay for taxis?”

“When I finish in the community will I have to go back (to the service) or go home to stare at the four walls”

Is there anything else you want to say about this book? ‘I am lonely, please give me the skills to deal with this’ (Standard 1.9) Sub367

The Features underpinning this Standard prescribe a proportional sensitive approach to complaints which is welcome. New Directions requires a partnership approach whereby good relationships between the person with a disability and the service provider aid the development of a person-centred plan that genuinely meets the wishes and needs of the person as they move through life. Access to advocacy services can greatly enhance a person’s experience of a complaints process and its inclusion is welcome here. Learners felt that this standard is essential, “being listened to will help the person feel valued and confident to speak up for themselves. More courage is given to the person when their opinion is listened to and valued”. Others said “it is very important to know where to go to voice a complaint or a worry”. Sub370

1.9 Family members state that some people are not able to verbalise their concerns, they can show they are not happy but they cannot state the cause of their unhappiness. It is therefore difficult to support and act in a timely fashion. The input of additional support from speech and language therapists is required as currently a lot of priority is directed towards children’s services. Sub412

1.9: Recording of complaints, whether informal or formal, provides a strong mechanism for learning in the service and supports the easy identification of recurring issues. It may be useful to include this. Sub424

Feature 1.9.1

No data

Feature 1.9.2

No data

Feature 1.9.3

No data

Feature 1.9.4

No data

Feature 1.9.5

No data

Feature 1.9.6

No data

Feature 1.9.7

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. Sub353

Feature 1.9.7 Access to advocacy services can greatly enhance a person's experience of a complaints process and its inclusion is welcome here. However, some of our respondents expressed concern about the availability of independent advocates. Sub355

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. Sub374

Feature 1.9.8

1.9.8 The understanding of such behaviour is a dynamic and specific skill. Standard 1.9.8. does not go far enough in outlining the need for staff training in this regard.

Service providers need to have clear responsibility in providing training to meet this standard. Sub291

Feature 1.9.8 refers to the management of behaviours that challenge the service. It is important that processes to manage behaviours that challenge are fully covered by the Standards to ensure that the framework is useful to supporting services which provide support to people with a broad range of needs, including those with the most complex or challenging needs. This Standard should also be reconsidered to ensure that it meets the needs of people with communication difficulties or who are non-verbal. This Standard seems to focus very much on those who have the ability to verbalise their compliment or complaint. Sub355

Feature 1.9.8 refers to the management of behaviours that challenge the service. It is important that processes to manage behaviours that challenge are fully covered by the Standards to ensure that the framework supports services to people with a broad range of needs, including those with the most complex or challenging needs. This Standard should also be reconsidered to ensure that it meets the needs of people with communication difficulties or who are non-verbal. This Standard seems to focus very much on those who have the ability to verbalise their compliment or complaint. Sub370

Theme 2: Effective Services and Supports

General Comments

Theme 2: In theory yes, but how to see how they can be implemented Sub032

Theme 2: Some standards difficult to understand/wordy (e.g. 2.6, 2.10, 2.11) Sub049

I read the guide and its fine. I was interested to read in the second section about buildings being easy to access etc. I would love to see a bigger lift going into my service provider building and also button press access on all doors except personal care. I attend adult services in (Service Provider Name, Location Name). Sub101

'In line with their Choices, Needs and Abilities' statement evident throughout Theme 2. This is the essence of where 'New Directions' can lead us to, which should enable the facilitation of a 'person centred' individualised service provision for each service user, our Goal! Sub106

Part 2: Same layout as part one so similar issues; The pictures are clear and easy to see; Pictures should be in colour; This explains well what we can expect from our service; Pictures matched well with the writing. Sub107

This follows on well from theme 1. Theme two breaks down the types of supports the service users should be getting and is clearly worded. Families felt that most of the supports mentioned were in place and felt the themes were clear and easy to understand. Sub107

We are concerned that there is not enough mention of employment or work-related training as part of this new initiative. While paid employment and vocational training are referenced, we feel strongly that everyone should feel valued and feel that they are making a meaningful contribution to society. As participants on a Rehabilitative Training programme, we are always being encouraged to look to the wider world, and see where we can use our skills and talents for the betterment of society. Sub249

Too many standards in Theme 1 & 2. Sub109

General theme – personal plans – the role of the family supporting an individual to develop these plans is not adequately represented in this standard. Sub266

Overall this entire theme raised questions from staff as to how it would work in practice – complete change in the manner in which the service is currently operating. Sub263

Theme 1: The word "Individualised" was difficult for some people to understand. Although the meaning is explained underneath we suggest putting the word Individualised before "It is about providing support one person at a time" as is done with the word "Effective" in Theme 2. Sub109

The speech and language therapist plus the psychologist are superb in our daughters service. The staff are totally dedicated and are friends both of the service user and the parents. We could not survive without them. Implementing individual plans for each service user requires massive staff input so there needs to be an increase in funding for extra staff to carry out all that is required for the standards to become a reality. Sub239

May be good in theory but can't see how this would practically work in our current environment where, generally speaking from my experience the general public can be uneasy with special needs people. Especially when the general public /communities have so many self expectations in our current environment/lifestyle e.g.- expectations, pressures/ stress with current Austerity, etc. Also often a personal selfishness Sub073

My fear would be instead of improving the person's (User/Client) lifestyle as is the goal of New Direction we would be compromising the person with special needs. I have seen the community working in favour of the person (Client) but have often seen a very negative side and reaction to the special needs person. My fear would be without this being thought out correctly/appropriately, if the special needs person/people were put in this type of situation this would have a huge detrimental negative impact on the person/people in question. This would lead to them going in to a huge decline with a long time effect Sub073

I would ask who are we, or what right would we have to inflict this on these people, if the correct plan and input in to creating this New Direction did not take place, and from what I understand and have read I do not think that this is catering for all possible aspects to such scenarios/ fundamental points, or how these concerns would be mitigated Sub073

How is this determined or arrived at Sub073

How / What staff training has been identified. If this has been identified then at what cost. If this is known has there been budget approval. If none of the above has been identified then how would any of this plan work Sub073

Who would systematically monitor the effectiveness of services? Sub073

Satisfied with layout / wording; Services and supports are not so effective because of lack of staff Sub252

evaluation of Service? Does our Service need to look at evaluation? Sub252

Difficulty envisaged around Supported Employment and Vocational Training. Individuals competing in a highly competitive environment for jobs and opportunities. Sub254

Schemes such as Tus for the unemployed (individuals on DA do not qualify) now highly involved in volunteer community work in all areas. This will impact on individuals in our Service getting equal opportunities to participate in same Sub254.

Availability of suitable Training in the community an ongoing difficulty Sub254.

Would like the pictures in colour, Sub263

Consideration should be given to developing standards and themes which would deal with management of medication risks for ensuring safety of people. This could also address helping to ensure that the service provider has arrangements in place for assurances about effective implementation of such a policy Sub424

Three general observations: (1) What about people who are unable to understand or who do not have capacity to make decisions around health care? Perhaps there should be a responsibility on the provider to promote positive health for people, whilst ensuring that the promotion of personal responsibility in other sections of the features would not be lost? (2) What about people at normal retirement age – age appropriate, mainstream response? Meeting the needs of people with age appropriate interventions rather than always driving education, training etc (3) What about appropriate end-of-life care? Sub424

Standard 2.1

Comment on Standard 2.1: I agree that it should be person-centred. I think the person would feel better. Sub049

Regarding standard 2.1 the ‘Statement of Purpose’ should be made available and accessible to all who use that service. This should be checked by inspectors. Sub066

Standard 2.1 the picture for “Statement of Purpose” is not accessible to people who can’t read- suggestion change picture to one that isn’t just words. Standard 2.1 the word “Service provider” is very confusing for people supported, none in fact understood it suggestions organisation could be used in place of “service provider”? Sub109

2.1 Statement of Purpose – We consult with members individually and as a group to inform the Annual Plan for each service. This directs the type of service and activities requested by service users. Sub113

Are the order and structure of the Draft Interim Standards Logical for services and support for adults with disabilities? Standard 2.1 (Understanding) In line with the Service Providers Statement Purpose? This is important. Clients should have all their needs attended to with no excuses. Service Provider is expected to have all in place for them. Sub142

Standard 2.1 effective means working well. The organisation provides different types of support. Sub213

2. 1 Responsive – Agreed [*Supports are goal oriented & Evenings/weekends are offered but poorly supported*] Sub242

To whom it may concern

Thank you for giving us the opportunity to comment on the plans for new and

updated services for clients. My brothers and I (and our late mother) are grateful to the (Service Provider Name) (and its many guises and name changes) over the last 40 years. Our brother, Persons Name based in (Area Name) has been one of the clients since then. I understand that you are updating and creating new standard operating procedures and protocols but I'm guessing that some of these procedures are already in place and that you wish to formalise them? Or is it all something new? We love the idea of involving the clients in more social events, perhaps in the evenings and at weekends. Our main concern with our brother is that he can be quite isolated outside of work hours. He is quite independant but a bit of a loner and we are often worried that he feels lonely as he lives alone. Most of his friends seem to live too far away to see them regularly. So it would be nice to know that there would be a couple of social events that he could go to without him having to think and stress about organising it himself. I would also like to know if each client will be assessed individually again?.... to see if they are getting enough out of life and indeed if life is getting enough out of them? We were a bit concerned about his general motivation. eg. getting himself up in the morning and getting out and having a purpose. Sub247

The Standards would appear to relate to people with moderate impairments but without clear mention of the requirements for adults with severe impairments in having the necessary support. Is it intended that 2.1 covers this area? Sub260

Standard 2.1: this area is vital for the success of any person choosing their own day service or other in the community. If the planning and supports are always there, everything will work according to the choices the service user makes. However the reality is, this is not always the outcome. Access can be an issue, physical, learning or environmental. Standard 2.3: When people start using supports, they are not always fair and it is difficult following just how they are decided. A better structure is needed and a sharing of information to all. Sub296

Standard 2.1: Day services are as flexible as they can be at present but they do not usually support people in the evenings or at weekends. How are services going to be able to provide these within existing day service, funding and structure 9-5 Monday-Friday – parents do not want to loose this. Difficult to support individual in group type funding day services. HSE – will they provide additional funds to resource this? Sub297

Standard 2.1 – Need clarity around statement of purpose, it this envisaged as a general statement of purpose across the service or individual statement of purpose and function for each person supported. Express concern that there is greater responsibility on the service provider to respond, be flexible and offer supports in evening and weekends when resources may not always be available. Sub351

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. Sub353

Standard 2.1 [quotes from Sub355]

“This is a very important Standard as an individual needs are unique to each individual and supports need to be person centred in order to meet each individuals needs effectively”. Sub355

“The ‘Statement of Purpose’ document is important and should be displayed on a prominent noticeboard in the centre so everyone is clear as to what (Service Provider Name) is all about. This needs a lot of explaining because people can and do read literally, and they can start to demand”

“This is an important Standard we think that the services should help us with our personal needs and our choices. We think that it is good that the services let people know what service they will be providing to people”

“All people should be given information on different types of support the organisation is willing to give them”

“Yes agree, we feel lucky to have a service like this already”

“All the service users are aware of the safety statement of purpose and feel it’s meeting their needs. This should be an ongoing element of service provision”

[end of quotes from Sub355]

Standard 2.1 How will this be measured to ensure that the services and supports are truly responsive and this is not a subjective assessment? What will happen if the achievement of goals is resource dependent and resources are not available? How will this take into consideration individuals who require support to make plans and require facilitated decision making. Whilst families are not mentioned there is a role for families and an individual’s circle of support here. Sub359

‘I live at home with my parents. I’d like the standards to work with/for my parents and me’ (Standard 1.5 and 2.1). Sub367

The focus of this Standard will be central to the successful implementation of *New Directions*. Each service provider should be able to provide supports which are responsive to a person’s needs. However there will be limitations to the service provider’s ability to provide services and supports that reflect the goals set out in each person’s personal plan in all cases. To an extent, service providers will be limited by the services available in the community to achieve the goals set out in each person’s personal plan. In addition, there may be costs associated with the person’s goals and these will have to be balanced with the person’s other needs and the resources available to the service provider. All service providers will be dedicated to implementing *New Directions* as far as possible but the Standards must reflect the limitations which do exist. This is particularly important in the context of future

external inspection where the service provider could be deemed non-compliant because it is not in a position to fulfil all the goals within a person's plan. Sub370

Learners felt that this standard is not clear, "It's important for the statement of purpose to exist while enabling supports to be used in such a way as to encourage a person-centred approach. The user should be able to choose the supports they needs, rather than it being forced upon them." They felt strongly that individual needs must come before the needs of the group. Other learners said that it is very important that people can access practical skills to build their independence. They highlighted the need for supports with money skills, travel skills and support to learn how to undertake cookery / domestic tasks. Sub370

Many of the Standards in Theme 2 are dependent on a person's needs' which could allow services to use the excuse of high support needs to deny 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 Section 2.1 – it seems that the service provider determining choice. Sub374

Standard 2.1 How will this be measured to ensure that the services and supports are truly responsive and this is not a subjective assessment? What will happen if the achievement of goals is resource dependent and resources are not available? How will this take into consideration individuals who require support to make plans and require facilitated decision making. Whilst families are not mentioned there is a role for families and an individual's circle of support here. Sub380

2.1 people found terminology difficult in this standard. Sub381

Feature 2.1.1

2.1.1. This is such an important standard, supports need to be clearly outlined, so they actually reflect goals. Therefore goals need to be practical, realistic and reviewed. This standard could go further in putting some responsibility on service providers, to systematically departmentalise goals into achievable components, time framed with clear accountability. Sub291

Feature 2.1.2

The layout is quite clear, however it was felt that at times the document was over professionalised. Simplifying the layout of the standards by not using 1.1.1.and 2.1.2 etc would make the document clearer. Because of the length of the document all families present felt the feedback time was too short for proper consideration to be given to each item. The strongly felt that the time period was unrealistic and more would prepare individual feedback if a longer time frame was given. Sub379

Feature 2.1.3

2.1.3: Flexible service and supports are provided; most day services are 9 to 5 with some evening social groups. We are not resourced to provide services at weekends. We can however support clients in accessing information on what is available over

the weekend in their own communities. We suggest to maybe look at the wording around this standard so as clients are clear on what our remit would be. Sub279

Service users: *Supports should help you look after your wellbeing.* Families: 2.1.3 – offering “evening and weekends”...show me the money. It feels like everything is changing and services are not providing much anymore – emphasis on using community for education/training/social activities is all well and good but this costs money and that always comes back to families. Sub291

2.1.3. Individual goals should not stop at any specific time in the day, a culture needs to exist to promote the concept that services & supports are not nine to five, Monday to Friday. However this may have resource implications. Some mention should be made regarding the use of volunteer schemes and peoples natural support networks in supporting people (shouldn't all be service led). Sub291

Feature 2.1.3 states that flexible supports may include offering supports in the evenings and weekends. This will require a number of actions: This will require a collective approach by the HSE and all relevant providers in partnership with Trade Unions to ensure that any Human Resource issues are cleared in order for this to happen. For example “role changes for staff”, “lone working”, “change in hours of work”, etc. This Standard gives the impression that it is the sole responsibility of the provider to support people at weekends and evenings. Primary responsibility must be placed with the family. This must be made very clear prior to HIQA's inspection of the Standards. This Standard could also give the impression that support at weekends and evenings is in addition to the day service element while it may be that resources only allow the provision of evening and weekend services in lieu of day service time. Additional funding will need to be made available for this Standard to be implemented. Sub355

2.1.4 - Services and supports need to protect changing needs and wishes of an aging population. Emphasis should be put on providing Advocate for person with I.D. Sub252

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. Sub353

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 persons wishes without taking action to support their preferences. Sub374

Standard 2.2

"Standard 2.2: People are involved in the planning, design, delivery, monitoring and evaluation of services." Should be amended by including: People are involved in the planning, design, delivery, monitoring and evaluation of services. Where profound impact on communication abilities by way of speech, writing and other forms of communication exists, an advocacy group composed of volunteer family members, members of staff or people interested in the general welfare of that person from the

wider community, should be set up to represent that persons needs on an ongoing basis. A focus of that group should be the maintenance of records on meetings of the group. Sub004

2.2 Identifying supports for each and every individual is an enormous task and assumes that the independent assessment of needs is done independently and thoroughly. No indication of costs. Identifying such supports is ideal but an awful lot of work needs to be done before we reach that stage The assumption service users have the capacity to be involved in the design /formation / evaluation and monitoring of the Standards is over stated. Sub095

2.2 Every summer, there is an individual plan review when service users have the opportunity to review their choices. Sub113

Standard 2.2 sets out that service users are involved in the planning, design, delivery, monitoring and evaluation of services. This mentions that service users are to be involved in staff recruitment, staff training and staff development. This will be very difficult to implement and get agreement from staff on. Sub141

2. 2 Involved - Agreed [Opportunities in policy making, etc exist but few are interested or able & Involvement in staff recruitment & training is not VFM. Clarification is needed for when consultation with representative organizations is “appropriate”]. Sub242

Standard 2.5 were rated as the most important. (68.9%). Standard 2.2, Standard 2.4 and 2.11 rated the next most important.(55.1%). Sub245

Standard 2.2 Training and upskilling needed for organisations to enter into this consultation process, what is best practice in this area and how does one make it work effectively (not just tokenism). Consultation in the area of staff recruitment, service location, staff training and development are totally new concepts and will require a significant change in organisation culture and approach. Sub263

Is there anything else you want to say about this book? Use “you” or “my” etc. Part 2: “effective services & supports” “right services and supports for me. “statement of purpose” —> “what we have in _____ to offer you”. 2.2: Picture is ok (could use for 2.2 & 2.3) Sub292

Standard 2.2: Welcome this Standard but in the majority of cases once parents have secured a day service for their son/daughter they seem to take a limited role in the running etc of services. They want a full service that meets their needs. Will the HSE fund all of the above staff training and development? Who will train and support service users to be involved in staff recruitment etc so that it is a meaningful experience – recruitment is a very complicated process – HR departments do not always get it right!! Sub297

2.2 It should be interesting. Sub303

2.2 Service Users involved in recruitment of staff support. Training required for providers to make this happen. Sub342

2.2 Adults accessing day supports / services need support in order to have a more involved and meaningful role in the planning, designing, monitoring and evaluation of services. Sub352

Standard 2.2 [quotes from Sub355]

“It is an important Standard as it is good to know when a support or plan may or may not be working as effectively as possible. Therefore it is always important to revise and check to see if supports are working well”.

“Staff and service users work together to ensure that all supports work well”

“Yes, people need to be auditing it to see how well it is performing and whether its aims are still appropriate, or feasible or up-to-date”.

“This is an important Standard as each person has different abilities and supports can be provided for each person’s different needs and they can have a say in their own plan”

“All service users should be involved in all aspects of planning and support that is required for them to live a fulfilling life”.

“Choice is highlighted a lot as important but this may mean we don’t have a say in who looks at our files”.

“It is important to have concrete work done between staff and service users. The work done by a service user is done in consultation with a staff member and not by a staff member. The Standard is especially important because it is all about the inclusion of the service user in this process”.

[end quotes from Sub355]

Standard 2.2 Quarterly meetings should take place in services with staff and service users. Advocates should be sought to attend meetings on behalf of service users to voice any issues, concerns or suggestions. Sub355

2.2 Dedicated resources needed to support, engage, educate and facilitate people who use services and their families to be involved in planning, design, delivery monitoring and evaluation of services. This model won’t just happen without training and awareness raising. This takes time if it is to be meaningful engagement and not a paper/token exercise. Sub372

2.2 Family members felt that they are given input but not involved. With some service users they would not understand the concept of policies. Also with some of the service users being part of staff recruitment it would be tokenism. They felt that this point was applicable to a minority of individuals. Some of the service users can

choose their keyworker after getting to know the people they are working with.
Sub412

Feature 2.2.1

Feature 2.2.1 provides that individuals have access to information to allow them to participate in the development and review of policies and practices which affect the service they receive. This information should be provided in accessible formats and the person should be as fully engaged as possible in the process of policy development. Concern was expressed in some more traditional day services within (Service Provider Name), that this level of engagement would be difficult given the funding available for staff:service user ratio. Sub355

Feature 2.2.1 provides that individuals have access to information to allow them to participate in the development and review of policies and practices which affect the service they receive. This information should be provided in accessible formats and the person should be as fully engaged as possible in the process of policy development. Sub370

Feature 2.2.2

Standard 2.2.2 I would query the appropriateness of families having participation in staff recruitment and training. Also service users in staff training. Sub038

2.2.2 Supports and formal structures are in place to recruit staff to make the evaluation of the service successful to meet with HIQA demands. Sub142

Standard 2.2.2 very positive and powerful statement “the user is a partner in service rather than a recipient”. Overall this entire theme raised questions from staff as to how it would work in practice – complete change in the manner in which the service is currently operating. Sub263

2.2.2: We feel it would be positive for clients to contribute to staff recruitment and would look at developing a policy to meet this support. We would like at clients getting involved with the process and look at overview of duties and competencies required for the position advertised. Sub279

2.2.2. Without adequate staff training New Directions will not work. Specific areas of training should be outlined as to streamline the skills needed for appropriate service delivery. Sub291

2.2.2 remove "where appropriate". Sub343

Feature 2.2.2 – The following amendment is proposed to the introductory paragraph to reflect the need to fully consult with people with disabilities and their families in relation to service issues: Supports and formal structures are in place to consult with people with disabilities and their families, where appropriate, and to enable them to contribute their views in areas such as: [check source document for rest of quote]
Sub355

Feature 2.2.3

Feature 2.2.3 recognises that staff require training and support to listen and respond to people's views and are equipped to work in services where the user is a partner in service rather than a recipient. Similar training and support will also be required for people who are using the service, many of whom have passively received services for many decades. Training in empowerment and advocacy will be necessary. In addition, capacity legislation will be needed to enable people to assert their rights to make decisions about their lives both within the service and outside with their families. In our family focus groups there was a strong sense that families want to be more aware of changes that are taking place in services, particularly with the introduction of *New Directions*. Many participants in the family focus group were concerned about that the implementation of the Standards could mean the closure of the resource centre or the reduction of the 9-4 service that they relied upon in their lives. To ensure that families are fully informed and can support the roll-out of *New Directions*, it would be appropriate for the Standards to require service providers to demonstrate that they had mechanisms for consultation and engagement with families, where that is the choice of the person with a disability and that there would be a specific standard and criteria established for that. Sub355

Feature 2.2.3 recognises that staff require training and support to listen and respond to people's views and are equipped to work in services where the user is a partner in service rather than a recipient. Training in empowerment and advocacy will be necessary for people with disabilities. In addition, capacity legislation will be needed to enable people to assert their rights to make decisions about their lives both within the service and outside with their families. Sub370

Feature 2.2.4

2.2.4 requires amendment to include: The service provider takes the views and preferences of the people who use their services into account when they are planning and delivering services and supports. These views should include the views of both service users and their representatives and advocates outlined in 1.4.7 and previously. Sub004

4.2.4 include a time frame, needs deadlines for all parties to act on changes. Sub263

Standard 2.3

Comment on Standard 2.3: True. Sub049

2.3 That things would be explained as many service users are unable to read. Sub081

Standard 2.3: some people think some individuals get more support and attention than others at times. Some people were not sure about this standard. Sub096

I note from the draft (Standard 2.3) that "access to services and supports is determined on the basis of fair and transparent criteria". Key to this is obviously an identification of individual needs, in this regard can the following information be provided: Who is responsible for determining the fair and transparent criteria? What are the fair and transparent criteria for access to services and supports? What are

the criteria for determining individual needs? Who will be responsible for determining individual needs? When and by whom will the assessment of individual needs be completed? Sub114

Standard 2.3 Should encompass a transition period where it is statutory that each Su get a phasing in period from school to day service. Sub226

Standard 2.3 is very vague because it doesn't explain how fairness will be applied/ensured. The statement of purpose is confusing, it should be explained more. 2.10 is also confusing- 'bridging programme' should be explained with examples. Sub261

Standard 2.3 - a more formal structured approach to admissions and contracts for service provision could only be a very positive thing in outlining clearly what is being offered and accepted and for what period of time. Sub263

2.3 "gets support in a fair way" should say something about people being involved in interviewing their supports as these supporters will be working for them. Sub281

2.3 Did not understand picture. Sub292

Please comment below. Include the specific standard and/or feature number that you are referring to. Standard 2.1: this area is vital for the success of any person choosing their own day service or other in the community. If the planning and supports are always there, everything will work according to the choices the service user makes. However the reality is, this is not always the outcome. Access can be an issue, physical, learning or environmental. Standard 2.3: When people start using supports, they are not always fair and it is difficult following just how they are decided. A better structure is needed and a sharing of information to all. Sub296

Standard 2.3: All of the above very welcome – service agreements will clarify what supports and services are available in a day service and if people accept this (limitations and all) the family sign up for same – avoids confusion along the way. Not always easy to discharge a person from Services especially if they have nowhere else to go – resistance from families. If we are to assume that everyone has capacity (as this document suggests) tell me how a person with severe/profound ID will be able to engage in the above. Sub297

Standard 2.3 [quotes from Sub355]

"Important Standard as each person has different needs that are identified and it is important that the support given meet those needs accordingly".

"Fairness is important – it's important that each individual feels equally valued, and that supports are clearly discussed".

"This is an important Standard for us. It is very important that people are treated fairly it is also important that we know what supports services can give to us".

“It is important that supports are given fairly, if one Su requires more support in order to live an independent life than another they should be able to get these supports”.

“Fairness is important. Especially in terms of time and attention. Sometimes people that are the most disruptive and loud get the most attention - to stop them upsetting people. They expect a lot. Also some people ask or expect staff to do things they can and should do for themselves. Everyone should be treated fairly and this is a good Standard”.

“Supports in a fair way is debatable. Some people get more support than others. Yes, to decisions been made clear to each person. Group is divided on behavioural procedure”.

“We get support when we need it. Sometimes our families might want us to have different supports. This is a difficult one”.

[end quotes from Sub355]

Standard 2.3 In a responsive service meeting the changing needs of an individual how can this be reflected within a written agreement. Will there be examples available to demonstrate what is required. This aspect of the standards will increase the level of paperwork required and where an individual's needs are constantly changing this may be difficult to maintain. If a service is unable to meet the identified needs of an individual due to resource constraints how will this be viewed. There should be a standardised needs assessment as otherwise there could be a level of subjectiveness in needs identification. Sub359

2.3 Who will train staff to listen respond and how this will be delivered? Sub372

Standard 2.3m – each person's supports are based on fair and transparent criteria – is this going to be at the discretion of individual organisations or will national guidelines be developed? It was felt that a standardised needs assessment should be provided and this would make the provision of supports less discretionary. Sub379

Standard 2.3 In a responsive service meeting the changing needs of an individual how can this be reflected within a written agreement. Will there be examples available to demonstrate what is required. This aspect of the standards will increase the level of paperwork required and where an individual's needs are constantly changing this may be difficult to maintain. If a service is unable to meet the identified needs of an individual due to resource constraints how will this be viewed. There should be a standardised needs assessment as otherwise there could be a level of subjectiveness in needs identification. Sub380

2.3 Decision about using a service, and trying it out before committing to it. One of the parents said that it could take her daughter a couple of months to get to know somewhere re staff etc. and vice versa. How realistic is this in the real world? Sub412

Feature 2.3.1

2.3.1. / 2.3.4 The language used here implies a formal day service support arrangement and reflects the language used in the residential standards. Sub352

Feature 2.3.2

No data

Feature 2.3.3

No data

Feature 2.3.4

2.3.1. / 2.3.4 The language used here implies a formal day service support arrangement and reflects the language used in the residential standards. Sub352

Feature 2.3.4 The language of this Standard is very medical with a focus on words like admission and discharge. This is unfortunate as day services need to move fully away from medical provision to health and social care services. It is however appropriate for entry to and leaving a service to take place in a timely way, determined on the basis of fair and transparent criteria. Sub355

Feature 2.3.4 The language of this Standard is very medical with a focus on words like admission and discharge. This is unfortunate as day services and rehabilitative training programmes aren't medical services and need to move fully away from medical provision to health and social care services. It is however appropriate for entry to and leaving a service to take place in a timely way, determined on the basis of fair and transparent criteria. Sub370

Feature 2.3.5

2.3.5 Signed agreement between service users and service providers needs in most cases the involvement of carers. Sub095

2.3.5. "Each person and/or their representative sign" should be "Each person or their representative signs" Sub343

Feature 2.3.5 states that the person and/or their representative sign an agreement. It is necessary to consider the contexts in which a person's representatives would sign rather than the person. Where a person is physically unable to sign a document but has capacity to do so it is not necessary to ask their representative to sign but a record should be kept. A representative should sign only in a small number of situations where the person does not have the capacity to do so, otherwise the contract should be between the person and the service provider. The emphasis on signed documentation in this Standard may not be appropriate given the nature of the client group. In some cases a video recording of an agreement may be more appropriate to facilitate a person to fully participate. In the *what it means for you* section of this Standard it states that *When you decide to start using a service, there is a written agreement between you and the service provider.* The terms of this agreement will need to be strictly articulated. It will need to be based on a very strict personal assessment tool that is agreed between the HSE and the provider and will need

rigorous testing. The details of this agreement will need to be included in the SLA between the provider and the HSE. Furthermore, consideration needs to be given to how best to providing such agreements and assessments to existing service providers. Sub355

2.3.5. "Each person and/or their representative sign" should be "Each person or their representative signs". Sub365

Feature 2.3.5 states that the person and/or their representative sign an agreement. It is necessary to consider the contexts in which a person's representatives would sign rather than the person. Where a person is physically unable to sign a document but has capacity to do so it is not necessary to ask their representative to sign but a record should be kept. A representative should sign only in a small number of situations where the person does not have the capacity to do so, otherwise the contract should be between the person and the service provider. The emphasis on signed documentation in this Standard may not be appropriate depending on the client group. In some cases a video recording of an agreement may be more appropriate to facilitate a person to fully participate. Sub370

Feature 2.3.6

2.3.6 This standard feature refers to a service statement – the definition of which is in the glossary of terms as 'a statement which specifies the services and supports which will be provided to an individual by or on behalf of the HSE and the period of time within which such services and supports will be provided.' This is in addition to the signed 'agreement', which is not explained in the glossary of terms, and the 'personal plan'. This has potential to be very confusing and it needs to be made explicit what is intended and the difference between the three documents in order to avoid confusion. Sub352

Feature 2.3.7

2.3.7 There is a planned introduction for each person when they start using services and supports. This may be phased (e.g. shorter day initially) to allow for transition to a new environment. Sub344

Feature 2.3.8

If New Directions proposes to allow adults using services to live a life of their choosing and in accordance with their own wishes, needs and aspirations, why is there need for Section 2.3.8. 'People who decide to move or who are requested to move from a service?'. Under what circumstances can a person be requested to move from one service to another maybe yet another? Sub301

Standard 2.4

Regarding standard 2.4 All types of support should be examined, eg, paid/unpaid, staff/family/volunteer/friend/peer etc. Sub066

Theme 2: effective services and supports: (2.4) great ideas but how will they be funded? E.g if deemed appropriate evening and weekends existing services on the point of collapse funding. Sub232

2. 4 Social Skills – Agreed [*relevant, community based, reviewed –but community is under-resourced see2.1*] Sub242

Standard 2.5 were rated as the most important. (68.9%). Standard 2.2, Standard 2.4 and 2.11 rated the next most important.(55.1%). Sub245

As before when you work with adults with disabilities who cannot understand or comprehend what is being said it is very hard to enable them to develop personal skills and social skills without the aid of staff standard 2.4. Sub262

Standard 2.4 - for the large part supporting individuals who avail of day services in the evenings and at weekends is not being done at the moment. This will present a challenge to organisations from a staffing and resource point of view. Sub263

2.4 should also have pictures of i-pads and smart phones. Sub281

2.4 – 2.11 – Pics ok. Sub292

Standard 2.4: Welcome this Standard. Can be difficult for day service staff to link with residential/respite staff with the difference in shift patterns/evening and weekend work. Would be great for the individual if this could be seamless. I think evening and weekend supports need to be facilitated by friends and family who have contacts in their own local community days service supports/centre not always in people's local community. Sub297

Standard 2.4 People develop their personal and social skills in line with their choices, needs and abilities, so that they can realise their goals and aspirations. This Standard is strong as it recognises peoples' needs to achieve their goals in areas of their life other than education. Sub355

Standard 2.4 [quotes from Sub355]

“Communication is very important and supports need to be available for people to be able to communicate in whichever way needed. This is a very important Standard as communication is such an important part of everyday life”.

“Communication needs to be done on a 1:1 basis suited to each person”.

“Generally, communication is verbal (the use of technology is limited – through lack of skills/ lack of technology on part of service users. More education / remember to use your resources not only staff, some services users have come from very knowledgeable backgrounds”.

“This is an important Standard to all of us that people have support with their communication if they need it”.

“Communication is very important and there is different ways that some people communicate. We need to be understood as individuals and we need to understand others. Some people need assistive technology in order to communicate successfully”.

“People may need support to use this technology and extra support in order to communicate our needs and be understood”.

“We need to be fair and understanding for this and give all people equal opportunities to communicate their needs”.

“Supports for communication are important because it gives you hope that nothing is out of reach”.

[end of quotes from Sub355]

Standard 2.4 – this does not take into account the geographical difficulty some individuals face within rural settings. Offering supports in the evening is a great idea but if there is a lack of transport infrastructure locally this may not be possible as individuals may be unable to get home after being out. The family and other supports should also be included within this standard as to facilitate socialisation and community based programmes it is essential that these links are available and support is achieved through this areas as well as from services. Sub359

Standard 2.4 This Standard must include access to free social time with peers. Many adults with a disability talk of loneliness or feelings of isolation, in relation to peers more than local community or supporters. Community based and community focussed social activity must be complemented by opportunities to meet and socialise with peers, and make friends with peers beyond their own communities/day services. This social development opportunity could be facilitated between families, day service providers, and communities or possibly independent networks. Sub367

(2.4) SU's strongly felt that they are restricted on what they can and cannot do when relief or ordinary staff from the residential houses support them in Day Services as staff are not sure what to do. SU's suggested if there were more full time day service staff, they would be supported much better as they know the running of the centre and can take more calculated risk's with them through training. Sub368

Standard 2.4 People develop their personal and social skills in line with their choices, needs and abilities, so that they can realise their goals and aspirations. This Standard is strong as it recognises peoples' needs to achieve their goals in areas of their life other than education. Learners were happy with this Standard, as they felt that it would help with communication which is key to helping the person to develop. Supports such as sign language and speech therapy, etc should be made available. People need to communicate with others to get support. Sub370

Standard 2.4 – this does not take into account the geographical difficulty some individuals face within rural settings. Offering supports in the evening is a great idea but if there is a lack of transport infrastructure locally this may not be possible as individuals may be unable to get home after being out. The family and other supports should also be included within this standard as to facilitate socialisation and community based programmes it is essential that these links are available and support is achieved through this areas as well as from services. Sub380

2.4 Offered activities in evenings and weekends. Families want the security of their 'day placement Mon Fri 9 a.m. 4 p.m. or whatever the agreed hours are. If they do not have access to a day service this will result in earlier requests for residential places and increased demands on Respite services. Many families viewed day services as an extension of Respite and they would be unable to cope without it in view of the significant support needs of their family member. It was felt that a lot of responsibility currently rests with service providers to source the community opportunities and there is little sign of it happening the other way round. Sub412

Feature 2.4.1

No data

Feature 2.4.2

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. Sub353

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 psychology and to be free to partake in ordinary life experiences without being shielded by the service. Sub374

Feature 2.4.3

2.4.3 Family response to this feature was if it meant the day service supports had to be restructured to meet this standard, they would not be happy about this. The majority of families want Mon-Fri 9-5 day service support. Unless the HSE are providing extra funding to enable supports to be in place for week end and evening supports it will not be possible to provide this service within the current budgets. The people we support were happy to have this support in the evenings and weekends. Sub077

Feature 2.4.3 requires clarification as including supports in the evening and at weekends will present challenges to existing services and staff. It may lead to a reliance on day service staff to fulfil more support roles in people's lives and result again in over-stretching and a lack of clarity in relation to responsibilities. Social activity and event support is important and is carried out within the day service but for many individuals no support is required. More evening and weekend work would affect staff structure, ratios in day services and increased costs in terms of budget. It would also raise lone worker concerns. Sub355

Feature 2.4.4

No Data

Standard 2.5

2.5 more help to make my daughter more independent. Sub078

2.5 Independent living unfortunately is outside the scope of many service users and this must be taken into account in any plans. Sub095

Standard 2.5: Some people felt that some individuals need a lot of support from staff to make choices and that this is important to recognise in the standards. Sub096

2. 5 Independent- Agreed [resources needed to manage risk i.e more staff & community resources] Family support is variable & Provider is not “In Locus Parentis”] Sub242

Standard 2.5 were rated as the most important. (68.9%). Standard 2.2, Standard 2.4 and 2.11 rated the next most important.(55.1%). Sub245

Standard 2.5- this is raising the issue of extra supports outside of those on offer by the day service, supports for independent living provided in the individual's home, community integration in evenings and weekends - new approaches needed which will require increased funding and resources and perhaps new models of service delivery being designed. Sub263

Standard 2.5 the role of the family is integral to this process and is not reflected well. Whilst families are expected to encourage people to take responsibility for their own lives they are not included in the other aspects of this process. Sub266

Part 3 picture of Fireman was confusing for people - but was meant to be about “people making decisions about the supports they get.” & “People have the right to choose to take appropriate risks.” Sub281

Standard 2.5: It would be great if people are supported to reach full independence in all areas of their lives. skills, training, etc. Some families find it difficult to risk-take with their son/daughter's safety. The words “risk”, “risk-taking” and “risk assessment” are emotive for families – they will need a great deal of support regarding this and risk has to be measured and managed properly. Sub297

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. Sub353

Standard 2.5 People develop skills to manage their own lives and maximise their independence in line with their choices, needs and abilities: All of the features provided for under this Standard will contribute to services enabling people in services to attain a greater level of independence. These should be central to all Day Services One issue to be considered was a raised at one of (Service Provider Name) focus groups – a sibling of an older person with a disability expressed concern about the stress that greater independence was placing on her sister. She said that the person had not been treated as an adult during her whole life and now at the age of 60 and having joined (Service Provider Name) for the first time she was being asked to consider a far greater level of independence and this was causing her anxiety. A consideration of independence must be age appropriate and must acknowledge that

older people with and without disabilities can be slower to embrace change than younger people. Sub355

Standard 2.5 [quotes from Sub355]

“This is also an important Standard as promoting independence through means of support is essential. It is important for us as a service to provide the correct support while trying to promote independence where appropriate on a daily basis”.

“This is important as the ultimate aim of (Service Provider Name) is probably to rehabilitate individuals back to as normal and independent a life as is possible for them, and having access to supports is vital as they navigate that journey – Most important Standard of all”.

“This is an important Standard to us. Supports like this will help us outside the centre and help us become more independent”.

“Some people may always need supports in life to improve our skills and manage our lives. This support should be given”.

“Respecting independence and choice is key for maintaining good mental health for some”.

“Yes people say they are being encouraged to be independent in the Centre. Support to be independent is very good. Staff are very good”

“If you want to move forward in your life independence has to be promoted and the aim of your focus. Independence is a basic human right and needs to be encouraged and promoted”

It could be a good thing to help people build skills to manage their own lives better. This Standard will help us to realise what help we do need to manage different parts of our lives”

[end of quotes Sub355]

Standard 2.5 the role of the family is integral to this process and is not reflected well. Whilst families are expected to encourage people to take responsibility for their own lives they are not included in the other aspects of this process. The partnership approach to risk assessment is essential however in some situations family or circles of support should also be included as otherwise it is the individual and the service making decisions in isolation of the other support avenues for the individual. Sub359

The Draft Interim Standards in their entirety are suitable and relevant to people with mild to moderate disabilities. For those with more profound disabilities many of the proposed Standards including access to further education, vocational training, paid employment and managing health and independence are not realistic (2.5, 2.8, 2.9, 2.10 and 2.11). The standards must reflect and be appropriate for people with a wide range of abilities. Sub367

'I depend on my family too much. I need to know on my own about money, food, job, bills for living' (Standard 2.5). Sub367

(2.5) SU's felt that more communication was needed with Houses and Day Service's to make decisions for them to be more independent. Sub368

Standard 2.5 People develop skills to manage their own lives and maximise their independence in line with their choices, needs and abilities. All of the features provided for under this Standard will contribute to enabling people in services to attain a greater level of independence. These should be central to all Day Services and Rehabilitative Training programmes. Learners said that "independent living is important but not everyone may be ready for it, depending on what stage they are at in their lives. For those who are, independent living is important and should be encouraged. Users should be told it is ok to ask for help and continued moral support". One learner said that developing independent living skills was very important because they had a goal of living on their own one day and they had recognised that support might be needed for a period of time to help then with the transition. Sub370

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 ie. the need should be adequately supported: 1.6 – 1.7 – 2.5 – 2.6 – 2.7 – 2.9 – 2.10. Sub374

Standard 2.5 the role of the family is integral to this process and is not reflected well. Whilst families are expected to encourage people to take responsibility for their own lives they are not included in the other aspects of this process. Sub378

Standard 2.5 the role of the family is integral to this process and is not reflected well. Whilst families are expected to encourage people to take responsibility for their own lives they are not included in the other aspects of this process. Sub379

Standard 2.5 the role of the family is integral to this process and is not reflected well. Whilst families are expected to encourage people to take responsibility for their own lives they are not included in the other aspects of this process. The partnership approach to risk assessment is essential however in some situations family or circles of support should also be included as otherwise it is the individual and the service making decisions in isolation of the other support avenues for the individual. Sub380

2.5 People felt that this standard is one of the most important. Service users said when they get support in this area, they can do much more for themselves. Sub381

2.5 Families feel that for people with severe and profound intellectual disability they will always need significant support and will not be able to live independent lives. A lot of time and knowledge of the person is necessary to enable them to make choices or have someone advocate on their behalf. Sub412

Feature 2.5.1

No data

Feature 2.5.2

No data

Feature 2.5.3

2.5.3: Risk assessments need to be carried out, not only in partnership with the service user, but also with the advocate/parent so that independence is a learned skill, as well as a safe practice. Sometimes the balance between 'safety' and 'risk' is tenuous but independence cannot be achieved unless risk is attempted. Sub103

2.5.3 Positive risk taking, personal responsibility versus service responsibility, again this is an area which requires a lot of work when it comes down to implementation, interpretation and monitoring. Suggestion would be to emphasise positive risk taking more in the standard with the message that services would be credited for supporting positive risk taking. Sub110

2.5.3 It is imperative that positive risk taking should be in banner headlines in this section. "Safe – to manage risk in the environment and an environment for risk". Sub283

Feature 2.5.4

No data

Feature 2.5.5

2.5.5 Developing skills and independence. Sub210

Feature 2.5.5 requires that service providers work with the person to coordinate an integrated package of supports to meet the person's needs and ensure appropriate links between home life and other services that support independence. This would lead to the service acting in a case manager role which is more the responsibility of the social worker. Services need to have boundaries and this could cause uncertainty in terms of responsibility when these links or supports break down. Sub355

Feature 2.5.6

2.5.6: "The service provider will work with your family and other services, where appropriate, to co-ordinate the supports you need to develop and maintain your independence, in line with your wishes" is noted but requires specific outlining per amendments outlined already.

2.5.6 Needs to be highlighted more – mentioned regularly through the document. but particularly at the start of the document. Sub038

Feature 2.5.6 requires the service provider to encourage families to support and enable people to take as much responsibility as possible for their own lives. An additional control could include a formal discussion with families about the level of support that families are able to and willing to give in terms of supports on the weekends. This would deliver a partnership approach to supporting the individual, with actions by both the service provider and the family. Sub355

a) Areas that should be included: 1. Working with families. The standards provide for families to be involved in support plan development (Standard 1.5.8 and 2.5.6), however there are times when a families well-intentioned fears or caution inhibit people from supported risk taking, pursuing opportunities or achievable goals, available to them, or making choices about the activities they'd like to pursue. This is particularly in the case of people living at home. Services would like to assist the person in setting their own goals, and the steps that are needed to achieve these goals and choices, but this is sometimes made more difficult by parents. A set of guidelines for parents to guide them through how to best support their adult with a disability would be very helpful. A set of guidelines for working with families would be useful to both people with a disability and their day service providers. Education and training for parents, in the skills to deal with challenging behaviour, supported risk taking, and managing independence may also alleviate this situation and be helpful for young adults who wish to become more independent and make their own choices. Sub367

a) Areas that should be included 2. Rights, and access to support for romantic and sexual relationships. The Standard's only brief mention of sexuality and romantic relationships is in relation to health (Standard 2.8.2), however the standards should more explicitly advocate for the right of adults with a disability to explore and practice their sexuality and romantic feelings in a safe and supported environment. In particular, people who live with their families, may feel their privacy and dignity will be better preserved by asking for the support and advocacy of their day services in relation to romantic and sexual relationships. Comments from people with a disability: "I want the right to have a family." "I'd like to have a boyfriend (girlfriend) and maybe have a baby." Sub367

a) Areas that should be included 3. Working with local communities: For adults with more profound disabilities, local community can be a place where they are not treated as adults with autonomy, and freedom of thought. Many people experience neighbours and members of local community who will defer conversation to parents or support workers. These attitudes will take time to adjust and although those who are more able and interested will spend more time in local communities, some people will still chose to not undertake activities outside of the environments where they feel included and valued. Sub367

Standard 2.6

May be good in theory but can't see how this would practically work in our current environment where, generally speaking from my experience the general public can be uneasy with special needs people. Especially when the general public /communities have so many self expectations in our current environment/lifestyle e.g.- expectations, pressures/ stress with current Austerity, etc. Also often a personal selfishness. Sub073

My fear would be instead of improving the person's (User/Client) lifestyle as is the goal of New Direction we would be compromising the person with special needs. I have seen the community working in favour of the person (Client) but have often

seen a very negative side and reaction to the special needs person. My fear would be without this being thought out correctly/appropriately, if the special needs person/people were put in this type of situation this would have a huge detrimental negative impact on the person/people in question. This would lead to them going in to a huge decline with a long time effect. Sub073

I would ask who are we, or what right would we have to inflict this on these people, if the correct plan and input in to creating this New Direction did not take place, and from what I understand and have read I do not think that this is catering for all possible aspects to such scenarios/ fundamental points, or how these concerns would be mitigated. Sub073

2.6 volunteering – help and elderly person with their shopping or housework, become a friend to someone living alone. Sub222

2. 6 Social Role – Agreed [There is a limit to what provider can do without family support]. Sub242

Standard 2.6 – I am pleased to see this included, I think for a person with a disability and who does not work outside the resource centre this would greatly improve their mental health and self esteem. Sub255

2.6 should also have picture of sports activities. Sub281

Standard 2.6: Developing social roles for any individual can be difficult, it takes a great deal of time and investment by support staff and families to get to know the individual and recognise their disabilities/skills, their interests and build on these to enable them to develop meaningful social roles/social valuations. Sub297

2.6 Training required for staff in relation to community networking. Sub342

Standard 2.6 In the standard statement use valued social roles but in some of the features it states social roles, need to be consistent and include the word valued ie valued social roles. Social roles can be valued or devalued and people with disabilities are at risk of filling devalued social roles. Sub351

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. Sub353

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”. Sub353

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. Sub353

Standard 2.6 needs more development on Socially Valued Roles and what this means, based on the key interests of the person. Sub353

Standard 2.6: People explore, identify and are supported to develop valued social roles in their community, in line with their choices, needs and abilities: The language in this Standard has needed universal explanation in our focus groups. In particular, the concept of valued social roles has not been widely understood by families and people with disabilities. An alternative such as “and are supported to develop roles of importance and value in their local society and community...” might be easier to comprehend. The use of social role in the what it means for you section also requires consideration and replacement with a simpler wording. The features under this Standard state that people should be supported to explore what would represent a valued social role in their community. While service providers can play a strong role in support the person in finding and participating in a social role, most people's valued social roles come from a variety of interactions, e.g. through family links, through engagement with local community groups or the local church. This is an area where a true partnership approach by all stakeholders involved in the person's life will be essential. Training is required to support staff to fully support people to identify social roles and families could also benefit from training. Funding for this training should be considered as part of the roll-out of New Directions. In the easy read version of 2.6 the word contribution caused confusion to people with disabilities because the word is understood by some to mean pay for. Sub355

Standard 2.6 [quotes from Sub355]

“This is an important Standard as it is vital that individuals have connections and relationships with their families, wider community etc. It is important that as a service we provide the support necessary to promote these relationships and ensure that each individual has positive connections with all aspects of their lives”.

“Needs to be done on a 1:1 basis and no one made to contribute to the local community if they do not wish too”

“That's very important that supports are available because while an individual's 'persona/worth' changes as far as the wider community and society is concerned, to family and friends they are still seen as valuable, vital with worthwhile contributions to make to the lives of others”

“This Standard has been working well, in the most part up to now. Don't try to alter or engineer it to fit any new academically researched scenarios, listen to service users, use service users – Very important Standard”

“This is an important Standard. It is important for us to contribute to the community as much as we can and get involved in groups in the community”

“It is good to have other people in our lives, sometimes it is hard to give , family and friends to give contributions to our lives and we need staff to support us to keep these connections with family and friends”

“The more choice we have the less we rely on services. However sometimes people want more contact with services for peace of mind”

“Taking part in community activities is important and it helps to make us feel like we belong. Sharing is a part of life and it makes people feel good by sharing abilities and talents”

“We feel this is important because doing things for others makes us feel good about ourselves”

[end quotes from Sub355]

Standard 2.6: People explore, identify and are supported to develop valued social roles in their community, in line with their choices, needs and abilities: The features under this Standard state that people should be supported to explore what would represent a valued social role in their community. While service providers can play a strong role in supporting the person to find and participate in a social role, most people’s valued social roles come from a variety of interactions, e.g. through family links, through engagement with local community groups or the local church. This is an area where a true partnership approach by all stakeholders involved in the person’s life will be essential. Learners felt that this standard is important because “encouraging users to contribute and give back is important to personal development. Active citizenship should be encouraged. Everyone should contribute in communities. Family and friends are important things to have in life”. Sub370

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 ie. the need should be adequately supported: 1.6 – 1.7 – 2.5 – 2.6 – 2.7 – 2.9 – 2.10. Sub374

Many of the Standards in Theme 2 are dependent on a person’s needs’ which could allow services to use the excuse of high support needs to deny 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 Section 2.1 – it seems that the service provider determining choice. Sub374

Standard 2.6 needs much more development on Socially Valued Roles and what this means, based on the key interests of the person. Sub374

2.6 Service users found language difficult to understand in this standard. Sub381

2.6 Review of a person's progress re taking up a social role in their community needs to be included. Sub392

2.6 Role in the community. If a class or job works well in the community, it becomes the 'thing for people to do in the community' and can become an isolated class within the community. Likewise if more than one person with a disability joins a group or class, other group members can object or drop out. Getting the balance is a challenge when there are a number of people with disabilities living in an area especially in the city. Sub412

Feature 2.6.1

2.6.1: Community setting: Many service users are not located in their own community & have to travel distances from their home & local community and in this sense they are not part of their local community, so this standard is not achievable in many instances. Sub103

Feature 2.6.2

No data

Feature 2.6.3

No data

Feature 2.6.4

2.6.4: Meaningful role in the community is very positive. However, we need to protect all involved including client confidentiality and ensuring all are safe within the meaningful role. Strategies and supports must be put in place for our clients to ensure they are safe in reaching their full potential. Sub279

Standard 2.7

Regarding standard 2.7 these roles should happen in the community alongside other with or with out disabilities. Sub066

Good standard. Standard 2.7 We think facilitating a persons creative expression is vital in a person reaching their full potential. Sub094

Standard 2.7 the concept of "creative roles" was not clear to some people, although it was explained some people still didn't grasp the concept. Sub109

2.7 the Annual Plan has a wide variety of creative programmes. Sub113

2. 7 Creativity - Agreed [see 2.1 Community opportunities are scarce & costly – more cost-effective in-house] Sub242

2.7 should also have pictures of musician, entertainer and gardener. Sub281

Standard 2.7: Good Standard. People are entitled to develop their talents etc and explore/develop their creative side. Day services are giving people opportunities to do so at present but may not always have a formal plan etc to show evidence of and record same. Sub281

2.7 Increased costs associated with accessing dance, music outings etc. in local communities. Increased staffing resources required. Sub342

2.7 This standard feature assumes that people have hobbies and again raises questions in relation to transport and the costs involved in accessing community activities. Sub352

Standard 2.7 People explore their own creativity and find their own means of self-expression, in line with their choices, needs and abilities: This Standard is welcome. It is (Service Provider Name) experience that people accessing its services can gain a great deal of confidence from development of self-expression and participation in creative activities. Sub355

Standard 2.7 [quotes from Sub355]

“This Standard is of vital importance as it is hugely important for people to make choices and see what they would like to do in their lives. It is then necessary for us as a service to support them in making that choice and providing any support needed in carrying out the decisions and choices that individuals make and make it achievable to them”.

“Being creative and developing new skills is important because human beings are naturally curious and want new and exciting diversions to become absorbed in”.

“This is an important Standard for each person to be able to use their creativity in the services and outside the services. We think that this is good for people so that they are able to express themselves through singing, art and dancing”.

“We all have hidden talents and it is important that we are given the opportunity to explore our creative sides”.

“Find out yes! AND Maintain! This is important and not mentioned as far as we can see”.

“The group agreed that people should get “support to be creative”. “Support to try hobbies” and the “chance to try out” things out such as “drama, music” were mentioned. “Everyone should be able to try things out”. (This) “could be used to try things outside of the centre”.

[end quotes from Sub355]

Standard 2.7 People explore their own creativity and find their own means of self-expression, in line with their choices, needs and abilities; This standard is welcome. It is (Service Provider Name) experience that people accessing its services can gain a great deal of confidence from development of self-expression and participation in creative activities. Learners stated that “it is important to focus on the creative side because it’s not just the academic side that counts. People’s talents: singing, cooking, acting should be allowed to be developed. You could use the supports to give back

to the community. Everyone needs to find out what kind of creative roles are right for them". Sub370

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 ie. the need should be adequately supported: 1.6 – 1.7 – 2.5 – 2.6 – 2.7 – 2.9 – 2.10. Sub374

Many of the Standards in Theme 2 are dependent on a person's needs' which could allow services to use the excuse of high support needs to deny 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 Section 2.1 – it seems that the service provider determining choice. Sub374

2.7 All agreed this standard is good , again there was a caution about "keeping it real". Sub381

2.7 Yes with the right support but this requires more 1:1 support and the resources to achieve this may not be available. There is also a lack of suitable age appropriate activities for the service users and at times a lack of willingness on the part of the general public to welcome people to join some activity groups. Also some of the classes are too advanced for people with high support needs. Sub412

Feature 2.7.1

No Data

Feature 2.7.2

In relation to Feature 2.7.2, in many towns in Ireland opportunities to access and participate in opportunities for creativity and self-expression in the local community simply aren't available. Services have historically invited such services into a centre and paid for them because they aren't available in the mainstream, in the community. In the implementation of these Standards there will need to be a recognition of the limitations that exist in relation to services in the community, particularly in rural Ireland. Where necessary, service providers must have the flexibility to innovate in order to achieve the spirit of the Standards for individuals. Sub355

In relation to Feature 2.7.2, in many towns in Ireland opportunities to access and participate in opportunities for creativity and self-expression in the local community aren't available. In the implementation of these Standards there will need to be a recognition of the limitations that exist in relation to services in the community, particularly in rural Ireland. Where necessary, service providers must have the flexibility to innovate in order to achieve the spirit of the Standards for individuals. Sub370

Feature 2.7.3

2.7.3 With current ratios of staffing:people supported, it is difficult to see how the standards and features outlined in relation to individuals creativity / self-expression can be met - particularly during the evening time and at weekends. Sub352

Feature 2.7.3 states that people should be provided with supports to meet their needs for creativity and states that this may include offering supports in the evening and weekends. Many of our services have already begun to provide an outreach element to services to facilitate weekend or evening activities and this has helped greatly in facilitating community integration. A problem which arises is the cost of activities in the evening. The people using our services often don't have the extra money required to pay for an evening class or to take part in an evening or weekend event. HSE funding covers the cost of the staff member but does not extend to the cost of the activity. At one (Service Provider Name) family focus group, family members present specifically requested that the cost of activities outside the centre be kept low as they simply could not afford them. Sub355

Feature 2.7.3 states that people should be provided with supports to meet their needs for creativity and states that this may include offering supports in the evening and weekends. (Service Provider Name) services are currently funded on a whole time equivalent basis based on a 30 hour week, which limits flexibility in providing supports outside 9 to 4. The current funding structure does not, therefore, lend itself to out-of-hour services. Sub370

A further problem is the cost of activities in the evening. The people using our services often don't have the extra money required to pay for an evening class or to take part in an evening or weekend event. HSE funding covers the cost of the staff member but does not extend to the cost of the activity. Learners highlighted the possible financial implications saying "Volunteering would be free with no financial cost whereas extra classes in the community could cost extra money. If a student is not on a payment, where do they get the money from to take part in these classes" Sub370

Standard 2.8



This picture they did not understand one person said the door was too small for the wheelchair going into the shop. It should list the health services that people might use and picture of the same. On this standard the services users said choice around what Doctor they use and other health services is important. People don't feel that they always have choice about what health care providers they can use. Service users don't always know about VHI etc. They may only access private healthcare if they have supportive staff & family. Sub093

or (b) excluded? Standard 2.8 How can a person with profound disability be expected to take responsibility for their own health – “utter rubbish” Standard 2.8 I have kept all information so I will keep my eyes open! Please read 2.8 to understand ‘where’ I a relation to a client who has serious med. problems be expected to take care of their own health. HIQA would be shocked and dissatisfied with this “comment”. Of course I’m annoyed – confused – horrified at this comment. Sub142

Standard 2.8 - Lack of clarity about responsibility of service if Service User is living at home part-time and in Residential part-time. Sub252

Content of Personal Centred Plan: If service providers are, both, the preparers of the Personal Centred Plan and providers of some of the services, there is a danger that they will favour services that they themselves provide despite the requirements of 2.8, 2.10 and 2.11. Capacity should be allowed for Personal Centred Plan developers who are not service providers. Sub273

2.8 speech therapists and OTs are important for accessible health centres. Sub281

Standard 2.8; To-date supporting people to visit local GP etc has not been the responsibility of day services families – families have this role. People can be encouraged to maintain good habits through education programmes in day services. Sub297

2.8 Readiness of Health Care facilities to facilitate access for people with an ID. Sub342

Standard 2.8: ‘heading’: People are supported to access health services..... transport must be available for this to happen. Will service providers continue to provide transport in the future?? Availability of public transport/rural transport scheme (e.g. Service Provider in Location Name) and community transport providers must be taken into account if this standard is to be met. Getting a health service appointment is one thing – but making your way to it can be another days work. Can a standard be added re Transport? Sub344

Standard 2.8 In relation to accessing health services day services and supports play an advisory/educational role with regard to health matters, eg. diet, nutrition through the individual planning process with families. However, it is generally the family that take responsibility for this aspect of their life. I think this standard and features need to reflect the partnership role with families in relation to this more. The concern is that this will become more a service provider responsibility with the introduction of regulations. Sub351

Standard 2.8 [Quotes from Sub355]

“This is an important Standard to have as a person’s health is vital. It is also very important to give an individual independence to manage their own health needs where appropriate and possible to promote their independence”.

“People feel it is important to get support and information around health concerns, changing GP’s etc”.

“Health services does not only mean medicine/treatments but also includes a holistic approach to the person e.g. physiotherapy, yoga, reflexology, Indian head massage and what about acupuncture, massage etc” Don’t make any promises – where have we just come from a (Recession). Very important Standard”.

“This is an important Standard to us because some people can be nervous going to any health services. It is good to know that we can get this help from services”.

“Health services should respond to people’s needs and respect people rights and skills in self care. I am in charge in my life. I want to be respected as that”.

“Fundamental that people have access to healthcare and take personal responsibility to look after their own health. If we don’t learn to look after our own health who will”.

[end of quotes Sub355]

Standard 2.8 requires the service provider to support individuals to access health services. Whilst in some cases this may be the most appropriate avenue for support, it may not be in all cases. The person requiring support should be facilitated to identify who they would like to support them and this should not be limited to within the service provider. An advocate, family member or member of their circle of support may be more appropriate and this should be included within the standard. Sub359

The Draft Interim Standards in their entirety are suitable and relevant to people with mild to moderate disabilities. For those with more profound disabilities many of the proposed Standards including access to further education, vocational training, paid employment and managing health and independence are not realistic (2.5, 2.8, 2.9, 2.10 and 2.11). The standards must reflect and be appropriate for people with a wide range of abilities. Sub367

(2.8) SU’s felt that decisions need to be made quicker in relation to this point as what tends to happen is “I have to get back to you on this” SU’s posed the question “ Who will look after health services, the house or Day Services” Sub368

Standard 2.8 People are supported to access health services and to take responsibility for their own health and well-being, in line with their choices, needs and abilities: People with disabilities require specific supports in order to access the health services that they need. Historically, people with disabilities may not have received relevant interventions or information at different stages of their lives and this has contributed to greater health problems than are present in the rest of the population. Sub370

2.8. Suggest addition of “with emphasis on providing oral and health checks on a fixed regular basis” .” (Ref; Easy to read Standards 1-3) Sub372

Standard 2.8 requires the service provider to support individuals to access health services. Whilst in some cases this may be the most appropriate avenue for support, it may not be in all cases. The person requiring support should be facilitated to identify who they would like to support them and this should not be limited to within the service provider. An advocate, family member or member of their circle of support may be more appropriate and this should be included within the standard. Sub380

2.8 Lots of G.P. practices are not skilled at supporting families in relation to people with intellectual disabilities. People with intellectual disabilities who have mental health issues have not access to these services in the local community. A lot of work required to make this happen and questionable if the resources are currently available. Sub412

Feature 2.8.1

Standard 2.8.1 I feel this needs further explanation and detail. The focus for services should be on education re health needs only. Actual attendance, access at G.P.s, hospital apt.s, etc. lies with families or residential services. This needs to be specifically specified. Sub038

2.8.1 Management of one’s own health needs a great deal of understanding and a sense of time (in relation to taking medicine). Sub100

Feature 2.8.1 provides a positive statement regarding equipping people with the skills to access local health services, but services should not do for people what they can do for themselves. Input regarding health services will vary from person to person and will primarily relate to needs identified rather than scrutiny in people’s independent lives which is neither requested nor needed. This would be particularly the case in physical and sensory services where people often choose not to share such information – these Standards should not compel service providers to ask. Sub355

2.8.1 This statement is too broad and does not take account of the limitations of people who may not be able to be equipped to take the steps outlined. Sub392

Feature 2.8.2

Standard 2.8.1 I feel this needs further explanation and detail. The focus for services should be on education re health needs only. Actual attendance, access at G.P.s, hospital apt.s, etc. lies with families or residential services. This needs to be specifically specified. Sub038

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2.8.1 This statement is too broad and does not take account of the limitations of people who may not be able to be equipped to take the steps outlined. Sub392

Feature 2.8.3

Standard 2.8.3 - In reality the specialised support that many individuals need is not available within their community in a mainstream setting. Access to multi-disciplinary team services is not readily available and only through persistence from Service providers can an individual access these necessary supports. More is needed to enable individuals to progress in their lives by getting the professional support that they require. Sub263

Where possible they can ensure the person has access to a multi-disciplinary team but they cannot ensure the existence of that team (Feature 2.8.3). This Standard ought to include a commitment by the HSE to provide multi-disciplinary team supports as part of the SLA in order to achieve this Standard. Sub355

However, this should not be solely the responsibility of the service provider. In the context of New Directions services, staff may only see the person for a day or even a few hours a week to support them to take part in a particular activity. Where possible they can ensure the person has access to a multi-disciplinary team but they cannot ensure the existence of that team (Feature 2.8.3). Sub370

Learners agreed, saying “People need to look after their own health. It important to help people to access health services in their community”. One said that they had a good doctor who knew them well and was easily accessible in the community and this was very important. Sub370

Feature 2.8.4

2.8.4: Most adult day and training services are not medically staffed and do not manage medication. Sub279

2.8.4 The service provider must have medication management policies and procedures in place that comply with legislative and professional regulatory requirements and best practice guidelines. Sub344

Final bullet point (page 42): If you need to take medication, you are encouraged to take responsibility for taking it yourself, if appropriate and approved by medical professional, in line with you wishes and needs. Sub344

In many day services, no person with a disability would require support with medication management and in that case a specific policy would not be required (Feature 2.8.4). Sub355

In (Service Provider Name) services, people with disabilities do not normally require support with medication management and a specific policy would not be required (Feature 2.8.4). Sub370

2.8.4: Best practice guidelines tend to change over time, and there are differing perspectives on best practice. This presents challenges in non-nursing environments. Sub424

Feature 2.8.5

No Data

Feature 2.8.6

2.8.6: Accessing mainstream health services is necessary but would be outside of our remit as our day services are rehabilitative and training in nature not medical. We can however support clients in accessing information on health services available to them. Sub279

2.8.6 This feature indicates that service providers will work with community and mainstream health service providers to widen access for people with disabilities and maximise opportunities for people to access mainstream health services – is this broader than what day services will provide? What is the role of other stakeholders e.g. families (particularly for people who are living at home), health care providers, HSE, etc? Sub352

Service providers can work with community and mainstream health service providers to widen access for people with disabilities and maximise opportunities for people to access mainstream health services (Feature 2.8.6). Two issues arise here. Firstly, it must be the responsibility of mainstream health service providers to orientate their services towards the needs of patients with disabilities. They must play their role in ensuring continuity of service for patients with disabilities. Secondly, day services are less likely to directly offer health services than a residential service. Such services would not be available in most (Service Provider Name) services. However, in a small number of cases, mostly in services for people with significant physical and/or sensory disabilities, the availability of physiotherapy and speech and language supports within the service are considered very important by the people with disabilities, who have great difficulty travelling to frequent medical appointments and need considerable support to do so. In these cases, the availability of relevant health services all in one location can be the only way that people can access such supports as frequently as they need to. Sub355

This issue goes further than health services. (Service Provider Name) carried out a focus group with people with disabilities in a physical and sensory day service. This group questioned whether the Standards should apply to services for people with physical and sensory disabilities who often come to a day service, not to access

community activities, but to access all the supports that they need in an easy and accessible way. Many struggle at home without 24 hour supports and getting into the community can be difficult from a travel, accessibility and fatigue perspective. This is the kind of service they want and they are very clear about their wishes, as many have acquired their disability and lived fully independent lives in the past. This aspect of service provision needs to be considered in the context of the implementation of the Standards to ensure that implementation of the Standards enables this group to access supports of their choice. Sub355

No reference is made under this Standard to access to sexual education and reproductive health. These are issues which are explicitly referred to in the HIQA Standards for Residential Settings for People with Disabilities and are issues that should be dealt with in these Standards. Sub355

(Feature 2.8.6). Two issues arise here. Firstly, it must be the responsibility of mainstream health service providers to orientate their services towards the needs of patients with disabilities. They must play their role in ensuring continuity of service for patients with disabilities. Secondly, day services or rehabilitative training services are less likely to directly offer health services than a residential service. In (Service Provider Name) services people are provided with information to access a mainstream health service where a need arises. Sub370

2.8.6. Service providers 'will work with'... aspirational. Where is the support to build capacity for community and mainstream health services to include people with an Intellectual disability? Where is the role of the family? Sub372

Standard 2.9

2.9 Some service users felt limited because of their poor reading and writing skills. They felt education providers cater for the more able. Sub040

Regarding standard 2.9 Need to inspect mainstream education providers as they often stop people with disabilities attending courses with excuses such as 'we are too full' or 'we don't cater for people with disabilities'. Sub066

2.9: Education Programmes need to be formalised and become standard practice within services funded by the H.S.E., e.g. literacy and computer programmes. This indicates to the service user/s that they are valued members of society when offered courses that increase their knowledge and skills in line with the general public. Sub103

2.9 education. We deliver Fetac programmes and some service users study part-time in college. Sub113

2.9 education - (Service Provider Name) Sub222

2. 9 Education – Agreed [see 2.5 In 33 years no trainees have sought or could sustain 3rd level education]. Sub242

Standard 2.9 - mainstream educational opportunities are more available over the past two years. However, the opportunities for progression to employment from educational programmes is not there and is it fair to create an unrealistic expectation for individuals. Sub263

What did you not like in this book? A. Would like the pictures in colour, Standard 2.9 - felt it was misleading for different levels of ability. Sub263

Standard 2.9 to standard 2.11 – is there any proposal as to how these special people are supposed to access the education courses. No public transport in lots of cases and no staff to assist transport to other main towns. Sub270

Standard 2.9: Need more co-operation between Department of Health, HSE and Department of Education to look and develop opportunities for people with ID. Most need 1:1 supports, transport, limited non-specialised places. Sub297

Standard 2.9 (page 43): 2.9.4 Transport provision to/from educational programmes must be discussed and agreed prior to commencement of educational course. PCP should document this also. PCP should include a Transport heading at all times. Sub344

Government / Inter-departmental commitment: In reconfiguring and delivering day services there is a need for full commitment from key agencies and Government Departments. For example Standard 2.9 relates to people accessing formal education programmes in line with their choices, needs and abilities – this requires a commitment from mainstream educational providers to widen access to programmes, commitment from the Dept. of the Environment in terms of transport and so forth. The expectation that service providers can continue to provide a 'wrap-around' service / meet all of an individual's day service needs and take full responsibility for meeting this standard is not realistic. Sub352

While there are many good practice examples of educational / going to college type projects many have ceased due to lack of funding. There needs to be full commitment from the government and educational providers to meet this standard / features. How well this standard and its associated features is met is outside the control of service providers. Sub352

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. Sub353

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. Sub353

Standard 2.9 People access formal education programmes, in line with their choices, needs and abilities: The requirement that service providers work with community and mainstream educational providers to widen access for people with disabilities and maximise opportunities to access mainstream education is welcome. Service providers can play a role in this regard; however, education providers also have a responsibility to ensure that their programmes are accessible and that reasonable accommodation is provided to meet the needs of people with disabilities. There have been instances where mainstream education providers have placed a limit on the number of people with disabilities who can take up an education programme which can be a considerable problem in smaller towns and rural areas where a multiplicity of opportunities simply isn't available. In their responses some people using our services reacted negatively to this Standard. Care is also required in relation to the proportionality of these Standards. For people with acquired disabilities access to education may not be an option because of the impact of their disability and therefore an undue emphasis on work, training and education is likely to have a demoralising effect. Sub355

Standard 2.9 [quotes from Sub355]

“This Standard is very important as it is important that each person has the choice to an education if they may wish. As a service it is vital for us to promote this choice and provide the support necessary for an individual to access education”.

“Due to the nature of most people's disability this is not a focus or priority for them anymore because of degenerating, acquired disability. They educate themselves in areas they wish e.g. computer”.

“This is very important as we are living in an ever-changing world of ‘lifelong learning’ and a person (should they be so inclined) should be encouraged to pursue this option. People should be supported financially in this area (be it academic studies, vocational skills, or hobbies) so that they can become productive citizens or at least achieve some sense of personal fulfilment (instead of feeling that they are being left behind the rest of society”.

“This is an important Standard for us to be able to get an education in the centre and in the community and to be able to avail of these services”.

“Some people need support to take part in Education or to get transport us to areas where we can receive education. In the country facilities are not necessarily in the town we live in”

“Queries about future though: Place in service for some contact during summer, will this be allowed to be maintained in the future?”.

“One group felt this was “up to the individual”; “they know it’s [support] there”. The other group said that this was “very important”; “attending courses in the community”; “support given, even if it’s just at the beginning”.

“Education that suits the individual is an important Standard to have. It is also important that there is access to education and there should be more funds set up to make education financially accessible for all”.

“The service users stated how they found that the educational programmes that took part in were very important and stated that they like partaking in these such as read and write group, or library group”.

[quotes from Sub355]

The Draft Interim Standards in their entirety are suitable and relevant to people with mild to moderate disabilities. For those with more profound disabilities many of the proposed Standards including access to further education, vocational training, paid employment and managing health and independence are not realistic (2.5, 2.8, 2.9, 2.10 and 2.11). The standards must reflect and be appropriate for people with a wide range of abilities. Sub367

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Many of the Standards in Theme 2 are dependent on a person’s needs’ which could allow services to use the excuse of high support needs to deny 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 Section 2.1 – it seems that the service provider determining choice. Sub374

2.9 Families felt this was not applicable to their family member; also educational providers do not have the physical environment or educational programmes available

that meet the ability level for people with severe or profound intellectual disability.
Sub412

2.9/2.10 Formal education and vocational training, again all felt this was not an option for their son or daughter. Sub412

Feature 2.9.1

No Data

Feature 2.9.2

2.9.2: Accessing mainstream education programmes is a very positive outcome, however in our experience especially with brain injury it would not be a first option as strategies and supports need to be developed with clients in a specialised setting in order to prepare them for mainstream education. Also we support clients in achieving mainstream qualifications (FETAC level 2 to 4) which are necessary in obtaining a place on a mainstream programme. Sub279

With specific reference to Standard 2.9.2, (Service Provider Name) has found access to mainstream education very difficult to source for its service users. This situation may change as the profile of New Directions grows nationally, but even with reasonable accommodation policies in place we are finding mainstream facilities very reluctant to be truly inclusive. Sub300

2.9.2 ? Capacity of mainstream education programmes to support people with an intellectual disability if this capacity does not exist? Are there government funding being ring fenced to support this? Not the aspiration of all people to access formal/accredited education. The Department of Education needs to be fully on board with New Directions and build capacity and respond to diverse learning needs and engagement and adapt learning best serve people. Sub372

2.9.2 Shouldn't this link back to the person's personal plan? Also access is one thing, what about the need for ongoing supports to ensure that the person is facilitated to stay in the education programme? Sub392

Feature 2.9.3

2.9.3 Clarity required around specialist education programmes in integrated settings. What about the cohort of individuals who wish to retire or have profound disabilities. Sub342

Feature 2.9.3 states that people should be provided with specialist educational programmes where required. This feature should make it clear that service providers are not responsible for the provision of specialist education, an area that they would have little expertise in, unless they are providers of Rehabilitative Training, such as (Service Provider Name) sister company, (Service Provider Name). Specialist education / training options simply might not be available in the local community. This is a need to take a measured approach to the implementation of this Standard based on the availability of local services. A rewording of this feature is proposed as

follows: "People are supported to access specialist educational programmes, where required and where available". Sub355

Standard 2.10

Some standards difficult to understand/wordy (e.g. 2.6, 2.10, 2.11). Sub049

Regarding standard 2.10 : This standard is not necessary, people should be able to learn on the job, in college but not in training programmes based in centres only for people with disabilities. Sub066

Standard 2.10 suggestion that the line vocational training is swapped with the line this is sometimes.....it was felt that it was clearer if the explanations on vocational training came first then line about bridging programme. All people supported who were consulted had never heard of bridging programme. Sub109

2.10 Bridge - Agreed [see 2.6 – not many will seek this or be supported]. Sub242

Availability of suitable Training in the community an ongoing difficulty. Sub254

Standard 2.3 is very vague because it doesn't explain how fairness will be applied/ensured. The statement of purpose is confusing, it should be explained more. 2.10 is also confusing- 'bridging programme' should be explained with examples. Sub261

Standard 2.9 to standard 2.11 – is there any proposal as to how these special people are supposed to access the education courses. No public transport in lots of cases and no staff to assist transport to other main towns. Sub270

Content of Personal Centred Plan: If service providers are, both, the preparers of the Personal Centred Plan and providers of some of the services, there is a danger that they will favour services that they themselves provide despite the requirements of 2.8, 2.10 and 2.11. Capacity should be allowed for Personal Centred Plan developers who are not service providers. Sub273

I am concerned at the overall service base of the directions. The phrase often used "in line with their choices, needs and abilities" Standard 2.10: "People access bridging programmes to vocational training, in line with their choices, needs and abilities" could end up being a limiting rather than empowering a person to develop their potential in its application. A person's assessed ability or assumed ability is often limits the vocational opportunities available to individuals. Current opportunities are limited to persons of a certain assessed level of ability leaving a large population with intellectual disability without formal training opportunities. Sub277

2.10 & 2.11: Only applies to a cohort of individuals with high ability. Sub342

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. Sub353

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. Sub353

Standard 2.10 [quotes from Sub355]

This Standard is important as it is important to have available for an individual as these programmes can be a necessary step in aiming towards attending a vocational programme for an individual who may wish to do so.

“This is good as some people have practical skills and experience that they would like to get qualifications in, but have not been in an educational setting for many years and would feel intimidated – so a bridging programme is a nice friendly way of getting confidence”

“This is important Standard for people to know that they can get help if they want to go back to work or start working for the first time”

“Workability programme helps prepare everyone here for work. Jobs have come from the programme”

“A programme to help get ready for vocational training is important because preparation is vital otherwise you can't move on. You have to have the opportunity to lay the ground work before you can move forward in life”

[end of quotes Sub355]

The Draft Interim Standards in their entirety are suitable and relevant to people with mild to moderate disabilities. For those with more profound disabilities many of the proposed Standards including access to further education, vocational training, paid employment and managing health and independence are not realistic (2.5, 2.8, 2.9, 2.10 and 2.11). The standards must reflect and be appropriate for people with a wide range of abilities. Sub367

This recognition of the need to support people to take up vocational training is welcome. However, the requirement appears quite limited as it focuses people's choices on vocational training and not on other available types of educational provision. While vocational training may a good option for many people with disabilities some people can aspire to higher education with the appropriate supports. In addition, this Standard specifically states that people should be supported towards vocational training in line with their choices, needs and abilities. For some people with significant intellectual disabilities or physical disabilities, the rigours of a full-time training course may not be appropriate. Rehabilitative Training may be more appropriate. For older people with disabilities, employment is unlikely to be a goal. Sub370

A concern that the Standards were aimed at people with lower support needs was voiced by one parent who said, “I am concerned that they [the Standards] have been developed mainly in consultation with people who have disabilities who are very vocal and strong. I fear for some people who need a lot of support”. Sub370

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 ie. the need should be adequately supported: 1.6 – 1.7 – 2.5 – 2.6 – 2.7 – 2.9 – 2.10. Sub374

Many of the Standards in Theme 2 are dependent on a person’s needs’ which could allow services to use the excuse of high support needs to deny 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 Section 2.1 – it seems that the service provider determining choice. Sub374

2.9/2.10 Formal education and vocational training, again all felt this was not an option for their son or daughter. Sub412

Feature 2.10.1

Feature 2.10.1 states that service providers should specifically work with mainstream vocational training providers to jointly develop and provide bridging programmes to vocational training. Service providers should not be required to provide bridging programmes but should be required to refer people with disabilities to bridging programmes where that is in line with the choices, needs and abilities of the person. Sub355

Feature 2.10.1 states that service provider should work with mainstream vocational training providers to jointly develop and provide bridging programmes to vocational training. (Service Provider Name) Rehabilitative Training (RT) acts as a highly effective bridging programme to vocational training. Learners have the opportunity to sample vocational programmes with (Service Provider Name) before commencing and this can help to ensure the course is right for them. (Service Provider Name) RT is available in towns and cities throughout the country. It is considered a specialist rather than a mainstream service although it incorporates a wide range of activities in the community. For many people using day services, a mainstream service will not be in a position to provide for their needs and specialist rehabilitative and psychological supports will be required. Sub370

Rather than focusing on mainstream inputs, the Standards should emphasise mainstream outputs. Nine out of ten People completing Service Providers Name specialist vocational training will progress to education and training. Nearly 40% go on to employment which is a very strong employability outcome and one not replicated by many mainstream vocational training providers. Disability service providers must have the flexibility, in consultation with the person and their family to

select the most appropriate provider of vocational training and to focus on possible outcomes rather than on inputs. Sub370

Feature 2.10.2

Feature 2.10.2 states that the content and duration of bridging programmes to vocational training should be tailored to individual need. Again, (Service Provider Name) RT provides a strong blueprint for this kind of training. Sub370

Feature 2.10.3

Feature 2.10.3 Service providers without expertise in the area of vocational training and bridging programmes to access vocational training programmes would not be in a position to develop carefully designed bridging programmes. Again, this feature should clearly enable service providers to refer people with disabilities to available bridging programmes and should clarify that service providers are not required to deliver bridging programmes. Sub355

Feature 2.10.3 A key benefit of (Service Provider Name) RT is its co-location with vocational training which means that people acquire and strengthen their capacity to benefit from vocational training in the same environment as vocational training takes place. They gain experience in travelling to and from training and can begin to build a network of support that will help them through vocational training. Sub370

Feature 2.10.4

No data

Feature 2.10.5


2.10.5.....add on sentence 'This may include transport provision'. Sub344

Feature 2.10.5 states that service providers should put the supports that people need to participate in training in place. Under equality legislation, vocational training providers must make reasonable accommodation for people with disabilities to enable them to take part in training. It shouldn't, therefore, be the responsibility of the service provider, or the HSE, to fund the supports that a person needs to access such training. This Standard should be reworded to reflect the real responsibility for accessibility in vocational training or should be removed from the Standards. Sub355

Feature 2.10.5 states that service providers should put the supports that people need to participate in training in place. Under equality legislation, vocational training providers must make reasonable accommodation for people with disabilities to enable them to take part in training. The Standard should not, therefore, require a HSE-funded provider to provide these supports. Sub370

Standard 2.11

Theme 2: Effective Services and Supports: Some standards difficult to understand/wordy (e.g. 2.6, 2.10, 2.11). Sub049

	<p>Work</p> <p>All focus groups spoke about the importance of having a job</p> <p>This came across as the most important part of our Service Users lives, a lot spoke of the work they are doing, that they have got through the Lets get to work project. They want this project to continue.</p> <p>Service users want support to get to their place of work, they want support to seek employment, they want support in the work place until they are job ready.</p> <p>Day services should be about helping people who want work, to get work (paid or otherwise)</p> <p>Some service users want to work in the centre, they have worked hard in developing enterprises within their centres. Sub093</p>
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Standard 2.5 were rated as the most important. (68.9%). Standard 2.2, Standard 2.4 and 2.11 rated the next most important.(55.1%). Sub245

We are concerned that there is not enough mention of employment or work-related training as part of this new initiative. While paid employment and vocational training are referenced, we feel strongly that everyone should feel valued and feel that they are making a meaningful contribution to society. As participants on a Rehabilitative Training programme, we are always being encouraged to look to the wider world, and see where we can use our skills and talents for the betterment of society. Sub249

Difficulty envisaged around Supported Employment and Vocational Training. Individuals competing in a highly competitive environment for jobs and opportunities. Sub254

Schemes such as TUS for the unemployed (individuals on DA do not qualify) now highly involved in volunteer community work in all areas. This will impact on individuals in our Service getting equal opportunities to participate in same. Sub254

Standard 2.11 Progression from training to open employment / supported employment is a significant challenge and there is a gap in service provision for the many students who are unable to progress or those who need considerably more interventions to support them to progress. Sub263

Standard 2.9 to standard 2.11 – is there any proposal as to how these special people are supposed to access the education courses. No public transport in lots of cases and no staff to assist transport to other main towns. Sub270

Content of Personal Centred Plan: If service providers are, both, the preparers of the Personal Centred Plan and providers of some of the services, there is a danger that they will favour services that they themselves provide despite the requirements of 2.8, 2.10 and 2.11. Capacity should be allowed for Personal Centred Plan developers who are not service providers. Sub273

2.11 Inaccessible Education - Access to education is important BUT there are very few courses for us such as VETAC levels 1 & 2 & courses for people who do not read and write. There is no point in having a right to education and then not having courses available. Sub281

2.11 Pic of payslips – better to use picture of person getting euros. Sub292

2.10 & 2.11: Only applies to a cohort of individuals with high ability. Sub342

2.11.4 Transport requirements to/from training to be discussed and agreed. Sub342

2.11 These standards and the features detailed i.e. access to formal education / bridging programmes / vocational training / employment won't apply to many people who are availing of day services / supports as only a small percentage of people with an intellectual disability currently attend formal education. But this should ideally increase over time once the implementation of the vision of New Directions advances. Sub352

Standard 2.11 [quotes from Sub355]

“This is important for an individual who wishes to further themselves and gain knowledge and experience in doing a vocational training if they may wish. This training would be a very positive step to make in aiming to gain paid employment for an individual which in turn would be positive for an individual in becoming a working part of the community”.

“Does not apply anymore it upset some clients as they would love to be able to do this but are not able anymore. This highlights the need for different Standards within different disability groups. We are very much a social day out for clients and carers appreciate the break”.

“Yes if a person would like to get a job then the support should be made available”

“Getting payment for your day’s work is the ultimate goal for any prospective worker (as far as society is concerned voluntary work, while fulfilling, does not have the same status as paid work”.

“This is important Standard that this help is available for people who want it or need it in the services. It is important for people to get paid work”.

“We would all like to get a paid job but this is hard as most jobs are looking for people with qualifications, even work experience in Jobs can be very satisfactory and give us an insight into what we would need to do education wise to get work in the area we have interest in”.

“Choice again is key as stated in the Standard. Moving on from services or reliance on services positive for many but often chosen as a part time option. People want to maintain the supports in the lives especially when they work well and they want to maintain contact with a social group that may not always be available or willing to meet in evening / night time. Also people don’t want to lose other benefits such as travel pass, DA, medical card etc. Would not be worth the stress or wages”.

“How will there be enough jobs and things for people to do in small communities”

[end quotes Sub355]

Standard 2.11 Health Care Services and the HSE should consider lobbying the Government to force employers to hire a percentage of people with disabilities. More work opportunities should be created by employers to accommodate and support specific disabilities and levels of disabilities. Sub355

For those with more profound disabilities many of the proposed Standards including access to further education, vocational training, paid employment and managing health and independence are not realistic (2.5, 2.8, 2.9, 2.10 and 2.11). The standards must reflect and be appropriate for people with a wide range of abilities. Sub367

‘I’d like to get a job’ (Standard 2.11) ‘I’d like experience on a real farm with cattle and driving’ (Standard 2.11); ‘I’d like to have training to use the lawnmower. I’m sick of health and safety’. Sub367

Standard 2.11 People access vocational training and employment, in line with their choices, needs and abilities: Many of the comments made in relation to Standard 2.10 are relevant here: The emphasis on vocational training focuses the Standard on a particular client cohort and seems to exclude those whose capacity would allow them to take up Higher Education. Sub370

Our learners have highlighted their wish to take up employment in an area of their choice and of the need to participate in appropriate training in order to do so. One said “I would like a job to have money. Work experience can help with this. A paid job can come out of work experience, or an interest”. Many families focused on the availability of employment opportunities in the local area. One asked “Is there any plans to realistically integrate people with disabilities to the workplace with

meaningful employment? This needs to be tackled at a national level as most have a part to play. AT present there is no incentive or push to get employees on board". Sub370

2.11 in the present economic climate there are significant challenges to people with Intellectual disabilities to securing meaningful employment. However work is a significant feature of an ordinary life upskilling of staff to meet this will be needed. Sub372

2.11 All agreed. All stakeholders felt there should be more emphasis on paid work. The majority of people present felt paid work and "having a Job" is the most important element of support they want. Sub372

2.11 Families said this was not relevant for their family members. It was felt that the (Name of Educational Programme) was more suitable for their family members who were unable to access mainstream education. Mainstream education is not as yet prepared for the needs of some of the people with a significant intellectual disability. Sub412

Feature 2.11.1

No Data

Feature 2.11.2

Standard 2.11.2 I feel this standard needs further clarification – services users are supported to access supported employment. Services support and maintain and should be the remit of employment services and not day service. Sub038

Feature 2.11.2 states that people should be supported to access and maintain employment in their community or supported employment programme. The inclusion of the concept of “employment in their community” is very welcome here. Many (Service Provider Name) services support clients in part-time employment with a local employer. Key to the success of this employment is the person’s ability to return to the centre for other supports when they are not working. Employment can greatly enhance a person’s well-being and independence but it is not a panacea and people will continue to need the supports of a day service to access activities in the local community. In some cases, work is not a goal for the person and he/she may have fears about the loss of DA, loss of medical cards and loss of travel pass if earning wage is factored in. Sub355

Feature 2.11.2 states that people should be supported to access and maintain employment in their community or supported employment programme. The inclusion of the concept of “employment in their community” is very welcome here. Many (Service Provider Name) training programmes support learners to take up work experience and part-time employment with a local employer. (Service Provider Name) funded Employer-based Training is an excellent place and train model which combines work experience with FETAC-accredited training and improves the person with a disability’s chances of gaining employment. Sub370

Feature 2.11.3

2.11.3 providing an appropriate alternative response for those people who are unable to progress to employment is a challenge. Support from other Government departments (Enterprise) is needed to be able to provide meaningful alternatives for individuals. Sub263

Feature 2.11.3 states that service providers will provide an appropriate, alternative response for people who do not access open or supported employment. Clarity is required in relation to this Feature. Employment should be offered as one possible activity that is supported by a day service. Alternative activities should be available on a routine basis. This feature could be construed as referring to the provision of some kind of work-like activity which would be a backwards step. Furthermore, who will decide what is appropriate? This should be based on a resource centre model of activities relating to PCP and social and leisure. Activities that are fulfilling and meaningful for each person should be available. People with disabilities should decide what is appropriate for themselves and should have the flexibility to include group activities. A focus on work can be unsettling, particularly in for people for whom mobility is an issue, and time is essential to supporting people to explore this without fear of being left behind or out. Sub355

Feature 2.11.3 states that service providers will provide an appropriate, alternative response for people who do not access open or supported employment. Clarity is required in relation to this Feature. Progression to employment should be offered as one possible activity that is supported by a day service or rehabilitative training. Alternative activities should be available on a routine basis. Sub370

Standard 2.12

Re "Standard 2.12: Premises and facilities are designed to support the delivery of community-focussed, high quality, person-centred, and safe services and supports."

2.12 Requires greater clarity defining local and international models for the type of buildings with architectural drawings outlining the size of buildings, number of rooms, layout models, space. A study with sample data describing minimum layout requirements of group homes, community based homes, apartments should lay out standards including required access to recreational, medical, educational and location and staffing requirements. This should include data on optimum client numbers for each setting. Sub004

Regarding standard 2.12 : Check if day services centres are located close to public transport and make it easy for people to access their communities otherwise they are a waste of time. Sub066

How / What staff training has been identified. If this has been identified then at what cost. If this is known has there been budget approval. If none of the above has been identified then how would any of this plan work. Sub073

2.12 2.13 The concept of Hub is seen by some parents as a threat to day centres. The existing day centres are central to the lives of service users and gives them structure /routine—gives meaning to their lives —motivation to get up in the

morning—gives them safety—gives them friends and many other contributions to their quality of life. Sub095

Standard 2.12: Some people felt that when people are using community resources then the organisation does not have control over the space where community activities take place. Sub096

Standard 2.12 the picture for standard 2.12 is very confusing and many people did not understand it suggestions that maybe a door with a ramp could be used instead. Sub109

2.12 Premises - Agreed [our facilities are integrated in community & act as a hub] Sub242

Personal care – out in the community it is rare, if not impossible, to find premises which has sufficient facilities i.e. a bathroom with a hoist and changing bench. What does a person do if they are expected to be out in the community for the most of a day! Section 2.12 mentions the design of premises, but how many community based projects could afford to put sufficient facilities in place for wheelchair users. Sub260

2.12 - premises and facilities - all staff agreed with the details of this standard. In reality many services are operating with less than ideal facilities, inherited from a very different model of service delivery in the past. Significant investment in premises upgrading and redesign is required to bring facilities up to standard and to ensure that they provide the best settings for person centred service delivery. Sub263

2.12 Buildings should be a good standard: well maintained, good quality, modernised not just the ones for staff to use. Sub281

Similarly some service users often misinterpreted pictures e.g. standard 2.12, with regards to person-centred supports, team members identified this as a picture of a woman being left out with a group of people standing behind her talking about her. Sub285

2.12 additional resources and capital development plans will need to be resourced to make this feasible. Sub291

2.12 Strange picture – bath not in the community. Sub292

Standard 2.12: Agree with principle of the Standard. Just please note that the HSE has not provided capital monies for the past number of years so that service providers can maintain current premises. Buildings are getting older and hard to maintain to a good standard. If they are now to be integrated into community-based facilities where is the money going to come from to do this. If you use community facilities not all building a fully safe, fire safety and accessibility for wheelchairs and people with mobility issues. Transport needs to be kept to a safe standard and fit for purpose. Sub297

Is there anything else you want to say about this book? iT is important to me that when I move out to a Community Hub, that it is accessible to me as I use a wheelchair, and need a premise that meets my needs, I would also need a swimming pool in the community that has overhead hoists and proper change tables. This would also be very important to me to have these facilities in all wheelchair accessible toilets as I require full assistance with my personal care. Sub317

2.12 Further clarity required in relation to “hubs” i.e. numbers accessing a “hub”. Is it envisaged that activities will occur in the hub? How will current Day Services transition to New Directions model. What plan is proposed in relation to current large Day Service buildings. What plan is proposed for current Service Users accessing 9 – 5 Service to transition to New model. Will school leavers access new model - will HSE cease to refer individuals for a 5 day Service. What plan is proposed to cease funding for transport for individuals to and from services or will HSE continue to fund same. Sourcing buildings (hubs) in local community settings may be extremely difficult if premises have to comply with Universal Design. It may prohibit use e.g. a room in a local Community Centre.

Difficulty envisaged around supported Employment and Vocational Training. Individuals competing in a highly competitive environment for jobs and opportunities. Schemes such as TUS for the unemployed (individuals on DA do not qualify) now highly involved in volunteer community work in all areas. This will impact on individuals with ID getting equal opportunities to participate in same. Availability of suitable training in the Community is currently an ongoing difficulty. Sub342

2.12 There may be significant costs incurred in meeting this standard and the particular features outlined. What will be the responsibility on service providers in relation to community buildings that are being accessed as part of community integration / inclusion activities? Sub352

Standard 2.12 Premises and facilities are designed to support the delivery of community-focussed, high quality, person-centred, and safe services and supports: All of the features under this Standard are requirements for the provision of good, quality, centre-based day services. However, in the implementation of New Directions and these Standards, there will be a need for service providers to innovate in terms of location to deliver for the needs of their people with disabilities. Supports may be provided in a public building or a local community building or even a local coffee shop on a short-term basis and would not be possible for the service provider to achieve all of the features under this Standard in all of the locations where services operate. This must be reflected in the Standards. Across (Service Provider Name), resource centres operate as hubs where people can come to get support to access other community-based services. The social aspect is a very important part of attending the service – it promotes peer support, natural support development, community integration and confidence building. Sub355

Standard 2.12 [quotes from Sub355]

“It defines the operational structures of the service and how the buildings ensure that we provide services within a safe environment and also ensure they are person centred and meet everyone’s needs. For example, wheelchair access and wheelchair accessible toilets”.

“Our centre is accessible and clients feel happy here. Community trips are more difficult for assessing toilets etc. Transport is essential for provision of this service for clients with physical and sensory needs. Community access needs 1-1 staffing levels. Good to quality control all services. Regular reviews occur within the service”.

“It is very important to place buildings on the public bus / transport routes when deciding on a service location and this should also be always done in consultation with service user’s as the building location has massive effect on the service users”.

“It’s important that buildings and their facilities are properly designed to take into account the varied needs of service users. The main problem in any building for wheelchair users in particular, who are trying to be independent, is the ‘disabled toilets’ – some can be hard to manoeuvre (e.g. lip at door entrance, heavy door that is hard to close as it opens outwards, space cramped making it hard to turn wheelchair). Generally, the building should be wide and inviting – making it a user-friendly space for everyone. Make these services more available I do not just live between 9.am and 5pm. Most important if it’s done regularly and outcomes and changes done quickly”.

“This is an important Standard. It is very important for us to be in a safe and comfortable building and to be safe in our community. We want the services to help us with all of our personal needs”

“It is important to have easy access to services and transport available to take us to services. In the country public transport is very limited and we need services to put on transport in order for us to attend”

“Good transport links are essential this is key to developing skills and confidence and trying options and services available”

“Community-based is the most important aspect of a service location or building / premises”

“Disabled access is very important in Community Buildings. It is not fair that some people cannot even get into some shops”

[end quotes Sub355]

Standard 2.12 if supports are being provided in community based facilities who is responsible to ensure the accessibility of these premises. Rented property or rooms in a mainstream building should be exempt from this standard and subject to general health and safety legislation. Sub359

Standard 2.12 Premises and facilities are designed to support the delivery of community-focussed, high quality, person-centred, and safe services and supports: All of the features under this Standard are requirements for the provision of good, quality, centre-based supports to people with disabilities. Our learners were very clear that in the future they want to continue to have a centre to come to in order to meet with their friends and peers in a positive environment and where staff understand their needs. Another group said that this Standard could “help people by giving good quality supports in the community. Places and buildings should have high quality services and supports put in place”. However, in the implementation of New Directions and these Standards, there will be a need for service providers to innovate in terms of location to deliver for the needs of people with disabilities. Supports may be provided in a public building or a local community building or even a local coffee shop on a short-term basis and would not be possible for the service provider to achieve all of the features under this Standard in all of the locations where services operate. This must be reflected in the Standards. Sub370

2.12 The availability of locations in integrated community based facilities and the notion of the hub can still lead to people spending times unproductively in buildings. Rather would suggest that people who use services are sharing the same ordinary places where people of a similar age go to on a daily basis perhaps should be the standard. Following the principles of O'Brien, Kendrick... 'people using services doing things in ordinary places that most members of the community would be doing.' It is about building and delivering ordinary, community based opportunities and supports. Sub372

Standard 2.12 if supports are being provided in community based facilities who is responsible to ensure the accessibility of these premises. Individuals with high physical needs are often excluded from accessing community facilities as changing and toilet facilities are not appropriate. Sub378

Standard 2.12 if supports are being provided in community based facilities who is responsible to ensure the accessibility of these premises. Individuals with high physical needs are often excluded from accessing community facilities as changing and toilet facilities are not appropriate. Also who will fund these activities. Sub379

Standard 2.12 if supports are being provided in community based facilities who is responsible to ensure the accessibility of these premises. Rented property or rooms in a mainstream building should be exempt from this standard and subject to general health and safety legislation. Sub380

2.12 People commented that Day Service premises should be bright, cheerful, office like and welcoming. Location in the town is important also. Sub381

2.12 Families expressed a lot of concerns about this standard. Their experience has been that community facilities are not well designed and do not support the needs of people with significant disabilities e.g. lack of availability of toilet facilities that have hoists or are of a proper size to fit large customized wheelchairs, no ramps on some

buildings etc. Failure to address this area will result in people staying in centre based services that are purpose built. Sub412

Feature 2.12.1

Standard 2.12 and its associated features 2.12.1, 2.12.2, 2.12.5, 2.16.6 places huge responsibility on service providers particularly when accessing integrated community based supports where the service provider may not be the owner or have control over such matters with regard the building or premises accessed by people with disabilities. These could mitigate a service provider engaging and collaborating with a local community group on the basis the building does not fulfil all the requirements. In the advent of regulations this could result in service providers retreating to delivering supports and services that go against the principles of national policies advocating more inclusive and active citizenship for individuals. Sub351

Feature 2.12.2

2.12.2 Statement of Purpose – should be typed with initial capital letters at all times for S and P – to highlight that it is an actual formal document. Page 57 and page 63 - also needs to be amended with capital letter for S and P. Sub344

Standard 2.12 and its associated features 2.12.1, 2.12.2, 2.12.5, 2.16.6 places huge responsibility on service providers particularly when accessing integrated community based supports where the service provider may not be the owner or have control over such matters with regard the building or premises accessed by people with disabilities. These could mitigate a service provider engaging and collaborating with a local community group on the basis the building does not fulfil all the requirements. In the advent of regulations this could result in service providers retreating to delivering supports and services that go against the principles of national policies advocating more inclusive and active citizenship for individuals. Sub351

Feature 2.12.3

Feature 2.12.3 states that in as far as possible, services are located in integrated community-based settings to maximise the potential for inclusion. This Standard is not robust enough. Instead it needs to give guidance on the optimum numbers per building and the location of the service in an integrated environment. Reference needs to be made to “legacy” buildings currently located in the grounds of hospitals, large complex environments and industrial estates with a view to relocating services to community-based integrated settings. This Standard should be rewritten to reflect the need for services to plan for a future where all services are based in appropriate buildings. Funding will need to be made available to support the relocation of existing services and for new services at the development stage. Sub355

Feature 2.12.4

No Data

Feature 2.12.5

Standard 2.12 and its associated features 2.12.1, 2.12.2, 2.12.5, 2.16.6 places huge responsibility on service providers particularly when accessing integrated community

based supports where the service provider may not be the owner or have control over such matters with regard the building or premises accessed by people with disabilities. These could mitigate a service provider engaging and collaborating with a local community group on the basis the building does not fulfil all the requirements. In the advent of regulations this could result in service providers retreating to delivering supports and services that go against the principles of national policies advocating more inclusive and active citizenship for individuals. Sub351

Feature 2.12.6

Standard 2.12 and its associated features 2.12.1, 2.12.2, 2.12.5, 2.16.6 places huge responsibility on service providers particularly when accessing integrated community based supports where the service provider may not be the owner or have control over such matters with regard the building or premises accessed by people with disabilities. These could mitigate a service provider engaging and collaborating with a local community group on the basis the building does not fulfil all the requirements. In the advent of regulations this could result in service providers retreating to delivering supports and services that go against the principles of national policies advocating more inclusive and active citizenship for individuals. Sub351

Feature 2.12.7

No data

Feature 2.12.8

No data

Feature 2.12.9

2.12.9: Add on sentence 'Correct ratio of care staff to assist Driver should be available at all times.' Sub344

Feature 2.12.10

No data

Standard 2.13


Re: Standard 2.13 "The effectiveness of services is systematically monitored, evaluated and continuously improved." Sub004

This should include the amendment: 2.13.9. Arrangements for a formal monitoring service should be put in place to include regular provision on a 6 monthly basis of inspector reports outlining a check list of compliance to standards. Inspectors from an independent monitoring agency should carry out inspection on an annual basis with freedom to visit unannounced if they choose. Accountability with false reporting or inexcusable failure to meet standards, should include loss of employment and if required, prosecution by law and other sanctions as befit. Such accountability should be vested in the person/s trusted to make these signature verified returns and those responsible for failures. Sub004

2.13: The group felt that this standard also needs to include the evaluating and monitoring of the individual goals and programmes. Sub007

Regarding standard 2.13: Check to see there is service user involvement in this area. Sub066

Who would systematically monitor the effectiveness of services? Sub073

	<p>Monitoring Services – management call to Day Services to talk to staff, but not to service users. Day services should be monitored by a staff member to see if people are happy there – every six months.</p> <p>The questions were asked</p> <p>Who checks the plan, the service users? The manager? An inspector?</p> <p>Generally groups felt it was about time that someone was going to keep a check on Day Services form outside of (Service Provider Name) Sub093</p>
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2.12 2.13 The concept of Hub is seen by some parents as a threat to day centres. The existing day centres are central to the lives of service users and gives them structure /routine—gives meaning to their lives —motivation to get up in the morning—gives them safety—gives them friends and many other contributions to their quality of life. Sub095

2.13 Monitored – Agreed (WIP re public reporting via website etc). Sub242

evaluation of Service?. Does our Service need to look at evaluation? Sub252

2.13 measurement of service delivery is something which is not done in human services. Concerns were expressed around how one can set targets and measure results when one is working with a person centred approach where individual goals are set for individuals. How does one measure success in getting to know individuals and working on their goals? Sub263

Standard 2.13 families are not included in the evaluation of supports and should be. Sub266

2.13 Feedback should set the standard like - everyone should have their planning meeting atleast two times a year and family members should return a feedback form at least once a year. Sub281

2.13 There are limitations on providing flexible weekend service – transport issues, remuneration. Sub342

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). Sub353

Standard 2.13 The effectiveness of services is systematically monitored, evaluated and continuously improved: This Standard is welcome and will contribute to greater monitoring of day services for people with disabilities. The focus on outcomes is very welcome as day services should be fully focused on delivering for the needs of the person. Some of our people with disabilities picked up on the features included under this Standard and expressed concern that a greater emphasis on reporting and on public reporting in particular could affect them and their quality of life as the service becomes more about red tape and less about supporting individuals. It could introduce a competitive approach which may result in developments but could also result in a lack of variety and overly cautious service delivery. Sub355

Standard 2.13 [quotes from Sub355]

“Very useful and important as it ensures that we as a service are always providing better Standards of care and support. We ensure this through regular team meetings and supervisions”.

“It is important that there is a service plan in each centre and that it is implemented and reviewed by each service”

“Use the internet more to inform service users, do not use all resources informing the powers that be, wasting valuable resources which staff and service users could be using”

“This is an important Standard to us. It is a good thing that we have people looking after the services and checking everything is working out”

“It is important to have review meetings to make sure the service is providing what we need to improve our lives”

“This sounds very formal. More red tape means things will be less flexible. Services will get too involved in peoples’ lives and overdo it. Not about numbers but quality of life, this should be recognised. The results would not look good if we talk about how the HSE let us down not our day services”.

“Housing needs are ignored by the HSE we have no choices but we are being told choice is key. Public services are poor in some cases but we are told to access the community more. Now we are told these Standards will ensure good quality services but it will mean services are afraid of things going wrong. Has to be all right, not just part.”

“Housing is so important to the people in day services. It impacts our mental well being and quality of life. It affects relationships, isolation and levels of community involvement. It affects our self worth and makes us afraid for our future. We are fobbed off as our rights to our own homes don’t exist and only when my elderly mother is dead will someone care, then I will probably end up in a nursing home. We don’t want our day service to get us homes but we want to know that they can help us plan for our future life, not only the parts we are told we can plan”.

[end quotes from Sub355]

Standard 2.13 The effectiveness of services is systematically monitored, evaluated and continuously improved: This Standard is welcome and will contribute to continuous improvement of day services and rehabilitative training for people with disabilities. The focus on outcomes is very welcome as these services should be fully focused on delivering for the needs of the person. (Service Provider Name) uses a number of measurement systems to gather data in relation to the outcomes of its learners. In particular, it collates details in relation to learners’ destinations on completion of training and the focus of training is on positive progression and transition planning. Sub370

2.13. The consultation with families will need to be supported by the HSE as drivers of New Directions in partnership with the service providers. Currently families see the availability of day services on a 9-5 basis and then evenings and weekend as an addition to this and not seeing supports being provided over seven days and evenings as a reconfiguration. Sub372

Currently families are not understanding the model of service proposed without their ‘buy in’ things will be difficult to move forward with. For some families having their family member attend day services is ‘respite hours’ away from home. Many People who live in community residential services do not have staff support hours during the day to have a more flexible day. In meeting the inspection of standards i.e. providing evidence should not take people away from direct support and have an over emphasis on administration and paperwork. Sub372

Standard 2.13 families are not included in the evaluation of supports and should be. Sub378

Standard 2.13 families are not included in the evaluation of supports and should be. Sub379

Feature 2.13.1

No data

Feature 2.13.2

No data

Feature 2.13.3

No data

Feature 2.13.4

No data

Feature 2.13.5

No data

Feature 2.13.6

2.13.6: Client confidentiality must be protected when reporting, further guidelines required for this standard. Sub279

Feature 2.13.7

No data

Theme 3

General Comments

Theme 3: Safe Services and Supports; In theory yes, but how to see how they can be implemented Sub032

Feedback was our service users felt safe coming to the centre each day and liked the fact that they have representative on the centre safety committee. Sub040

Theme 3: Safe Services and Supports; Fine Sub049

Comment on Part 3 (safe services and supports): [Note beside service providers must protect people using their supports from abuse]: 'True' Sub049

(Service Provider Name) strives to ensure that all staff have read, signed, and received training with regard to appropriate policies and procedures e.g. health and safety, recording and documentation etc Sub069

A general response is, as above How is this going to work? In theory I think this is an absolute but easier to identify in theory than in practise. In order for this to happen each requirement to make it happen must be identified and made possible e.g. staff, cost/budget and approval and made available etc. A comparison could be like building a solid house i.e. good plan/layout, to build a solid foundation, then a solid structure can be built that will last and one that will meet all requirements Sub073

This standard appears fine. All in agreement. Sub077

Excellent standard Sub094

Yes all good Sub095

Safe services & supports is an expected outcome of any service provider Sub103

As a service we have prioritised the promoted the safety of people using our services and have many of the noted 'features' within Standards 3;1, 3;2 & 3;3 in place. Sub106

Theme three is very understandable and easy to carry out Sub107

Overall feedback for this theme was very positive, all pictures seemed to match the words. As there were only 3 standards linked to this theme people supported found it easier to grasp Sub109

The organisation's policies ensure that service users are safe in their environment. This is backed up by national officers who advise on any concerns. Sub113

This is to make each person feel safe and secure when using services & support. Sub213

Each Su using day service should have training specific to their ability in health + safety. Sub226

The staff and service provider are totally compliant and have high standards when it comes to safety. Sub239

Wording is clear; The context on scope for safe services and supports are well explained and very clear; This Context on scope for safe services and supports appears relevant and cover the topic well. Sub252

Right to choose to take appropriate risk? Conflict for Service Providers. Risk assessments? Will this suffice? Sub252

2.1 to 5.1.2 outside times of 9.00am to 5.00pm Sub252

Will there be better access to Mental Health assessment for people with Intellectual Disabilities and continuous assessment for those? Sub253

Excellent Standard Sub254

Increased requirements for Independent Advocates. Query availability from National Advocacy Service. Increased staffing supports required to support individuals to access local community facilities. Some Day Service areas within the overall service currently have a Staff / Service User ratio of 1 to 15 and 1 to 10. Sub342

As a Service we have prioritised the promoted the safety of our people using our services and have many of the noted 'features' within Standards 3.1, 3.2 & 3.3 in place. Sub342

In regards to request for public consultation on Standards for New Directions, Services and Support for Adults with Disabilities and in particular in response to above standard, I wish to submit on the appropriate qualifications of staff in regards to providing appropriate support when working with individuals with behaviour that is difficult to manage or behaviour that challenges. I submit that the "specialist advice" and "appropriate support" should come from a specialist who has at minimum completed a master's degree (MSc. or MA) that was conferred in a Psychology (Applied Behaviour Analysis) or Master's degree in Applied Behaviour Analysis with coursework approved by Behaviour Analysis Certification Board (BACB). This approval ensures that the coursework satisfies that the Behaviour Analyst/Positive Behaviour Support Specialist has completed relevant modules and hours in Ethics, Definitions & Characteristics, Principles, Processes & Concepts (Principles of Behaviour), Behavioural Assessment and Selecting Intervention Outcomes and Strategies, Experimental Evaluation of Interventions, Measurement of Behaviour and Displaying & Interpreting Behavioural Data, Behaviour Change Procedures and Systems Support and discretionary behaviour analytic content (for example, ASD, Precision teaching, Pivotal Response Training). In addition, supervised field work of a minimum of 1500 hours plus 150 supervision hours is required to be completed during training. This supervision must include individual and group supervision hours and supervision of trainee on site (working directly with clients). Implementation of behaviour support plans and skills teaching for those with behaviours that challenge is clinical intervention. Therefore behaviour support plans

should be devised and supervised by those who are skilled and competent in evidence based science of Applied Behaviour Analysis which is the science underpinning Positive Behaviour Support. PBS specialists should therefore be required to be trained and competent to the level of training demanded by the BACB www.bacb.com as this is level of training that is sought to be competent in the supervision of functional analysis and behavioural assessment in order to select appropriate intervention outcomes and strategies. Sub271

General comment - Safe and clean services are essential. Buildings should be maintained to a very high standard and the approach to each building should be welcoming and pleasing. If an item is broken get it repaired without delay, as one would at home/at any place of employment. Risk assessments, fire drills, first aid and all health and safety legislation to be fully complied with at all times. No excuses. Sub344

These are very good proposals Sub270

Clients say that they feel safe at the day services, but can sometimes feel afraid if another client gets loud or angry. Sub282

Reference is made to the UN Convention on the Rights of Persons with Disabilities in Standard 1.1 As the Convention is internationally renowned as having a transformative effect on the lives of persons with disabilities it is disappointing that the complete repertoire of rights which are afforded to persons with disabilities are not fully utilised within the interim standards. It is recommended that Articles 1 and 3 and 5 of the UNCRPD should form an integral part of Standard 1.1 Sub291

Families: perfectly fine and necessary Sub291

(Service Provider Name) services current policies and practices are in line with Theme 3 Sub300

Once again: Parents need to know what the she or he is decision are making. Sub303

Our children who have moderate to severe learning disability are not capable of being left on their own, they need to be cared for, looked after and loved and above all else they need to be happy. To achieve this they require special care and such is the care being provided at the moment by the likes of (Service Provider Name) and other organisations like them. Sub350

Based on our comments above our concerns are: How will the routine healthcare requirements of service users be managed? If service users are working in the community, how will it be ensured that their best interests are represented so that they feel safe and appreciated in their work environment? Sub350

As a parent I have great concern that the people developing the standards have a full understanding of the challenges facing integration and support in the community. Will the people who will be helping our children will they have full garda vetting as this is

very important these children are very trusting and must be protected at all time in a safe environment e.g. wheelchair access etc. Sub350

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. Sub353

Standard 3: 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. Sub353

Theme 3: Safe Services and Supports: “The support that is here in the centre is very good.” “My brother is in town in (Service Provider Name); we found the enabling excellence good. It gave us a kick in the bum and it opened our eyes. He hadn’t done a course in a long time and he did an iPad course and she helped him [to] look up how to get there and everything and it was very good. We’re learning new things about him.” “(Service Provider Name) are fantastic, my sister attends and she’s done a few courses in (Service Provider Name) She loves it.” “I’m here (Service Provider Name) 37 years and it’s the best. The Standards here are very good. Persons Name, I do music with him and he’s excellent.” “The implementation will cost money. Will this come from the HSE?” “Since the economical crash the government have reduced funding and are passing the buck to charities, who are also strapped for cash. Now New Directions is putting more demand on services with independent supports or maybe having mobile supports services? There’s maybe going to be need for more staff but it takes three months minimum for Garda vetting. It’s not going to happen overnight. It’s an improvement on the last one, the code of practice for social workshops. (Service Provider Name) tried to implement it but the government didn’t. “In theory it’s a good idea but there are gaps, supports, staff levels, management levels, funding, we all know how skint the government is. It’s not going

to happen in the next year, you're looking at ten years minimum, I think." "There's training for care workers. There needs to be education for the family too to open our eyes. I think that needs to be included in the Standards." "There should be funding for supporting the family to support the individual." Sub355

General theme – assessment of risk requires further definition. Previously a culture of positive risk taking had been mentioned if this is the approach it should be detailed within the general theme statement Sub359

While it is vital that Adults with Disabilities are included in our society and included into the "community" "mainstream education", "vocational education", it is important to guarantee their safety and wellbeing in such environments, what measures and or training will be in place to ensure this? I was also unsure in what context the word "community" is meant. Sub366

Again, as above. Standard 2.7: those accessing day service solely shouldn't feel that they have to describe and actively seek support with creative self-expression. There is a fear of creating a concept that people with disability need to be "more normal than normal", by creating a framework of what is considered best practice to live a life by. There is no obligation on others to have to have activities or interests, this should be an option, not a standard. Sub369

General theme – assessment of risk requires further definition. Previously a culture of positive risk taking had been mentioned if this is the approach it should be detailed within the general theme statement. Sub380

Theme 3: Very good standards in this section. Only question would be that some clarity is needed around the boundaries of responsibility. E.g. if a service users, through their key worker takes up employment, voluntary or paid with a company in the community, who is responsible for the service user and any issues, adverse or otherwise that may arise during the time of the employment? How can a service provider without any statutory powers monitor a private company? The same is applicable to a service user engagement in any activity in the community. Sub385

Part 3 Safe Services and Supports: All the ladies commented that the standard to feel safe is very important to have in the book. The ladies again spoke about different aspects of what being safe meant to them including the importance of talking to staff if they had a problem. They talked about 'being nice to each other', 'respecting each other's stuff' another lady spoke about how we keep safe at work, 'by having the chain on door when answering it so as not to let a stranger in'. Another lady commented 'we also have a complaints poster on the wall and the phone number for the person who deals with problems if we want to phone someone in private' Sub390

Theme 3: Safe Services and Supports: Couldn't digest and read. Sub401

All agreed with the content of 'Safe Service and Supports'. Sub412

Theme 3: Safe Services and Supports: Staff also need to be supervised and supported. Sub415

Theme 3: Safe Services and Supports: Don't have it so can't comment Sub418

Theme 3: Safe Services and Supports: The standards should recognise the service user's ability or inability to formulate or contribute to the formulation of a personal plan or to make cogent decisions. Sub419

Standard 3.1

Regarding standard 3.1 : Check to see if service's vehicles are safe and up to standard. Sub066

3.1 that a child or adult is protected when out of centre at all times as they can be vulnerable. Sub078

The abuse protocol is very good but I don't know how those with language difficulties would let someone know especially if they have no understanding of sexual matters. Sub100

As a service we have prioritised the promoted the safety of people using our services and have many of the noted 'features' within Standards 3;1, 3;2 & 3;3 in place. Sub106

(3.1) I fully support the standards to protect from abuse and ensure the service users safety. I do however feel the policy is weighted and designed around those who can communicate instances of abuse i.e mild/moderate. How can this be applied for non-verbal clients? Sub232

3.1 Protected – Agreed [re Advocacy see 1.1 nb no national standards available. Sub242

Standard 3.1 – I think it's important to have an facility whereby a person outside the service provider can report abuse or a concern on behalf of a person using the service. Sub255

Standard 3.1: Risk assessments are these going to be clearly defined is there going to be a nationally accredited tool to use or is this going to be subjective depending on the organisation. Sub266

Increased requirements for Independent Advocates. Query availability from National Advocacy Service. Sub342

As a Service we have prioritised the promoted the safety of our people using our services and have many of the noted 'features' within Standards 3.1, 3.2 & 3.3 in place. Sub342

Standard 3.1. There is a total absence of information on how to protect oneself. Sub353

Standard 3.1 Each person is protected from abuse and their safety and welfare is promoted, while using services and supports. All of the features of this Standard are welcome and form a key part of any safe and appropriate support service. Two issues arise: Firstly, some additional emphasis on positive risk taking is required to balance statements such as “each person is protected from all forms of abuse”. Without some acknowledgement of calculated risk, community-based services cannot function. Services based out in the community where the person’s independence is maximised do carry higher risks. Service providers need to have a framework to balance negative and positive risks and to support their staff to do so. Secondly, the current lack of effective capacity legislation is an obstacle to ensuring informed consent. In the absence of capacity legislation and where a person’s capacity is in question it can be difficult to support them to make progress in their lives. Sub355

Standard 3.1 [quotes from Sub355]

“This Standard is of vital importance to ensure that while a service is providing support to people it is doing so in a safe way and in a safe environment. In order for a service to ensure this there are various different protocols and policies on this aspect of safety for staff and service users to adhere by within the service”.

“Everyone needs to respect each other. Health and safety in the work place ensure that the service is safe”.

“It’s very important that all service users are cared for by qualified, highly motivated, kind, progressive staff, and that the service provides a ‘home from home’ environment where users feel comfortable, safe and valued”.

“This is a very important Standard to us because it’s important to feel and be safe for our well-being as we attend the services and to be safe in community services that we use”.

“It is important to be able to talk to staff in our service if we feel we are being abused or treated badly”.

“Safety is essential but people have to take chances in life too. The important part is that people access services that help plan and support people through life. Can’t protect people from everything, there should be appropriate services in the community especially for mental well being to be supported if needed”.

“This is important as we need to be safe. Some people are rude and ignorant to us in the community – bully or ignore us”.

“This is important because everyone must have trust and respect for one another. Everyone wishes to feel safe and it is a basic human right to have our safety in place as a Standard. We believe that an objective Standard of what it means to be safe should be established”.

“We feel it is very important to feel safe. We feel safe in (Service Provider Name). We feel safe in groups when we go into the community or if we have a staff member with us”.

[end quotes Sub355]

Standard 3.1: Risk assessments are these going to be clearly defined is there going to be a nationally accredited tool to use or is this going to be subjective depending on the organisation. Whilst the partnership approach with the individual receiving supports is promoted the standard should also reflect the need of some individuals for members of their family and/or circle of support to be involved in this process. Sub359

Standard 3.1 is quiet thorough, but could also include an anti-bullying sentiment from peer-to-peer bullying. Sub367

Standard 3.1 Each person is protected from abuse and their safety and welfare is promoted, while using services and supports. All of the features of this Standard are welcome and form a key part of any safe and appropriate support service. Two issues arise: Firstly, some additional emphasis on positive risk taking is required to balance statements such as “each person is protected from all forms of abuse”. Without some acknowledgement of calculated risk, community-based services cannot function. Services based out in the community where the person’s independence is maximised do carry higher risks. Service providers need to have a framework to balance negative and positive risks and to support their staff to do so. Secondly, the current lack of effective capacity legislation is an obstacle to ensuring informed consent. In the absence of capacity legislation and where a person’s capacity is in question it can be difficult to support them to make progress in their lives. In our family focus groups, one family member stated, “Yes I always worry about my child’s safety, he is vulnerable in today’s world and when there is so many muggings and stabbings...” Safety of their family member is a primary concern for families and one which will need to be allayed in the roll-out of New Directions. Our learner focus groups highlighted the need to feel safe in their training course. One respondent said “it [this Standard] is important so no bullying takes place as this can make you feel bad”. Another focused on the need to feel happy and good about themselves and identified that the instructors, rehabilitative officers and rehabilitative psychologists were there to talk to if things went wrong. Some learners said that they “felt safer being in a centre rather than being out and about in the community” Sub370

Standard 3.1. There is a total absence of information on how to protect oneself. Sub374

Standard 3.1: Risk assessments are these going to be clearly defined is there going to be a nationally accredited tool to use or is this going to be subjective depending on the organisation. Sub378

Standard 3.1: Risk assessments are these going to be clearly defined is there going to be a nationally accredited tool to use or is this going to be subjective depending on the organisation. Sub379

Standard 3.1: Risk assessments are these going to be clearly defined is there going to be a nationally accredited tool to use or is this going to be subjective depending on the organisation. Whilst the partnership approach with the individual receiving supports is promoted the standard should also reflect the need of some individuals for members of their family and/or circle of support to be involved in this process. Sub380

3.1 Service users commented that they don't like the term "Abuse" and would prefer another term in the document. Sub381

3.1 Consideration should be given to creating a requirement for staff training and for ensuring that staff would have a good understanding of what is meant by abuse and also their responsibilities if they suspect abuse? Sub424

Feature 3.1.1

and 3.1.2 Given that Community Inclusion is a key principle in New Directions people will be using community services and supported in mainstream services more and more. This may be more of an implementation issue but does the standard need to give some consideration to the fact that people may be getting 90% of their service in mainstream settings and therefore is there a need for services to produce evidence of policies, procedures and practice in the mainstream services they are supporting people in? Sub110

3.1.1. and 3.1.2 Community inclusion is a key part of New Directions and with the development of new hub models of service provision clients may be receiving most of their service in mainstream settings, therefore we must ensure that such settings must have proper health and safety policies in place. Example: We had two of our service users (wheelchair users) placed on a 3rd floor classroom setting in a 3rd level institution. In case of a fire lift cannot be used! Sub283

Feature 3.1.2

3.1.2 Given that Community Inclusion is a key principle in New Directions people will be using community services and supported in mainstream services more and more. This may be more of an implementation issue but does the standard need to give some consideration to the fact that people may be getting 90% of their service in mainstream settings and therefore is there a need for services to produce evidence of policies, procedures and practice in the mainstream services they are supporting people in? Sub110

3.1.2: Terminology such as intimate is not conducive to a rehabilitative/training environment for adults. Sub279

3.1.1. and 3.1.2 Community inclusion is a key part of New Directions and with the development of new hub models of service provision clients may be receiving most of their service in mainstream settings, therefore we must ensure that such settings must have proper health and safety policies in place. Example: We had two of our service users (wheelchair users) placed on a 3rd floor classroom setting in a 3rd level institution. In case of a fire lift cannot be used! Sub283

Feature 3.1.3

3.1.3. Responsible risk taking is absolutely vital, and this standard is the “umbrella standard” to the enhancement of individual goals. This standard should be the “golden thread” that runs through all the New Directions themes. Sub291

Feature 3.1.4

No data

Feature 3.1.5

No data

Feature 3.1.6

3.1.6 This is very important to include family representative as the client belongs to a family and they play a very important role in the clients life within the service that they are using. This is mostly to involve the family when theirs a problem of a serious nature. And where their is progress in a certain stage of the clients life. Sub142

3.1.6 remove "where appropriate". Sub343

3.1.10. Add "This does not absolve the service from responsibility to inform and consult with the person's family." Sub343

3.1.6 remove "where appropriate". Sub365

Feature 3.1.7

3.1.7 The service provider should issue policies and procedures statements to all clients family's, so its very clear to a family member to follow. in the event of allegation of Abuse and support is given to the client [off page]. Sub142

Feature 3.1.8

Each person with behaviour support needs has a Positive Behaviour Support Plan ...again initial capital letters as it is a formal document. Sub344

Feature 3.1.9

No data

Feature 3.1.10

3.1.10. Add "This does not absolve the service from responsibility to inform and consult with the person's family." Sub365

Feature 3.1.11

No data

Feature 3.1.12

3.1.12. should be amended to include. "There is a designated person to act as a liaison with outside agencies and a resource person to staff members, carers or volunteers who have protection concerns. The designated person is responsible for reporting allegations or suspicions of abuse to the HSE or to An Garda Síochána in accordance with national guidance. (See 1.9.9 above) "To facilitate communication an advocacy group should appoint a liaison person from within the group to communicate between staff and group." The designated person should immediately inform the liaison person for that person's advocacy group should such a group exist. Sub004

Feature 3.1.13

No data

Feature 3.1.14

No data

Standard 3.2

Regarding standard 3.2 Check if there are easy to read versions of healthy eating plans, stress management plans, healthy living plans etc. Sub066

Standard 3.2 talk about positive behaviour supports. In one consultation the group noted that where someone does something wrong it should be explained clearly to them by staff. This group felt that there are occasions when there should be a reprimand for certain behaviours. Sub096

3.2 Strategies used to deal with challenging behaviour need to be communicated to the family so everyone is responding in the same manner. Sub100

As a service we have prioritised the promoted the safety of people using our services and have many of the noted 'features' within Standards 3;1, 3;2 & 3;3 in place. Sub106

Advice from professionals an 3.2 supporting positive behaviour and why a person behaves the way they do. A what they are trying to say finding ways to help people with their behaviour. Sub222

3.2 Supports –Agreed (WIP re behaviour support policy). Sub242

Standard 3.3 rated very high (76%). Standard 3.2 was also significantly high (72.4%). Sub245

Will there be better access to Mental Health assessment for people with Intellectual Disabilities and continuous assessment for those? Sub253

We were frequently required to completely change the language of entire slides on the presentation to make them more accessible e.g. we changed “standard 3.2 says that supports people use should support positive behaviour and emotional well-being” to “(Service Provider Name) should listen to you and help you to feel good. If you are angry or upset then (Service Provider Name) should help you to feel better”. Sub285

Standard 3.2 We very much welcome a standard which promotes appropriate supports for people with challenging needs. In this standard (section 3.2.4), it states that people should be supported to access Mental Health Services. In this regard we suggest feedback should note that for many years people with intellectual disability have been supported by services to access mental Health Services with little or no success. Sub291

3.2 comprehensive training for staff in area of positive behaviour support is urgently needed. Sub291

Standard 3.2 Emotional well being is very important, to ensure this we need more qualified people in the area of mental health to support service users in general. Sub296

As a Service we have prioritised the promoted the safety of our people using our services and have many of the noted ‘features’ within Standards 3.1, 3.2 & 3.3 in place. Sub342

3.2 Reinforces safety – all staff has been provided with training in the protection of vulnerable adults and a complaint book is in place. Sub348

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 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” Sub353

Standard 3.2 Each person receives services and supports that promote positive behaviour and emotional well-being The full implementation of this Standard would be positive within services and would enable those with significant and complex needs and those with behaviours that challenge to maximise their potential; however, the psychological and behavioural supports required are not always available within existing resources. The focus of this Standard on supporting positive behaviour support and emotional well-being was welcomed by the respondents to our consultation, particularly with the emphasis on continuous staff training as these issues can be difficult for services to manage and staff need the tools to do so. Personal development programmes are very important to help people with

disabilities to understand their feelings and how they can help themselves and other around them. Sub355

Standard 3.2 [quotes from Sub355]

“This Standard is very important when dealing with behaviours and behaviours that challenge. It is vital that within a service plans and supports are put into place in order to manage behaviours in an effective and positive way. Each individual will have their own behavioural management plans for staff to follow. These plans are person centred to the individual and their needs. It is also important to have steps put in place when dealing with behaviours and for communication tools to be available at all times for staff to understand the behaviour and deal with it in a positive way so as to promote good mental health for individuals”.

“This applies to both staff, and other service users. It’s important to be aware that other users may have issues and to be understanding in dealing with them. Do not block the way ahead for people who are gradually gaining back their independence”.

“This is a very important Standard to us. We want people to understand us and help us in a positive way. This is a good support for everyone to help them feel good about themselves”.

“It is important that the service provider understands why we have behaviours and help us to get supports to improve behaviours and support us to have positive behaviours and this enables us and all other service users in our service to be happier”.

“Self esteem, having choice respected, good quality of life etc all connected and important, and expected by service users. All support good mental health”.

“This is important and the centre supports positive behaviour and emotional well being, everyone agreed to this and was happy to do so”.

“Individuals felt that opinions should be listened to; support around emotional well-being is important. “Staff should be happy too”. “Support is available”. “Staff are available”. “It’s important for support to be there; to feel safe”. “It’s important to feel good; emotional and mental health”.

“This is important, it is the essence of a service and the whole point of attending”.

[end quotes from Sub355]

I wish to express my opinions on standards of experience to supervise (Service Provider Name) services & implement behavioural procedures for individuals with disabilities. The persons should have a minimum BCBA qualification. Sub356

Standard 3.2 is very wordy and could be written in a simpler format, there is a lot of terminology and jargon included. Sub359

STANDARD 3.2: I believe, although potentially well meaning, the definition and understanding of PBS as defined in the glossary 'PBS is behaviour analysis applied in support of individuals with behaviours of concern' is somewhat inaccurate. While this is partly correct, PBS has a much larger focus on increasing adaptive replacement behaviour, in a person centred manner, as opposed to simply focussing on behaviours of concern. The main achievement of well designed, well supervised and well implemented PBS to increase the overall quality of life for those who receive PBS services. The draft standards do not stipulate who should provide training, advice and supervision. It is strongly recommended that only those appropriately qualified to deliver ABA based services should be enabled to provide such training and supervision. Those implementing PBS and other ABA services need receive supervision from a qualified and competently experienced BCBA on a regular basis. Sub360

3.2 Suggest to add to the paragraph after the Standard Statement "mindful of the fact that people who are non verbal may simply be saying I am Bored". Also on the third paragraph starting with Emotional well being suggest to add – "It also means avoiding if at all possible over strong negative reaction to odd behavioural traits" (Ref Easy to read standards 1-3). Sub372

(Service Provider Name) Service considers that there is a general imbalance of power throughout the standards making the person the problem, particularly evident in standard 3.2. We suggest that while considerable effort has been taken with language, that in some circumstances it is still vague and wordy. We also suggest that the final version be reviewed by NALA and that accessible versions are developed. Sub374

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. The phrase "positive behaviour" is a judgement and implies that the person using the service does not have the ability to behave in accordance with services' preferred behaviour. Is the constant encouragement of positive behaviour in line with normalisation practises? Would any person be happy with people they work with constantly encouraging them to be positive all of the time? Standard 3.2 potentially makes the person the problem and removes the focus from environmental and social influences. The last phrase of 3.2 concretises this point and is very much un-person centred. "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" Sub374

Standard 3.2 is very wordy and could be written in a simpler format, there is a lot of terminology and jargon included. Sub379

Standard 3.2 is very wordy and could be written in a simpler format, there is a lot of terminology and jargon included. Sub380

3.2 Language difficult. Sub381

All agreed with the content of 'Safe Service and Supports' 3.2 - To plan and implement the positive behaviour support plan you need skilled experienced support staff – that is very difficult to achieve in the current climate. Sub412

3.2 The inclusion of therapeutic supports and interventions is welcome. The Draft does not explicitly deal with restrictive practices which some services deem essential. While the focus is on positive support, it may be worthwhile to be explicit and to directly acknowledge that restrictive practices are deemed necessary at times. Consideration should be given here to principles about requirements for informed assessment, least restrictive for shortest period, regular review, etc. Sub424

Feature 3.2.1

Sections 3.2.1, 3.2.7 and 3.2.10 describe the use of Positive Behaviour Support and related assessments. It should be specified that a functional assessment is required in the development of an evidence based PBS plan, as only using the term 'assessment' (3.2.7) leaves the guidelines open to interpretation. I am concerned that no mention is made of the required skills in order to carry out a functional assessment to inform a Positive Behaviour Support plan. This is a skill which requires training and experience to ensure that it can be carried out competently. Currently, the only recognised certification available to ensure that a practitioner has both the required background knowledge and training and the professional competency to carry out functional assessments is provided by the Behavior Analysis Certification Board (BACB). Until such time as an Irish/European equivalent is available, all people involved in the design and implementation of PBS plans should have access to a Board Certified Behaviour Analyst. I feel that in the absence of clear guidance around who is considered competent to carry out functional assessment, section 3.2.8 will lead to a hasty proliferation of poor quality PBS plans, conducted by staff who have completed a short course in PBS. Sub280

3.2.1. The service has a written policy on the provision of behavioural support to people using the service that is based on the principles of positive behaviour support and details how specialist and therapeutic interventions are implemented.” (Service Provider Name) suggests that “based on” is too loose a phrase and that instead this standard is changed to the following “The service has a written policy on the provision of positive behaviour support and details how specialist and therapeutic interventions are implemented.” (Service Provider Name) would also like to highlight organisations’ responsibilities to ensure that services monitor and support the ongoing implementation of individual plans and as such suggests the following addition to this standard “...and how the service's management system is set up to ensure the ongoing implementation of individual plans.” Sub386

Feature 3.2.2

3.2.2. This standard may benefit from a focus on staff training, the skills that are needed to extract feelings, and manage emotional wellbeing is a learned & dynamic skill. Service providers need to deliver on this necessity and a responsibility needs to in place to allow this to happen. Sub291

3.2.2. People are supported to express their feelings appropriately and to deal with issues that impact on their emotional wellbeing in a way that best suits their needs. (Service Provider Name) would like to highlight that behaviours that challenge are related not just to difficulties in expressing feelings appropriately but also to people expressing basic needs and preferences. We suggest therefore the following amendment “People are supported to express their feelings, needs and preferences appropriately.” Sub386

Feature 3.2.3

No data

Feature 3.2.4

Standard 3.2 We very much welcome a standard which promotes appropriate supports for people with challenging needs. In this standard (section 3 2. 4), it states that people should be supported to access Mental Health Services. In this regard we suggest feedback should note that for many years people with intellectual disability have been supported by services to access mental Health Services with little or no success. Sub291

3 .2.4 This standard feature states that people should be supported to access mental health services where appropriate. However it is the experience of many service providers that they have had very little success in supporting people with intellectual disability to access such services. Again this is outside the control of service providers and requires full co-operation from mental health services. Sub352

Feature 3.2.4 states that people are supported to access mental health supports. Supports are not always available where and when they are needed and it would be difficult for a service provider to access them where they are not available. There can be significant gaps between the person’s requirements and access and availability of services. Service providers should be able to support people to access mainstream mental health services rather than provide them in house in line with *New Directions* but this feature seems to suggest that service providers will support access to mental health services regardless of availability. Sub355

3.2.4. People are supported to access mental health services, where appropriate.

(Service Provider Name) would like to highlight the need for the appropriate mental health screening for people with intellectual disabilities as the need for mental health services is often not detected and as such left untreated. (Service Provider Name) would also like to highlight the importance of well co-ordinated multi-disciplinary supports as positive behaviour support requires an integrated assessment formulation and support plan. It is difficult to achieve such co-ordination when mental health supports services are provided by separate services. It is critical therefore that systems are in place that support the collaboration of the various clinicians i.e. psychology, psychiatry, speech and language therapy, behaviour support etc. Sub386

Feature 3.2.5

3.2.5: Very important to implement therapeutic supports however we are not funded for this even though it is best practice. More guidelines required. Sub279

3.2.5. Specialist and/or therapeutic supports are implemented in accordance with national policy and guidelines and with the informed consent of each person, or persons acting on their behalf and reviewed as part of the personal planning process.(Service Provider Name) members are not aware of any national policies or guidelines in relation to the provision of positive behaviour support other than the regulations associated with Health Act Statutory Instrument. (Service Provider Name) members would also like to highlight that the procedures necessary to acquire informed consent from people with intellectual disabilities are inherently tied to best interest processes and legislation i.e. that this process requires decisions to be made regarding the capacity of the person to understand and make decisions about the various supports they receive. It is unclear whether the provisions made within the proposed Assisted Decision Making Bill will account for such necessary procedures but until that time, it is likely that there will be inherent limitations in attempts to secure the informed consent of service users with intellectual disabilities. It should also be highlighted that in order to acquire informed consent, a functional approach towards capacity must be assumed, as recommended by The Law Reform Commission's Consultation Paper on Vulnerable Adults and the Law: Capacity" (LRC 37-2005). This emphasises that capacity is not something that is globally "present" or "absent," but that it is something that needs to be assessed in relation to each particular decision at the given moment in time. Sub386

Feature 3.2.6

3.2.6. Each person is consulted with and given an explanation regarding the effects of inappropriate behaviour and what is expected of them, in a manner consistent with their ability and capacity. (Service Provider Name) would like to highlight that explaining the effects of someone's behaviour is for many people contraindicated as it is likely to result in increases in behaviours that challenge or emotional distress for the focus person. We would therefore like to recommend that this be removed from the standards or at a minimum, that the following proviso to be included in the standards: "If there is evidence that explaining the effects of someone's behaviours that challenge could be counter-therapeutic, this is not necessary and the rationale for not providing this explanation is recorded on the person's file". (Service Provider Name) would also like to draw attention to the use of appropriate terminology throughout the standards document. The term "inappropriate behaviour" does not represent current practice and we would like to suggest therefore that one of the following terms is used in its place: "challenging behaviour," "behaviours that challenge," or "behaviour of concern." Sub386

Feature 3.2.7

Sections 3.2.1, 3.2.7 and 3.2.10 describe the use of Positive Behaviour Support and related assessments. It should be specified that a functional assessment is required in the development of an evidence based PBS plan, as only using the term 'assessment' (3.2.7) leaves the guidelines open to interpretation. I am concerned that no mention

is made of the required skills in order to carry out a functional assessment to inform a Positive Behaviour Support plan. This is a skill which requires training and experience to ensure that it can be carried out competently. Currently, the only recognised certification available to ensure that a practitioner has both the required background knowledge and training and the professional competency to carry out functional assessments is provided by the Behavior Analysis Certification Board (BACB). Until such time as an Irish/European equivalent is available, all people involved in the design and implementation of PBS plans should have access to a Board Certified Behaviour Analyst. I feel that in the absence of clear guidance around who is considered competent to carry out functional assessment, section 3.2.8 will lead to a hasty proliferation of poor quality PBS plans, conducted by staff who have completed a short course in PBS. Sub280

3.2.7. & 3.2.8. staff training needs to have a focus within the mentioned standards. The skills that are needed to work “non-aversively to behaviour” are learned and are not innate. The standards need to put specific responsibility on service providers, to implement training systems that are modern, responsive & practical to the needs of specific service users, who may need supports in this regard. Sub291

Feature 3.2.7 refers to how the needs of a person with behaviour support needs will be met. In order to fully achieve this feature, the need for additional resources for behaviour therapy and psychology supports will need to be identified and responded to by the funder. Sub355

3.2.7. Where a person has behaviour support needs, an assessment is carried out which outlines the needs and characteristics of the person and the contexts in which behaviour is likely to arise, in order to draw up a positive behaviour support plan. (Service Provider Name) would like to highlight that evidence based practice in supporting people with intellectual disabilities and behaviours that challenge indicates the necessity of what is called a Functional Assessment. A functional assessment goes beyond what is outlined in the above standard and includes the following six elements at a minimum. A description of the target behaviours. Reference to methods which will evaluate the outcomes of intervention i.e. behaviour recording / quality of life measures. Interviews with people who know the focus person well (and the focus person where possible). Direct observations of the person e.g. Observations conducted by the appropriately trained clinician and / or Behaviour recording which provides information regarding the conditions associated with behaviours that challenge OR a clear rationale for no direct observation A narrative or graphical formulation including reference to antecedents and consequences / function and that this formulation reflects the data collected Evidence of service user (or service user advocate) and staff input. Sub386

Feature 3.2.8

The list of trainings that are considered key for staff does not include PBS (5.4.3). It seems that, while all people should have a PBS plan (3.2.8) according to the guidelines, not all staff should have training in PBS (5.4.3), and should staff seek training or specialist support in PBS, there are no standards set out for said training

or for the competency levels required for practising at different levels of complexity within PBS (section 3). Sub280

3.2.7. & 3.2.8. staff training needs to have a focus within the mentioned standards. The skills that are needed to work “non-aversively to behaviour” are learned and are not innate. The standards need to put specific responsibility on service providers, to implement training systems that are modern, responsive & practical to the needs of specific service users, who may need supports in this regard. Sub291

Standard 3.2.8. We suggest that the standard needs to outline who will monitor and evaluate the plan. Sub353

Standard 3.2.8. We suggest that the standard needs to outline who will monitor and evaluate the plan. Sub374

3.2.8. Each person with behaviour support needs has a positive behaviour support plan. The plan includes ideas for adapting the environment, teaching skills and focused interventions which are designed to prevent challenging behaviour or reduce the likelihood of its occurrence. The plan also includes non-aversive reactive strategies. The plan is monitored and evaluated regularly. (Service Provider Name) would like to highlight that the behaviour support plan elements outlined above reflect only one model of positive behaviour support. There are variations within PBS which remain in line with international best practice. (Service Provider Name) therefore suggests the following as a substitution. A plan should include: Antecedent interventions to prevent and reduce the likelihood of behaviours that challenge including e.g. changes to the person’s living arrangements, the physical environment, the person’s daily routine and the activities they complete, their health, their quality of life, their day to day interactions etc. Skills teaching interventions which focus on teaching skills that meet the same needs as the behaviour (functionally equivalent skills) and skills to help the person cope with difficult / stressful situations. Reinforcement based interventions that focus on increasing the likelihood of functional skills. Reactive strategies which emphasize non-aversive supports e.g. de-escalation and which specify criteria for the use of restrictive interventions such as restraint, seclusion, PRN medication etc. where deemed necessary. Methods to evaluate the implementation of the plan. (Service Provider Name) would also like to highlight the importance of there being clear links made between the conclusions of the assessment and the recommended supports. Finally, (Service Provider Name) would like to suggest that PBS plans are not necessary for every person with behaviour support needs. Some people’s behaviour support needs can be met with simple changes to the person’s support. (Service Provider Name) would like to suggest that the following proviso be included with this standard “Where the person has behaviour support needs and it is determined that these needs can be addressed with straightforward adjustments to the person’s support (i.e. the full functional assessment and behaviour support planning process is not required), there is evidence of the following: A clearly written description of the rationale for not completing the full behaviour support process; A clearly written description of the recommended supports and why these supports will meet the need; and Objective

evidence that this method of support has reduced the frequency and / or impact of the person's behaviours that challenge." Sub386

Feature 3.2.9

The following is welcomed: "3.2.9. Staff consult with former carers, parents and family members, with the informed consent of each person, in order to develop the behaviour support plan." Sub004

3.2.9 consultation to what degree is practicable in light of former carer/ex-staff members as their information should be logged on the person file already? Gaining consent to what degree also in 3.2.5. Staff found it repetitive and lacking clear guidelines as to what to do for inspections. Following up parents/family/past staff on getting to know service users behaviours etc isn't feasible if the staff have left the organisation. Parent would need to link in with the service in order to do this and staff would need time / know what to be asking from families in order to do this. Yes the standard underpins the methods of positive behavioural support plans however agencies do not have allied health services and this poses difficulties in services developing plans. Training staff in MAPA is being done but further resources are needed to bring the staff up to a further level of expertise. Sub263

3.2.9. Staff consult with former carers, parents and family members, with the informed consent of each person, in order to develop the behaviour support plan. Sub386

Feature 3.2.10

All service users are protected by policies and supporting procedures from many forms of abuse as in standard 3.2.10. Staff of the service have a duty to ensure staff are trained in positive behaviour support and people are supported who have mental issues. Sub262

Sections 3.2.1, 3.2.7 and 3.2.10 describe the use of Positive Behaviour Support and related assessments. It should be specified that a functional assessment is required in the development of an evidence based PBS plan, as only using the term 'assessment' (3.2.7) leaves the guidelines open to interpretation. I am concerned that no mention is made of the required skills in order to carry out a functional assessment to inform a Positive Behaviour Support plan. This is a skill which requires training and experience to ensure that it can be carried out competently. Currently, the only recognised certification available to ensure that a practitioner has both the required background knowledge and training and the professional competency to carry out functional assessments is provided by the Behavior Analysis Certification Board (BACB). Until such time as an Irish/European equivalent is available, all people involved in the design and implementation of PBS plans should have access to a Board Certified Behaviour Analyst. I feel that in the absence of clear guidance around who is considered competent to carry out functional assessment, section 3.2.8 will lead to a hasty proliferation of poor quality PBS plans, conducted by staff who have completed a short course in PBS. Sub280

3.2.10 more staff training required there. Sub342

The (Service Provider Name) welcomes the recommendation in 3.2.10 that staff should be trained in the provision of PBS. However, it is the opinion of (Service Provider Name) that the quality of training sought by services should reach a recognised standard. Many services provide staff with mandatory training in crisis interventions such as Studio III or MAPA provided through the Crisis prevention Institute. Similarly organisations should be encouraged to provide appropriate training to staff in the correct implementation of Behaviour Support Plans and recommendations, such as training as a Registered Behaviour Technician (RBT) which is accredited by the BACB. Sub372

3.2.10. Staff are: trained in the provision of positive behaviour support to people with disabilities. (Service Provider Name) would like to highlight the importance of defining what training in positive behaviour support involves. To this end, we have provided a model outline of such training below which is relevant for both direct support staff and for their line managers. The ethical & legal frameworks relevant to Positive Behaviour Support. The ABC model (3 & 4 term contingencies). Behavioural function & the importance of understanding behavioural function. How to help collect data for a functional assessment. Systematic skills teaching principles and procedures. Non-aversive reactive strategies and crisis management. (Service Provider Name) would also like to draw attention to the need for direct support staff to receive training on the individual elements of each service users' person centred positive behaviour support plan. We suggest that an additional standard is included to reflect this need e.g. "Staff are: trained to competently implement each element of service users' person centred positive behaviour support plans." Sub386

3.2.10. Staff are: trained to deal with issues of disrupted attachment, neglect and abuse and how this can impact on the behaviour of people with disabilities. (Service Provider Name) would like to stress the importance that any training in relation to disrupted attachment, neglect and abuse should be evidence based and as such, any recommended training be more explicitly referenced. Sub386

3.2.10. Staff are: trained to understand and to respond non-aversively to behaviour and verbal and non-verbal communication that may indicate an issue of concern. (Service Provider Name) would like to highlight that many organisations provide training in reactively responding to behaviour and not in the other proactive preventative aspects of evidence based positive behaviour support. It is important therefore to examine this distinction when reviewing training records i.e. that staff have received both training in reactive management and training in proactive positive behaviour support i.e. functional assessment and function based antecedent, skills teaching and reinforcement based interventions as outlined above. Sub386

Feature 3.2.11

In order for PBS services to be implemented effectively and as designed they need to be supervised by a Board Certified Behaviour Analyst (BCBA) or somebody who is work towards this qualification. "3.2.11. Staff have access to specialist advice and appropriate support when working with people who present with behaviour that is difficult to manage." BCBA's are trained to understand behavioural function and to

help individuals to have their needs met appropriately; they follow ethical standards in relation to care, education and skills teaching for the individuals with whom they work.

If PBS is to be implemented effectively; and if individuals with LD in Ireland are to be afforded the best standards of care BCBA's ought to be employed in these services. Sub102

In regards to request for public consultation on Standards for New Directions, Services and Support for Adults with Disabilities and in particular in response to above standard, I wish to submit on the appropriate qualifications of staff in regards to providing appropriate support when working with individuals with behaviour that is difficult to manage or behaviour that challenges. I submit that the "specialist advice" and "appropriate support" should come from a specialist who has at minimum completed a master's degree (MSc. or MA) that was conferred in a Psychology (Applied Behaviour Analysis) or Master's degree in Applied Behaviour Analysis with coursework approved by Behaviour Analysis Certification Board (BACB). This approval ensures that the coursework satisfies that the Behaviour Analyst/Positive Behaviour Support Specialist has completed relevant modules and hours in Ethics, Definitions & Characteristics, Principles, Processes & Concepts (Principles of Behaviour), Behavioural Assessment and Selecting Intervention Outcomes and Strategies, Experimental Evaluation of Interventions, Measurement of Behaviour and Displaying & Interpreting Behavioural Data, Behaviour Change Procedures and Systems Support and discretionary behaviour analytic content (for example, ASD, Precision teaching, Pivotal Response Training). In addition, supervised field work of a minimum of 1500 hours plus 150 supervision hours is required to be completed during training. This supervision must include individual and group supervision hours and supervision of trainee on site (working directly with clients). Implementation of behaviour support plans and skills teaching for those with behaviours that challenge is clinical intervention. Therefore behaviour support plans should be devised and supervised by those who are skilled and competent in evidence based science of Applied Behaviour Analysis which is the science underpinning Positive Behaviour Support. PBS specialists should therefore be required to be trained and competent to the level of training demanded by the BACB (www.bacb.com) as this is level of training that is sought to be competent in the supervision of functional analysis and behavioural assessment in order to select appropriate intervention outcomes and strategies. Sub271

Section 3.2.11 mentions 'specialist advice', but is not clear on what constitutes 'specialist' or where this can be accessed. As above, more clarity is needed on who is competent to provide this specialist advice. Sub280

Section 3.2.11 suggests that staff working with people with challenging behaviour support needs should have access to advice and consultation outside of normal working hours. Clarity as to who should provide this support would be welcome- it may have further resource implications. Sub291

3.2.11. This is such an important standard when working with behaviours that challenge. Standard 3.2.11. needs to go further in providing responsibility to service providers to mainstream training for staff at the frontline of behaviours that challenge. This training should incorporate learnt & skill based approaches to managing behaviour that requires specific supports in order to maintain safety for individuals at risk. Sub291

3.2.11 Staff support and training required. Safety is priority in service delivery. Sub342

3.2.11 This standard feature suggests that staff working with people with challenging behaviour support needs should have access to advice and consultation outside of normal working hours. Clarity as to who should provide this support would be welcome - it may have further resource implications. Sub352

I am also pleased to read section 3.2.11. (Staff have access to specialist advice and appropriate support when working with people who present with behaviour that is difficult to manage) as I firmly believe that the right support can make a huge difference to overall quality of life for individuals who demonstrate behaviours that challenge and for their families and others in their circle of support. In relation to this, however, I must point out that such services **must** be provided by those with adequate training and experience. Interventions that are designed and delivered by those with insufficient training and support can do more harm than good and can often lead to further difficulties. When working with behaviours that challenge, behaviour support plans must be designed and delivered in a systematic, consistent way, utilising the most up-to-date evidence-based strategies. This work must be completed under the supervision of a Board Certified Behaviour Analyst (BCBA) in order to ensure that the highest standards of effective and ethical practice are upheld. Once a BCBA is on board, stakeholders can be assured that a minimum standard of training and experience has been reached by that practitioner. In brief, in order to earn the BCBA title, one must have a minimum of Masters degree, covering specific areas of the Task List as set out by our certification board. In addition, they must undergo 1500 hours of supervised practice in an applied setting. They must obtain 75 hours of supervision from a BCBA. Then they are eligible to sit the exam which will earn them the BCBA title should they pass. Furthermore, that individual must engage in continuous professional development activities in order to maintain their certification. The BCBA title is synonymous with a quality control assurance. I urge you to amend your policy to ensure that those receiving intervention for behaviours that challenge do so under the direct supervision, and with continuous input from a BCBA. Sub357

Recommendation 3.2.11 stipulates that specialist advice should be made available to staff using PBS. Unfortunately, the draft standards do not stipulate who should provide training, advice and supervision. This is an area that falls within the expertise of the DBA and its partners in the international ABA community who aim to promote PBS as a proficient, safe and effective treatment option for consumers. Sub372

3.2.11. Staff have access to specialist advice and appropriate support when working with people who present with behaviour that is difficult to manage. (Service Provider Name) would like to stress the importance of the above listed standard regarding specialist advice. The provision of effective positive behaviour support requires a technical assessment and intervention skill set that is achieved via significant post-graduate training and supervised experience. While individuals with many professional training backgrounds may be able to provide the appropriate specialist advice, positive behaviour support is a sub-specialism of the field of applied behaviour analysis (ABA) and as such, evidence based positive behaviour support requires either (1) the direct implementation or (2) supervision by a qualified Board Certified Behaviour Analyst (BCBA) or someone with a different professional background with post-graduate training in ABA / PBS. In many cases, direct support staff and their managers will be trained to conduct functional assessments and implement behaviour support plans. This is accepted as best practice but in instances where this model is utilised, the support process should always be supervised by someone with the qualifications and experience outlined above. 3.2.11. Such support includes: interventions designed to promote effective communication; guidelines for appropriate responses to particular situation; access to advice/consultation outside of normal working hours. (Service Provider Name) would like to highlight a distinction between proactively planned out of hours observations and skills training vs. reactively focussed support during periods of behavioural escalation. Positive behaviour support is a largely proactive discipline. A reactive strategy is described within each PBS plan. Staff are trained to follow the reactive strategy. When behavioural escalations occur, staff follow this plan in order to maintain safety and dignity in a crisis in-so-far as possible. Often little more can be done at this point. Drawing PBS specialists towards reactively focussed on-call work follows a medical model with the implicit assumption that a case needs diagnostic input in order to plan a response at that particular time. This is an inefficient use of the specialist's time unless there is occasion for the specialist to learn something from the event, in which case these observations would be planned ahead of time. The provision of such reactively focussed out-of-hours consultation advice would undermine the legitimacy of the PBS plan contents and the skills of the direct support team. As such, (Service Provider Name) recommends that this standard be removed. (Service Provider Name) suggests therefore that a more specific point is made regarding access to proactively planned out-of-hours support where needed. Otherwise, PBS plan implementation should be managed by the individual service's manager with training input from PBS specialists as required. Sub386

3.2.11. Such support includes: staff debriefing following involvement in a difficult incident (Service Provider Name) would like to highlight the distinction between critical incident stress debriefing and operational debriefing. Critical incident stress debriefing focuses upon facilitating the staff involved to process and manage the stress involved in an incident. This can be contrasted with operational debriefing which focuses on root causes and informing ongoing attempts to strengthen team responses by refining the PBS plan. These separate processes are often best delivered by different professionals. In particular, the competent implementation of

critical incident stress debriefing requires specific training. In addition, research suggests that for some people exposure to critical incident debriefing may increase traumatic symptoms. For these reasons it is important that debriefing should not be mandatory and rather that it should be offered and undertaken when the offer is accepted by the staff member involved. (Service Provider Name) recommends therefore that the above points be reflected in an amended version of the above standard e.g. “Such support includes: (1) the availability and offer of critical incident stress debriefing to staff following involvement in a difficult incident in order to support staff to appropriately process and manage any negative emotional consequences and (2) separate operational debriefing in order to examine root and situation specific causes and to refine and update the PBS plan. Sub386

Feature 3.2.12

3.2.12. The service regularly monitors and audits its approach to behaviour support, as outlined in the service’s policy. (Service Provider Name) would like to suggest an addition to this standard to highlight the need for responsive systems level action based on monitoring / auditing: “The service regularly monitors and audits its approach to behaviour support, as outlined in the service’s policy ...and there is evidence that this information is used to guide the ongoing development of its services for people who present with behaviours that challenge.” (Service Provider Name) would like to draw attention to the omission of any reference to restrictive interventions in the standards e.g. physical restraint, mechanical restraint, chemical restraint; seclusion, restricting access, aversive procedures etc. The area of restrictive interventions is an area which requires regulation in terms of the following: Strict adherence to the principle of least restrictive alternative as balanced with a person’s human rights; Robust authorisation procedures which include the focus person, their advocate, and a person external to the agency in question; Clear criteria for use of restrictions; Professional input from an appropriately qualified PBS Professional; and Ongoing evidence of monitoring and efforts to reduce restrictions over time. Finally, (Service Provider Name) would like to highlight the need to consider issues of service design for people with behaviours that challenge. While person-centred behaviour support plans and training can be effective, for many people with complex and enduring behaviour support needs, individualised service designs e.g. outreach day service programs, single occupancy services etc. may be necessary. (Service Provider Name) would like to recommend therefore that a standard that reflects this need is included e.g. “When there is evidence that people are presenting with chronic or severe behaviours that challenge, there is documented evidence that alternative service delivery models have been considered and / or trialled or are being implemented.” Sub386

Standard 3.3

Some people wanted to know of there would be guidelines or a procedure explaining the steps to be taken to make sure that something is done about things that go wrong and to make sure the organisation learns from it. Sub096

As a service we have prioritised the promoted the safety of people using our services and have many of the noted 'features' within Standards 3;1, 3;2 & 3;3 in place. Sub106

Standard 3.3 rated very high (76%). Standard 3.2 was also significantly high (72.4%). Sub245

3.3 This needs further clarification as to what it is asking for. Is it similar to notifiable incidents for HIQA in residential services. While having policies in place the organisation does not have specific officers / staff in place such as a managing abuse committee etc. Sub263

Increased staffing supports required to support individuals to access local community facilities. Some Day Service areas within the overall service currently have a Staff / Service User ratio of 1 to 15 and 1 to 10. Sub342

As a Service we have prioritised the promoted the safety of our people using our services and have many of the noted 'features' within Standards 3.1, 3.2 & 3.3 in place. Sub342

Standard 3.3 Adverse events and incidents are managed and reviewed in a timely manner and outcomes inform practice at all levels The requirements of this Standard are welcome; however the service provider cannot be responsible for the management and review of adverse events and incidents which occur outside of service provision hours. Sub355

Standard 3.3 [quotes from Sub355]

"This is very important as it is necessary for a service to have a plan in place in case something should go wrong. This can be done through risk assessments and ensuring that they are clear concise and up to date at all times within the service. It is also important for a service to provide training and meetings as well as regular supervision for staff to learn from in the case of something going wrong within the service and to ensure that something will be done about it so as to avoid things going wrong in the future".

"By your mistakes you learn, so analysing and putting recommendations in place if a similar situation happens again is very important for everyone. It speaks for itself".

"People need to be able to have trust in the service provider to make sure that things are being done to improve their lives and that the service is continually looking at the needs of the service users and changing the service as required".

"Sounds serious and formal. Services and staff will be afraid to relax or be flexible. Boundaries are important, services not responsible for everything. I take risks in the community every day I cross the road. Can't police people's lives, I am responsible for myself outside the day service, maybe not everybody can be but they should be".

“This Standard can be good sometimes and bad sometimes. If the Standard had to change it should change to improve the steps taken. It is a very important Standard for everyone”.

[end quotes Sub355]

Standard 3.3 should reflect the need to report adverse events to organisations other than the HSE (e.g. HSA). Sub359

3.3) SU's felt in relation to this point, this is not happening. Ie *“if something goes wrong, steps are put in place to make things better.”* Sub368

Standard 3.3 should reflect the need to report adverse events to organisations other than the HSE (e.g. HAS). Sub380

Feature 3.3.1

No data

Feature 3.3.2

No data

Feature 3.3.3

No data

Feature 3.3.4

No data

Theme 4

General Comments

The group felt that all organisations should have a steering group committee and hold regular meetings to discuss service development and the implementation of New Directions. This steering group should have family representatives. The group also felt it needs to be stated that all services have an open door policy and families are invited to have an input into the activities provided to their family member. Sub007

Theme 4: Leadership Governance and Management: In very short supply in (Service Provider Name) despite the dedication of staff members on the ground Sub032

(Service Provider Name) as an organisation promotes a culture of quality, person-centredness, community inclusion and active citizenship. The organisation has a Quality Assurance Department and (Name of Team) who audit us regularly to assess, evaluate and improve provision of service. Sub040

This section has identified some of the basic and critical functions that are absolutely required but will only be possible with the proper approach/plan. Again, this is totally dependent on the standards and features correctly outlined but is dependent on staff

availability with the appropriate training /skillset and absolutely on funding being available. The big question /issue here for me is how likely is this going to be. Sub073

Change can be scary /frightening and I have seen that most parents are frightened of this, but change should always be positive, an improvement and this should be possible learning from the past/history i.e. what does not currently work for the service provider and client/user but again the big question for me is where will the funding come from and who will sign off confirming this is available as required, considering in the current situation. I am consistently hearing about clinicians and staff not being available because of cut backs, so how can anybody believe that this fundamental requirement i.e. funding will be made available for New Directions and for something that seems already is being pushed through without all the basic and fundamental requirements being confirmed or even understood. Sub073

Good standard. Sub094

It seems to me that service providers are to become Facilitators /Consultants of a sort rather than the provider of services. The current role of well run efficient service providers is being undermined with misplaced assumptions of group activities. There is a lot that is good in the centres at present. Sub095

Quite a lot of reading is required to keep up with all the new regulations coming into force. Maybe one person should be responsible for this and pass on what is relevant to the staff. Sub100

This is understandable and clearly worded, and is evident in our organisation. Sub107

Theme 4: Leadership, Governance and Management: Is all part of the training and education of all who are caring for the special needs of people going to these training centres. Without proper management and governance there is no plan for the care required. Sub213

Good ideas in all theme 4 standards Sub222

Not enough awareness/community involvement. Need clarification on the role of each government department in mobilising new directions. How will this affect social + Health care budgets will resources allocated be spread throughout all departments or will there be more funding. Need media coverage. Sub226

Theme 4: Leadership: Ok. Sub233

We have excellent leadership in our organisation. The worry is that if sufficient funding is not available that the high standards in staff that we currently enjoy could be eroded. Sub239

Theme 4: General Comment: As a Service we welcome and agree to the introduction of the standards as outlined in the Draft. However, it must be recognised that we face an obstacle to achieve full implementation; that being the

lack of resources as vacancies have not been filled since the introduction of the moratorium on recruitment. Sub245

This theme is very comprehensive; No issues with the Standards and features under this theme. 2.1 to 5.1.2 outside times of 9.00am to 5.00pm. Sub252

Theme 4: Good Standard Sub254

Specific Feedback on Themes 4-7: The ideals outlined in these sections are laudable but would be impossible to implement in their totality unless sufficient funding is made available by the government. Also what procedures will be put in place to ensure the standards outlined will be realized; staff to service user ratios need to be low enough for an effective differentiated programme to be put in place; managers need to be allocated time to ensure training is provided for staff in order to improve outcomes for people using services and supports. Sub261

These are good proposals for those they suit, again my family member will not fall into this bracket. Sub270

Service users who are sick and attend a Residential Setting must have facilities for their Service User when they are sick, a bed to stay in if necessary, a place to keep warm and left rest. The sick person should not be sent into Adult Day Services if sick, and should be sent back to Residential area if they become sick during their day. It works as a dual role (i) promotes the care and well being and healing of the person who is sick, and (ii) prohibits the spread of sickness all over the service. Sub276

Themes 4-7: It would help our understanding of how services are run if we were included in these discussions. Repeat use of some pictures was confusing as they meant different things. Sub281

Theme 4: Similar to Standards QA00/01. Sub283

The standards look good on paper but I believe they are just aspirational. They will not work unless there is further funding which we all know is not available. I would like the NDA to publish the feedback on these standards. It would be very interesting for me to see if any other parent agrees with me on any of the above points. Sub293

These standards are comprehensive and easily achievable where not already in place. Sub300

This document's scope is too narrow. It would be more acceptable if Residential Services, Home Care, Home Support Packages and Home Help Services were also included, rather than 'ring fencing' day care services. The impression is that this document only concerns itself with one aspect of a disabled person's life and washes its hands of other services required on a daily basis. Vital daily services required are omitted. If different departments have to be approached regarding Travel, Residential Care, Health and Home Help issues, the task of linking all of these is daunting. It would seem that the division of services is tailored to suit Government Departments

rather than the disabled. Could all of these services be administered from one co-ordinating body? Sub301

Theme 4: Leadership, Governance and Management: Statement of Purpose to have initial capital letters Sub344

General comment: Lead from the top down. Management should be assessed twice yearly to see if they are meeting their aims/objectives – HSE to be responsible for this. Sub344

General Comment: After looking at the information in the new direction documents, I have never seen such a confusing document. For a group of intelligent people to produce such a vague document (with regard to how these objectives are going to be achieved), constantly repeating itself it states the service provider will be responsible without saying where the extra funding will come from. I just wonder how long it took to compile and what cost? The old saying "the devil is in the detail" there is a distinct lack of detail here. A lot of the stated objectives within the document are currently policies of day services around the country. They are trying to make the service users independent, and trying to include them in the community. Whatever improvements are capable of being implemented they will not under any circumstances be achieved without the local staff and services that are provided for at the moment. Having read through the proposal it seems to me that you are not aware of the policies and procedures in place at (Service Provider Name) as all the criteria you state are already being met. How will assessments be funded? How much scope will services providers have in implementing the standard - how prescriptive is it or is it interpretive? Sub350

Theme 4: Leadership Governance. It was felt that the standards and features relating to leadership and governance are strong and it is hoped that they will promote high quality person centred supports for people with disability. Sub352

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. 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. Sub353

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. Sub353

A close consideration of the administrative requirements of the service both in terms of cost and time away from the people who use the service, needs to be carefully considered in the overall implementation of these Standards. Sub355

Areas that should be included: A practical guide regarding when the standards should be implemented by would be helpful. As these standards have taken approximately two years to develop, how long will there be before formal auditing takes place. The requirement to provide future planning a rate greater than year by year, if planning was projected over a five year period and funding bodies were aware of people requiring additional resources within a greater time period this should assist in the funding process. Some consideration should be given to individuals who have been in supports for a vast number of years and are institutionalised to an extent, these individuals will take longer to embrace the changes – will this be taken into consideration. Are the standards going to apply to elder care supports being provided through disability support services? If so it should be taken into consideration that nursing homes and elder care have separate standards through HIQA. Who will be the auditing body and if this has not been agreed yet when will this occur? The role of the family within supporting an individual should be included. Social role valorisation theory places family at the first level of support. This is not accurately reflected within this document as families are rarely mentioned. The primary natural support for most people is their family, surely this should be the case for individual receiving supports from services. Circles of support should be included in the document throughout where reference to supports are made and decision making processes that need additional support. Sub359

I feel the principles within the standards will form a solid base for the development of services, the question does arise with regard to how the standards would be met within current funding. If standards are not met because of funding issues will this be an organisational problem or will the HSE take responsibility? Greater detail is required regarding how the standards will be met with regard to a specific timeline for achievement. Will guidance be available with regard to how systems should be implemented to ensure that there are equitable standards nationwide? From discussions with staff, family groups and individuals receiving supports the general principles are relevant. For individuals who cannot communicate independently there is a feeling that alternatives such as communication partners should be explored before a representative takes responsibility. Families feel very much excluded from the standards and feel that within the disability sector there are such wide ranging needs and abilities that to have one set of standards for all services is not the right way to go. They felt very strongly that individuals with higher needs were not accurately reflected within the document. Sub359

General theme – will create greater transparency within organisations in general. Sub359

For reading the “Draft Interim Standards for New Directions, Services and Supports for Adults with Disabilities”, I wonder how all these standards and assessments will be funded and monitored. Will funds be cut in other areas? Sub366

Theme 4: All the issues come back to leadership and management in my book. I am being told by both organizations which are to provide day service to my son, that while they love the whole New Directions policies, ideas, language etc they do not see it taking root in their organizations for a very long time. There are huge hurdles to overcome in staffing, resourcing, training, and the break up of big centres to provide small centres. Personally I do not think that breaking down big centres is the best idea, we put regular students in huge centre - universities, colleges and let them learn from one another and resource them. There are pro's and cons in each method. Small community delivered day service is a lovely idea but only if it can give active community involvement to its participants. Sub375

General theme – will create greater transparency within organisations in general. Sub378 and 379 identical.

Suggest adding the wording of inclusion of open and transparent use/direction of resources, more devolved budgets. However there are difficulties to extract from historical services the transfer of monies from ‘block’ funding to a person who uses services. In addition the funding levels are so low and not realistic to develop the new directions model e.g. €2,000 euro was available to a person which over 52 weeks in the year this would equate to €38 approx. a week. Sub372

Will there be a requirement for a more planned approach to future needs – organisations should be expected to develop plans for 5 or 10 years and these should then highlight the future support needs and funding requirements. Will this be taken into consideration or will planning be completed on an annual basis only? Sub379

There is broad agreement and support around all of the draft standards. A major concern for all service providers, however, is around resource issues and the current moratorium on recruitment of staff. This is having a significant impact on our ability to provide high quality, truly person centred services. In certain day centres, staff/person supported ratios do not lend themselves to an individualised approach/model. It is clear that we need to continue to be resourceful around our use of volunteers, unpaid supports, natural supports and community based opportunities, however there also needs to be a realistic staffing/resource plan in achieving the standards. There are unanswered questions around what resources, if any, will be available to implement the standards and evolve our supports to be centred on each person. Sub393

Theme 4: Leadership Governance and Management: Who supervises staff out working in the community? Sub415

Theme 4: Very clear and will greatly aid the management of service providers. However it needs to be highlighted that a or any service provider in the receipt of state funding through a service level agreement or other similar arrangement can only

offer the supports it is funded to offer. It needs to be clearly noted and brought to the attention of the relevant people that funding needs to be flexible in line with the ever changing needs of individuals with disability. Needs of individuals with a disability can greatly increase with age but funding only ever appears to decrease. Service Level Agreements and contracts between service providers and individuals need to clearly show the funding that is being made available and the dependency tool that is being used to determine the funding. Sub385

Standard 4.1

Standard 4.1 deals with the development and promotion of equality –centredness through their statements and service design. Sub262

Standard 4.1 does not go far enough in relation to the service provider's responsibility in relation to promoting community inclusion. The development of a strategy for HSE funded Adult Day Services to formally engage within local community structures as a means of enabling the participation of adults who use day services at a local community level and fulfilling the objectives on community engagement set out in New Directions is required. A Strategy on community engagement should be included in the features and could include the following key elements: Mapping of the community & voluntary sector. Identification of key local community structures to engage with and raise awareness of New Directions. Development of joint action plans around introducing, developing partnerships, and networking within these structures, creating pathways for people who use day services to access and participate in mainstream community life. Publically inform and actively involve the community of continuing action. Support community development agents to be connected, informed and supported in assisting the implementation of New Directions. Support disability services to build connections between people who use day services and organisations that have volunteering opportunities. Incorporate this strategy for local engagement into the HSE strategic development plan and all policies relating to mainstreaming, participation and social inclusion. Sub341

4.1 : Leadership support, standards put in place that there are responsibilities/ accountability by leadership to deliver a high standard service. Sub348

Standard 4.1 stating that regular reviews are required leaves this open to interpretation – an actual timeframe should be given e.g annual reviews should be completed. Sub359

Standard 4.1: The Service provider develops and promotes a culture of quality, person-centredness, community inclusion and active citizenship throughout the service . Sub370

Standard 4.1 stating that regular reviews are required leaves this open to interpretation – an actual timeframe should be given e.g annual reviews should be completed. Sub380

Feature 4.1.1

4.1.1 The Service Provider evaluates all progress and provides training to full fill all the Clients rehursts. Sub142

Feature 4.1.2

The third bullet could end by stating 'subject to budget and availability of resources' to indicate the need for realistic expectations

The very last bullet point in this section needs to end by stating 'within budget and subject to availability of resources'. Sub392

There is broad agreement and support around all of the draft standards. A major concern for all service providers, however, is around resource issues and the current moratorium on recruitment of staff. This is having a significant impact on our ability to provide high quality, truly person centred services. In certain day centres, staff/person supported ratios do not lend themselves to an individualised approach/model. It is clear that we need to continue to be resourceful around our use of volunteers, unpaid supports, natural supports and community based opportunities, however there also needs to be a realistic staffing/resource plan in achieving the standards. There are unanswered questions around what resources, if any, will be available to implement the standards and evolve our supports to be centred on each person. Sub393

Feature 4.1.3

This is such an important start to theme 4, where governance is highlighted with clear defined lines of responsibility. Frontline staff with specific responsibility needs to accountable for their area of importance. 4.2.1. Staff training needs to be highlighted. Staff training and competences need to be highlighted within standard 4.1.3. Skills development opportunities must be made available within services that meet the actual needs of individuals in their care. Sub291

Feature 4.1.4

4.1.4 Regular reviews carried by Provider and HIQA. This is proper for all clients to be treated fairly and in building the clients confidence to make more progress in their lives. Sub142

4.1.4 include families. Sub263

Standard 4.1.4.: Regular reviews are important where there is an action plan and a goal and not just talking shops. In the area of day services they tend to be second to other services , we need to value the importance of good day services for people. Sub296

Feature 4.1.4 refers to the need for regular reviews to identify areas for improvement in the culture of the service. In the provision of day services, ongoing review of all elements of the service is essential to ensuring that all needs and supports are identified for individuals and if changes are needed they are implemented. Sub355

4.1.4 It would be important to conclude this section by stating 'The reviews will ensure implementation of recommended actions' The last bullet point in this section needs to end by stating 'Their feedback is also used to ensure continuous improvement in the service'. Sub392

Standard 4.2

4.2 too much bookkeeping involved. Sub081

Families: where is the staff and money to ensure this (4.2/4.3) Sub291

Standard 4.2 We suggest that a demonstration of implementation would be useful. Sub353

Standard 4.2 The service provider performs its functions as outlined in the relevant legislation, regulations, national policies and Standards to protect each person and promote their welfare The requirements of this Standard are welcome because new policies and legislation will drive improvements in the services. It is important that the resource implication of new regulatory requirements are considered to ensure that the service provider can continue to focus the service on each person's individual needs rather than diverting core funding to administrative and regulatory requirements. In some cases additional resources will be required. A close consideration of the administrative requirements of the service in terms of both cost and time away from the people who use the service needs to be carefully considered in the overall implementation of these Standards. Sub355

Standard 4.2 the level of knowledge required by different staff members should be clarified. Sub359

Standard 4.2 The service provider performs its functions as outlined in the relevant legislation, regulations, national policies and standards to protect each person and promote their welfare: The requirements of this Standard are welcome because new policies and legislation will drive improvements in the services. It is important that the resource implication of new regulatory requirements are considered to ensure that the service provider can continue to focus the service on each person's individual needs rather than diverting core funding to administrative and regulatory requirements. In some cases additional resources will be required. Sub370

Standard 4.2 We suggest that a demonstration of implementation would be useful. Sub374

Standard 4.2 the level of knowledge required by different staff memebbers should be clarified. Sub380

Feature 4.2.1

4.2.1: Staff demonstrates knowledge of legislation is very necessary. Training however needs to be provided by related statutory bodies such as training on vulnerable adult legislation. Standards should specify which legislation is relevant. Flexibility around the level of understanding of the legislation should be considered,

as it may not be necessary for all staff members to have the same degree of understanding of the legislation, depending on role. Sub279

This is such an important start to theme 4, where governance is highlighted with clear defined lines of responsibility. Frontline staff with specific responsibility needs to be accountable for their area of importance. 4.2.1. Staff training needs to be highlighted. Staff training and competences need to be highlighted within standard 4.1.3. Skills development opportunities must be made available within services that meet the actual needs of individuals in their care. Sub291

Feature 4.2.1 requires staff to demonstrate a knowledge of legislation– what will this look like and how will it be assessed? Sub355

Feature 4.2.2

No data

Feature 4.2.3

No data

Feature 4.2.4

No data

Standard 4.3

As a service we have effective leadership, governance and management arrangements in place. Sub106

Families: where is the staff and money to ensure this (4.2/4.3). Sub291

Standard 4.3 – as a Service we have effective leadership, governance and management arrangements in place. The Service has an effective leadership, governance and management arrangements in place. Sub342

Feature 4.3.1

4.3.1: Is 4.3.1 similar to 4.3.5? Sub424

Feature 4.3.2

No Data

Feature 4.3.3

No Data

Feature 4.3.4

4.3.4 This standard as presently constructed is written for regulation and not to support the necessary change in culture that is required to deliver services that focus on individuals – the feature for example refers to the registered provider, the person in charge, etc. 'Standard 4.3.4 refers to the registered provider (not included in the glossary), the person in charge and all other persons involved in the management of the services – extracted directly from the residential standards. Who are these people? They are presently understood in the context of the care and support

regulations. Whilst the concept of 'fitness' is understood how will it be given life in the context of these standards?' Sub352

Feature 4.3.4 refers to the roles of 'registered provider' and 'person in charge'. This is terminology that has been used in the registration of residential services but is new to day services. Is it envisaged that day services will need to register in the same way as residential services with new service requiring inspection before they can operate. The method employed in residential service, where all supports are concentrated on a single location may not be appropriate to day service which should, under New Directions, be firmly based in the community. Sub355

Standard 4.3 The service provider has effective leadership, governance and management arrangements in place and clear lines of accountability Feature 4.3.4 refers to the roles of 'registered provider' and 'person in charge'. This is terminology that has been used in the registration of residential services but is new to day services and rehabilitative training programmes. Is it envisaged that day services will need to register in the same way as residential services? The methods employed in residential services, where all supports are concentrated on a single location may not be appropriate to a day service which should, under New Directions, be firmly based in the community. Sub370

Feature 4.3.5

4.3.5 provide ratios for management structure size to be efficient. Sub263

Feature 4.3.6

No Data

Feature 4.3.7

(4.3.7) will service providers be able to "cherry pick" the type of services they provide by putting "profit ahead of people". Sub232

Standard 4.3.7. may benefit from a focus on service providers to undertake and implement an ongoing assessment of resource needs within their service. Service provider's needs to prioritise training needs and this standard clearly allows for adequate responsibility on providers. Sub291

Feature 4.3.7 states that leaders direct sufficient resources to provide high quality, person-centred services; however, control over the resources available to a day service manager lies in the power of the HSE rather than the day service. This is important to reflect in the Standards because when these Standards begin to be inspected, all elements included within them should be within the power of the service provider to resolve. Current funding levels do not always allow for the provision of high quality person centred services. Additional funding will be required to support this Standard. Sub355

Feature 4.3.7 states that leaders direct sufficient resources to provide high quality, person-centred services; however, control over the resources available to a training centre manager lies with the HSE rather than the service. This is important to reflect

in the Standards because when these Standards begin to be inspected, all elements included within them should be within the power of the service provider to resolve. Sub370

Feature 4.3.8

No Data

Feature 4.3.9

No Data

Feature 4.3.10

No Data

Feature 4.3.11

4.3.11: Annual monitoring, specify if internal or external; Specify the management level of the person in charge. Sub263

4.3.11: Who or what should be doing this monitoring? Sub424

Feature 4.3.12

Standard 4.3.12 who will complete these audits? Is this a requirement that internal audits occur or will an external body be tasked with this? Sub359

Standard 4.3.12 who will complete these audits? Is this a requirement that internal audits occur or will an external body be tasked with this? Sub380

4.3.12: Is this similar to 4.3.11? Sub424

Feature 4.3.13

No Data

Feature 4.3.14

No Data

Feature 4.3.15

No Data

Standard 4.4

4.4: Statement of Purpose is a welcome development. Sub103

4.4—the requirements for a Statement of Purpose are very prescriptive. Recommend broadening it to, “accurately and clearly describes the services and supports provided.” Sub279

Standard 4.4 (page 63): Final bullet point – add on – The HSE will be informed immediately if a service is to be discontinued. Sub344

Standard 4.4 the experience of Statement of Purpose to date is they are very specific to the service location detailing specifically the numbers receiving service and the needs. In day supports where there are individualised supports to people, they are

not centre based and can vary in level, degree and intensity based on the individual how will this be configured? Sub351

4.4 In relation to this standard concern was expressed that it will be difficult to have a very clear statement of purpose that accurately and clearly describes the services and supports provided. 'We believe that this will be a huge challenge to services who are trying to reconfigure and transform into a non-centre based model where staffing and supports need to be flexible, where natural supports will be a key component and where the personal plan is the primary driver of the service to the individual. 'Sub352

Standard 4.4 in the statement of purpose the location of services is required – this does not reflect the community based approach and increased individualisation of programmes. A location in relation to a central supervision point for staff may be more appropriate than an identified service location as this could limit where supports are provided. Sub359

Standard 4.4 The service provider has a publicly available statement of purpose that accurately and clearly describes the services and supports provided . Feature 4.4.4 states that the statement of purpose is publicly available and communicated to all stakeholders, including people who use the service in a format that is accessible and can be easily understood by them. It may also be appropriate to require service providers to reflect the wishes and requirements of the people using services in the statement of purpose. Sub370

Standard 4.4 In the statement of purpose the location of services is required – this does not reflect the community based approach and increased individualisation of programmes. A location in relation to a central supervision point for staff may be more appropriate than an identified service location as this could limit where supports are provided. Sub380

Feature 4.4.1

No data

Feature 4.4.2

No data

Feature 4.4.3

No data

Feature 4.4.4

Feature 4.4.4 states that the statement of purpose is publicly available and communicated to all stakeholders, including people who use the service in a format that is accessible and can be easily understood by them. It may also be appropriate to require service providers to reflect the wishes and requirements of the people using services in the statement of purpose through consultation with in relation to its content. Sub355

Feature 4.4.5

No data

Standard 4.5

There is a lack of detail in: Standard 4.5 The service provider has appropriate service level agreements, contracts and/or other similar arrangements in place with the funding body or bodies. For example, (Service Provider Name) have upwards of 22 properties that are rented. This makes (Service Provider Name) vulnerable to sudden rent rises and lack of certainty on long term outcomes for these properties with consequent uncertainty for clients using these properties. A proper funding model should be put in place to enable (Service Provider Name) to acquire outright ownership of these properties or similar properties. This model requires advocacy with HSE, Dept Health, NAMA or religious or philanthropic bodies, or other institutions or individuals, to secure funding that will ensure a longterm viability of the services under its remit. The question of "appropriate service level agreements" does not explore the above questions. Sub004

Standard 4.5.5 - The date of signing and date for review should clearly be displayed on front page of the Service Level Agreement/Contract or other arrangement document. General comment: Lead from the top down. Management should be assessed twice yearly to see if they are meeting their aims/objectives – HSE to be responsible for this. Sub344

Standard 4.5 The service provider has appropriate service level agreements, contracts and/or other similar arrangements in place with the funding body or bodies. As a general comment, existing service level arrangements do not allow adequate scope to develop services within the requirements of these Standards. Additional resources will be required but also services will need the flexibility to be innovative in order to truly develop services that are responsive to the needs of the person. Specific reference should be made to the potential for service providers to negotiate a change in the SLA where changes due to a deterioration in a person's condition lead to a requirement to consider staffing levels and support needs and therefore funding levels for the service. As per Standard 2.3 above. The needs of each individual attending the service, or wishing to attend the service, must be accurately assessed based on a refined and accurate assessment too. These needs must be reviewed at regular intervals to determine whether there is an increase or decrease in needs and support. Sub355

Standard 4.5 if contracts and agreements regarding service delivery are to more clearly specified does this mean that additional funding will be made available or is there an expectation that changes will occur utilising current resources. How will quality of service delivery be measured – this can be very subjective. Sub359

Standard 4.5 if contracts and agreements regarding service delivery are to more clearly specified does this mean that additional funding will be made available or is there an expectation that changes will occur utilising current resources. The families

were all concerned that this is a money saving exercise. If a person requires an ongoing level of support in order to access programmes with this continue to be funded. Sub378

Standard 4.5 if contracts and agreements regarding service delivery are to more clearly specified does this mean that additional funding will be made available or is there an expectation that changes will occur utilising current resources. The families were all concerned that this is a money saving exercise. If a person requires an ongoing level of support in order to access programmes with this continue to be funded. Sub379

Standard 4.5 if contracts and agreements regarding service delivery are to more clearly specified does this mean that additional funding will be made available or is there an expectation that changes will occur utilising current resources. How will quality of service delivery be measured – this can be very subjective. Sub380

Feature 4.5.1

No Data

Feature 4.5.2

No Data

Feature 4.5.3

No Data

Theme 5

General Comments

In very short supply in the (Service Provider Name) despite the dedication of staff members on the ground Sub032

Theme 5: Responsive Workforce: Very good despite being under severe pressure; These comments refer to the (Service Provider Name) (all services), (Location Name) and the (Service Provider Name) Sub032

Are these Draft Interim Standards relevant to serviced and supports for adults with disabilities? Majority are. Theme 5 pg. 66 discusses performance appraisal as well as support and supervision of staff. While supervision and support is generally not an issue for Unions, performance appraisal may be & it may need further consultation with Unions before including in the Standard. Sub038

All staff are recruited via (Service Provider Name) with safe recruiting practices in place to ensure staff have the required qualities and skills. Sub040

Essential staff are trained in the areas of assistive technology, speech and language techniques, person centred plans and advocacy in order to provide optimum support to service users within their care. Sub069

Funding will need to be made available in order for services to recruit qualified staff with specialised skills. Sub094

Again much easier to write these Standards than to implement—having the right calibre of qualified staff with the optimum numbers –flexible to deliver a holistic support/service –is key in an area that by its nature is very stressful and demanding. With some signs of an improving economy there will be increasing difficulty in retaining good staff. There is a risk with the Standards of staff's time being deflected into admin functions to the detriment of caring for the service users. Sub095

Garda vetting is vital but is it swift enough? One of my daughters helped out at a Summer camp for autistic children. By the time the clearance came from the Gardaí the camp had finished. Sub100

Professionalism in many instances is lacking so it is important that staff are continuously trained and that their training is monitored and updated. Training in staff ability to communicate with service users and parents/carers is especially important. Sub103

Effective and positive outlook at recruiting. Sub107

This is already covered in the comments above – policies in place to ensure staff are responsive to service users' needs. We recruit only with Fetac 5 Healthcare or similar. Current staff are being supported to study this course over a period of time. Training is ongoing and mandatory. Sub113

Theme 5: Responsive Workforce: To me it is very important to have a responsive workforce who in my opinion would be trained committed to the needs of the people they work with in all aspects of their special needs Sub213

Extra staff due to need for greater support on individual basis; Due to nature of New directions staff will need to be more flexible will this be taken in a/c with pay scales; Mandatory new directions training for all staff. Concerns about the future for day service staff. Sub226

Theme 5: Responsive Workforce: Ok Sub233

What a responsive and supportive staff. However service user numbers are increasing and there is a long waiting list. If there is not sufficient funding there will be extra stress on staff and there is a danger of burnout. The staff really know the service users and treat them with great respect and care. They also know the carers very well and stay up to date on any problems that the service user is experiencing. Sub239

Where is funding and resourcing coming from to meet the provision of these new services? While much of what is outlined reads well in theory, it needs concrete financial support and a solid structure to make it a success. Also, will availability of service depend on geographic location? Sub249

Is the language clear? Yes language is very clear. Contemporaneous? – could it read “up to date?” Language okay otherwise. Sub252

2.1 to 5.1.2 outside times of 9.00am to 5.00pm. Sub252

This theme is complete and hopefully all included will be carried out. Workforce issues are presently an issue for all Service providers. This theme on Responsive workforce is a vital part of the Service. Sub252

Will staff be trained to fulfil the concepts of New Directions? Will this be linked into SOS Community Inclusion Project and EE Genio Project. Sub253

Specific Feedback on Themes 4-7: The ideals outlined in these sections are laudable but would be impossible to implement in their totality unless sufficient funding is made available by the government. Also what procedures will be put in place to ensure the standards outlined will be realized; staff to service user ratios need to be low enough for an effective differentiated programme to be put in place; managers need to be allocated time to ensure training is provided for staff in order to improve outcomes for people using services and supports. Sub261

Theme 5 – Again this will provide a more transparent process for organisations, there is a concern by families that in order to meet standards additional paperwork will be required and this will take form the time available to frontline supports. Sub266

I fully agree with these standards. Full recruitment practices should be in place at all times Sub270.

Service users who are sick and attend a Residential Setting must have facilities for their Service User when they are sick, a bed to stay in if necessary, a place to keep warm and left rest. The sick person should not be sent into Adult Day Services if sick, and should be sent back to Residential area if they become sick during their day. It works as a dual role (i) promotes the care and well being and healing of the person who is sick, and (ii) prohibits the spread of sickness all over the service. Sub276

Themes 4-7: It would help our understanding of how services are run if we were included in these discussions; Repeat use of some pictures was confusing as they meant different things. Sub281

Difficulties around transport/are there enough staff to provide individualised programme/accessing each individuals local communities. How do we improve decision making/access to local communities for clients with more complex needs? Sub282

Similar to Standards QA00/01 Sub283

In relation to provision of advocacy services there is an issue with regard to staff training, and availability of an advocacy services. Sub295

5. Are these Draft Interim Standards relevant to services and supports for adults with disabilities? Yes in some ways but need to look at the lack of access for people moving into the community and the lack of suitable qualified people to plan and manage the individual person moving into appropriate community services Sub296

Also, if someone with a disability develops another condition (for example, sight or hearing loss) then they should receive both medical care and education in order to help them deal with that condition. Furthermore, personnel caring for that person should have the education, training and skills (for example, sign language ability) required to support that person. Sub299

Theme 5: Last three words 'from significant harm'.take out the word 'significant'; Any harm would be too much harm. Sub344

General comment re Resources: Use the resources on site: For example if service providers have a kitchen - use it for teaching cookery and making daily lunch in. This can all be part of the daily tasks and documented in the PCP. Computers – ensure they are in perfect working order. Rooms in the facility can be developed into suitable teaching areas at little extra cost. Provide proper Sensory rooms and a quiet room. Do not leave excellent kitchen facilities unused. Health & Safety legislation is about minimising and controlling risks – it is not an excuse to stop carrying out cookery training. Sub344

There were many concerns amongst service providers in relation to this standard given the experience over recent years of budget cuts, the moratorium on

recruitment and reductions in employment ceilings. Also a concern was raised that this is not reflective of situations where people are assigned a budget and employ their own staff as envisaged in the VFM report. This feature appears to place staff at the centre in meeting individual's needs – it doesn't recognise that there are others who should be involved in the person's life e.g. 'circles of support' / natural and community networks / family members, etc. The 'What this means for you' section states that: "There are always enough staff to meet your needs and ensure that you are safe when you are using services and supports" Providers were taken aback by this feature and indicated that this would be outside of the remit and the capacity of organisations for a number of reasons; the current funding environment means that all organisations have experienced extensive cuts in funding with some organisations having received cuts of as much as 30% with consequential reductions in staff numbers; the demographics and changing needs of the people supported further challenge in this area. However, in addition to these issues the model of supports envisaged under key policies including the Value for Money report advocates people living included lives in community settings with a range of supports where necessary, including natural and community supports. The feature as written extends the responsibility of the service provider beyond the remit that they should have in this context. The retention of good staff is central to the objectives of all organisations, however there are difficulties in relation to this feature due to the lack of transparency of funding, and the lack of adequate resources preventing organisations from competing equally in the marketplace. Concern was expressed in relation to this feature, as it suggests a clinical model. As we understand it, the vision of New Directions is for a community-based approach that will call for different profiles of staff – such as community connectors, facilitators and development workers who will be likely to come from varied backgrounds outside health-related fields. There is concern that this feature may be drawn from the HIQA residential standards around health and care provision, whereas the aim of New Directions is around facilitating, enabling and creating opportunities to support inclusion. The implementation of this feature would instead take organisations back to a traditional model of supports.

Sub352

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. Sub353

The Standards don't give any consideration to how low staff numbers can hinder the provision of person-centred services, as those who require extra supports may not get the level of support that they require to participate in community activities.

Sub355

Theme 5 – This theme seems to be moving towards professionalising staff. This needs to be considered in relation to roles that are being undertaken. Will a standardised level of qualifications required for specific positions be provided? Will this take into consideration the needs of the individuals and the normalisation of supports (for example if someone wants to go on a vocational course for engine

building a mechanic may be the right person to provide the support rather than a qualified care assistant). Sub359

Theme 5: Responsive Workforce: The staff ratio to service users supported from the hubs needs to be appropriate, realistic and resourced for safety and success. Sub415

Theme 5: Responsive Workforce: Don't have it Sub418

happens it is management who allow it. Sub375

Theme 5 – Again this will provide a more transparent process for organisations, there is a concern by families that in order to meet standards additional paperwork will be required and this will take form the time available to frontline supports. Sub378

Theme 5 – Again this will provide a more transparent process for organisations, there is a concern by families that in order to meet standards additional paperwork will be required and this will take form the time available to frontline supports. Whilst there are pay scales available for temporary and permanent positions it was felt that relief staff should also have a pay scale to reference. Sub379

Theme 5 – This theme seems to be moving towards professionalising staff. This needs to be considered in relation to roles that are being undertaken. Will a standardised level of qualifications required for specific positions be provided? Will this take into consideration the needs of the individuals and the normalisation of supports (for example if someone wants to go on a vocational course for engine building a mechanic may be the right person to provide the support rather than a qualified care assistant). Sub380

Theme 5: Again a very important Theme for a service provider. National Dependency tools need to be made available to determine the supports needed by individuals as service providers need to be adequately funded and resourced to provide services to their service users. What will be seen as a recognised qualification for a day service instructor, programme facilitator, community mentor? How will a persons skills and fit for a job be judged? Sub385

Standard 5.1

5.1 that staff will get the most training to the highest standards in all areas. Sub078

Standard 5.1 the recruitment practice has to be inline with that of the organisation and be mindful of the time frame. May not be time or cost effective to consult every service user. Practically this may be very difficult to achieve. An organisation cannot garga vet all people that service users will come into contact with. Sub141

2.1 to 5.1.2 outside times of 9.00am to 5.00pm. Sub252

Feature 5.1.1

No data

Feature 5.1.2

Standard 5.1.2: Comment: Where staff are appointed from generic panel e.g. Care Assistant Panel within broader HSE region, they may not have the personal attributes required to work with persons with a disability. A better match to job profile is attained when the post is advertised for the specific Care Group/Unit/Centre.

Sub245

5.1.2—Providing supports to clients in line with their choices and needs is integral, though we envisage difficulty meeting “out of hours” needs within the current funding structure. Suggest making this standard flexible to promote supporting the client within resources, which could entail finding individualized community/natural supports as appropriate for evening and weekend support. Sub279

Feature 5.1.2 requires that service providers identify specific skills, competencies and personal attributes required of staff and recruits accordingly. For many years, (Service Provider Name) has worked to develop a staff complement which is committed to and equipped with the skills to provide person-centred services. Other services which have not progressed as far down the person-centred services journey will struggle to achieve this Standard initially and, therefore, it is proposed that this Standard would only apply to new staff. For existing staff, a detailed training needs analysis will need to be carried out regarding existing competencies and personal attributes with relevant training identified. Funding and resources will be required to provide this necessary training. Sub355

In addition, Feature 5.1.2 states that service providers should recruit staff who have flexibility to work in the evenings and weekends. In reality *New Directions* services will likely require a greater number of staff across a longer period of time each week. Service providers can only ensure there are sufficient numbers of staff with the necessary expertise and competencies to meet the needs of people if they can access the resources required to do so. Service providers can meet some need through more flexible employment contracts and innovative approaches but there will be times when a service provided in the evening time means a reduced service at another time during the day. In addition new employment contracts will be needed and this could lead to increased costs. During our family focus groups, families highlighted the value that the day service has in their families. It enables a period of respite every day and they can be certain that their family member is safe and has access to activities during the day. Without additional resources it is possible that the traditional 9-4 service will be diminished as resources are invested in supporting activities outside of these hours. Families are concerned about this and need to be fully informed about the benefits of the new type of supports over the previous full-time service. Sub355

5.1.2. The service provider identifies the skills, competencies and personal attributes required of staff and recruits accordingly, including people who have a community inclusion and participation focus or profile, and who have the flexibility to provide supports to people in the evenings and at weekends (outside of standard 9am to 5pm arrangements). This is an ideal world situation – the reality on the ground is that I am

seeing staff coming in to work to have their breakfast – That is not a situation that would be tolerated in any other organization/ company. This screams lack of respect, lack of management, lack of vision, and staff who really are just punching in the time. It is not the fault of staff that this happens it is management who allow it. Sub375

Feature 5.1.3

Feature 5.1.3 requires that each person is consulted on the skills and expertise required by staff who support them and contributes to the development of job descriptions, where appropriate. In the case of individualised services, it may also be appropriate for a person to take part in the recruitment and selection of the staff member who will support them in the community. The *what it means for you* section of this Standard does not specify that the service provider must consult with the person using the service on the skills and expertise required by staff as provided in Feature 5.1.3. This should be included as it is a specific responsibility of the person using the service. Sub355

Feature 5.1.4

5.1.4 Garda Vetting is carried out regularly as staff are exposed to different element outside the Provider Service where they are employed. (All staff should be monitored as our clients are at risk at all times. Even vetting should be carried out on employers of our clients – this is crucial. Proper vietting to keep our disability clients safe. Note: Ongoing vetting throughout the employee’s employment. Sub142

5.1.4 This standard needs to go further, ongoing vetting needs to be a responsibility on service providers. Sub291

Standard 5.1.4 References are checked and verified before employment commences. Sub344

Feature 5.1.5

No data

Feature 5.1.6

5.1.6: It is important and worthwhile to acknowledge the positive use of the term ‘relationship’. Equally, it would probably be advisable to be more specific. There have been cases of inappropriate personal relationships. Sub424

Feature 5.1.7

No Data

Feature 5.1.8

5.1.8 Training for staff is very important as support from management. It is a very demanding job. Sub100

Standard 5.1.8: Add in new first bullet point: Policies in place (dated and signed copies given to each staff member). Sub344

Feature 5.1.8 highlights the need for orientation and induction training for all staff – this is a positive addition. Sub355

5.1.8. suggest a final bullet point as ‘Service’s quality assurance process’. Sub392

Feature 5.1.9

5.1.9 What about resolution of any conflicts arising from the written code of conduct developed in conjunction with people who use services and those outlined by the professional regulatory body of the staff member? Sub372

Standard 5.2

Standard 5.2 requires amendment to include the following: Staff have the required competencies to manage and deliver high quality, person-centred and reliable services and supports. Sub004

5.2.7. Staff require remuneration and security of tenure in permanent employment that guarantees sufficient benefits for insured, pensionable, career development with promotional and further training and development opportunities. Sub004

5.2 a lot more staff required. Sub081

5.2.Competent managers are vital to the success and atmosphere of a centre. Sub100

Where is funding and resourcing coming from to meet the provision of these new services? While much of what is outlined reads well in theory, it needs concrete financial support and a solid structure to make it a success. Also, will availability of service depend on geographic location? Sub249

2.1 to 5.1.2 outside times of 9.00am to 5.00pm. Sub252

Will staff be trained to fulfil the concepts of New Directions? Will this be linked into SOS Community Inclusion Project and EE Genio Project. Sub253

Standard 5.2: Agree all staff should have competencies to do this job in day services. Need enough staff to keep people safe – funding? Flexible contents, positive to have keyworkers properly trained. Continuity of staffing not always possible – need support of a HR department. Not all agencies/service providers have this expertise. Sub297

5.2 “Always enough staff”. Difficulties with this statement with the current moratorium on staffing. Sub342

Standard 5.2 (page 69): Heading: Add in words training and skills after ‘required competencies’ to stress the importance of training and skills of staff, eventhough both may be understood to be included – but reiterating the words in this Standard will focus minds. Sub344

5.2 There were many concerns amongst service providers in relation to this standard given the experience over recent years of budget cuts, the moratorium on recruitment and reductions in employment ceilings. Also a concern was raised that

this is not reflective of situations where people are assigned a budget and employ their own staff as envisaged in the VFM report. Sub344

Standard 5.2 Staff have the required competencies to manage and deliver high quality, person-centred and reliable services and supports. New Directions services will likely require a greater number of staff across a longer period of time each week. Service providers can only ensure there are sufficient numbers of staff with the necessary expertise and competencies to meet the needs of people if they can access the resources required to do so. During (Service Provider Name) family focus groups, families highlighted the value that our current RT services have for families in terms of providing a safe place for their family member to go and experience new opportunities. Without additional resources it is possible that the traditional 9-4 service will be diminished as resources are invested in supporting activities outside of these hours. Families are concerned about this and need to be fully informed about the benefits of the new type of supports over the previous full-time service. As mentioned above, the funding structure currently established for (Service Provider Name) doesn't allow more flexibility for evening and weekend services. Sub370

5.2 Families highlighted the importance of having skilled staff that were able to develop a relationship with their family member and themselves. The identified the need to ensure that people with a lot of medical or health needs continue to be supported by nursing staff that are experienced and knowledgeable of this area of disability. Sub412

Feature 5.2.1

5.2.1 The will need to be an injection of funds for this theme to be really successful due to budgetary constraints this is difficult to achieve. Sub077

5.2.1 staffing level is crucial. A standardised tool is necessary to evaluate the level of support needed by individuals. Sub263

The issue of staff registration with their professional body is raised several times in section 5. However, there is currently no requirement for those providing PBS to be registered with the relevant professional body (BACB). Those who are providing training and supervision of PBS services should be registered with the BACB to ensure that they are accountable for their practice, which has to be in line with the codes of conduct set out by the BACB. This also provides evidence that staff have the necessary competencies to provide PBS services as described in section 5.2.1. There is a requirement that those who receive certification with the BACB carry out ongoing professional development, ensuring that practitioners will keep up to date with developments in the field of PBS (5.2.4). Sub280

Safe and effective recruitment practices are in place as service providers this is essential: but Standard 5.2.1.: To have at all times sufficient number of staff with the necessary experience and competencies to meet the needs of people as set out in their plan, is not going to happen unless more resources and staffing levels are increased and properly time managed to support their plan. Sub296

In relation to standard 5.2.1 and 5.2.2, there are funding issues to consider. Similar issues apply to standards 5.3.8 through 5.4 Sub300

5.2.1 This feature appears to place staff at the centre in meeting individual's needs – it doesn't recognise that there are others who should be involved in the person's life e.g. 'circles of support' / natural and community networks / family members, etc. The 'What this means for you' section states that: "There are always enough staff to meet your needs and ensure that you are safe when you are using services and supports" Providers were taken aback by this feature and indicated that this would be outside of the remit and the capacity of organisations for a number of reasons; the current funding environment means that all organisations have experienced extensive cuts in funding with some organisations having received cuts of as much as 30% with consequential reductions in staff numbers; the demographics and changing needs of the people supported further challenge in this area. However, in addition to these issues the model of supports envisaged under key policies including the Value for Money report advocates people living included lives in community settings with a range of supports where necessary, including natural and community supports. The feature as written extends the responsibility of the service provider beyond the remit that they should have in this context. Sub352

Feature 5.2.1 states that, at all times, there are sufficient numbers of staff with the necessary experience and competencies to meet the needs of people. It will be difficult to adhere to this Standard, as the term "sufficient" will need to be quantified and agreed with the local HSE. A ratio of service user: staff may be required, particularly in the case of a client group with significant support needs. At present there are insufficient staff available to meet the needs of people as set out in their personal plan. This has led to some curtailment of current personal plans. This needs careful consideration prior to the underpinning of these Standards by regulation in years to come. Sub355

5.2.1 Staffing levels who decides? Sub372

Feature 5.2.2

Standard 5.2.2 stating that there are contingency plans in place where there is shortfall of staff is beneficial. However, systems need to be identified to allow this to actually happen. Staff need to be available, with specific skills and competences in place to provide supports in specialised areas. Sub291

In relation to standard 5.2.1 and 5.2.2, there are funding issues to consider. Similar issues apply to standards 5.3.8 through 5.4. Sub300

Feature 5.2.3

Families: 5.2.3 – need consistent staff. Agency staff is not conducive to effective relationships. Sub291

5.2.3 Second bullet pointtake out the word 'excessive' – the service provider should avoid use of casual, short-term, temporary and agency workers other than in

exceptional circumstances. The service users may have intellectual disabilities and require consistency of service. Sub344

Standard 5.2.3. It is positive to see recommendations for services to have strategies for the retention of staff. Sub353

Standard 5.2.3. It is positive to see recommendations for services to have strategies for the retention of staff. Sub374

Feature 5.2.4

The issue of staff registration with their professional body is raised several times in section 5. However, there is currently no requirement for those providing PBS to be registered with the relevant professional body (BACB). Those who are providing training and supervision of PBS services should be registered with the BACB to ensure that they are accountable for their practice, which has to be in line with the codes of conduct set out by the BACB. This also provides evidence that staff have the necessary competencies to provide PBS services as described in section 5.2.1. There is a requirement that those who receive certification with the BACB carry out ongoing professional development, ensuring that practitioners will keep up to date with developments in the field of PBS (5.2.4). Sub280

Feature 5.2.4 in providing these kind of services service providers need to give consideration not only to ensuring that staff have the necessary skills to provide supports to people with disabilities but also that they have the patience, compassion, can do spirit and social skills that are required to deliver truly person-centred services. As mentioned above, in some cases it will be appropriate for the person to participate in recruitment and selection to ensure that a new staff member is the right fit for the person he/she will support. Another issue that is not considered in this section is the need to achieve a level of gender balance in disability services. Many men using day services report that they would like to have more men working in the service. While it would not be right to positively discriminate in favour of male candidates, there is a piece of work to be done to encourage young men to consider social care as a viable career. All stakeholders – the HSE, educational guidance counsellors and service providers in local areas can play a role in encouraging men into these roles. Sub355

Feature 5.2.4 in providing these kind of services service providers need to give consideration not only to ensuring that staff have the necessary skills to provide supports to people with disabilities but also that they have the patience, compassion and positivity that is required to deliver truly person-centred services. In some cases, where specific one-to-one services are being delivered it may be appropriate for the person to participate in recruitment and selection to ensure that a new staff member is the right fit for the person he/she will support. Sub370

5.2.4 'Staff maintain professional competence' *through organisational support* (my italics). Sub392

Feature 5.2.5

5.2.5. mentions for the first time key working and it puts a responsibility on key teams to initiate specific responsibilities for person centred planning. Key working needs to be incorporated throughout the New Directions standards. It is such a vital & beneficial system when used correctly and alternatively, such a waste of a vital tool when used without governance or leadership. Sub291

Feature 5.2.5 (Service Provider Name) has actively used the key worker approach to service provision for many years now and has found that it is fundamental to the delivery of person-centred services. Staff build up a strong relationship and foundation of trust with the person and this gives the person confidence to try out new activities and investigate new opportunities. Sub355

Feature 5.2.5. Staff in (Service Provider Name) build up a strong relationship and foundation of trust with the person and this gives the person confidence to try out new activities and investigate new opportunities. Sub370

Feature 5.2.6

No data

Standard 5.3

Standard 5.3 We very much welcome identification of Accredited Management Training for Front –line staff (section 5.3.9), However, it will be a significant resource challenge for services. Sub291

5.3 Accredited management training is provided to all new Managers. Who will provide and fund this training. Training in supervision therapy and practices for Manager. Who will provide and fund this training. Increased training needs required for staff in order to develop appropriate skills and competencies to deliver on some of the outcomes. Sub342

General comment re Resources: Use the resources on site: For example if service providers have a kitchen - use it for teaching cookery and making daily lunch in. This can all be part of the daily tasks and documented in the PCP. Computers – ensure they are in perfect working order. Rooms in the facility can be developed into suitable teaching areas at little extra cost. Provide proper Sensory rooms and a quiet room. Do not leave excellent kitchen facilities unused. Health & Safety legislation is about minimising and controlling risks – it is not an excuse to stop carrying out cookery training. Sub344

5.3: Staff are trained to high standard/ highly skilled that work affectivity to support and improve team work. All staff receives support / supervision to ensure that they perform their role to the best of their ability. Sub348

The retention of good staff is central to the objectives of all organisations, however there are difficulties in relation to this feature due to the lack of transparency of funding, and the lack of adequate resources preventing organisations from competing equally in the marketplace. Sub352

Standard 5.3 Staff are supported and supervised to carry out their duties to deliver high quality, person-centred and reliable services and supports. The features of this Standard focus on empowering staff to provide the supports that the person needs. Under New Directions staff are more likely to be working alone with people in the community than has previously been the case. They therefore need to have access to a framework of supports and policies that enable them to make decisions in consultation with the person when they are needed. Feature 4.3.4 refers to the registered provider and person in charge but in the context of person-centred service the most important person is the key worker who is enabling community participation. The balance of responsibility is different to that in residential services and this should be recognised in the Standards. Sub355

Standard 5.3 Staff are supported and supervised to carry out their duties to deliver high quality, person-centred and reliable services and supports. The features of this Standard focus on empowering staff to provide the supports that the person needs. Under New Directions staff are more likely to be working alone with people in the community than has previously been the case. They therefore need to have access to a framework of supports and policies that enable them to make decisions in consultation with the person when they are needed. Feature 4.3.4 refers to the registered provider and person in charge but in the context of person-centred service the most important person is the key worker who is enabling community participation. The balance of responsibility is different to that in residential services and this should be recognised in the Standards. Sub370

Feature 5.3.1

No data

Feature 5.3.2

No data

Feature 5.3.3

No data

Feature 5.3.4

No data

Feature 5.3.5

or (b) excluded? 5.3.5 Sub038

Feature 5.3.6

No data

Feature 5.3.7

5.3.7 staff are under too much pressure without more rules – writing Sub081

Feature 5.3.8

In relation to standard 5.2.1 and 5.2.2, there are funding issues to consider. Similar issues apply to standards 5.3.8 through 5.4 Sub300

Feature 5.3.8 states that staff are provided with training and development opportunities that equip them with the necessary skills required to meet the needs of people with disabilities. This will be particularly important in the roll-out of *New Directions* as it is (Service Provider Name) experience that a diverse skill-set is required to support people in the community than is required in a traditional day setting. Across the staff team, different qualities are required in order to balance risk management with positive risk taking. Sub355

5.3.8: Is this covered under next standard? Sub424

Feature 5.3.9

In relation to standard 5.2.1 and 5.2.2, there are funding issues to consider. Similar issues apply to standards 5.3.8 through 5.4. Sub300

5.3.9 Accredited management training is provided to all new managers who manage front line staff - should they not have this management training completed before they are offered the job?? Sub344

5.3.9 While the provision of accredited management training to all new managers who manage front-line staff is welcome it will however present a significant resource challenge to services. Sub352

5.3.9 References for the accredited management training stated here would be useful. Sub372

5.3.9 'Accredited management training and support (my italics). Sub392

Standard 5.4

Standard 5.4: Relevant in-service training is provided and support is given to staff. Sub106

5.4 This is the key element to promoting a progressive and dynamic *New Directions* approach. Sub291

Concern was expressed in relation to this feature, as it suggests a clinical model. As we understand it, the vision of *New Directions* is for a community-based approach that will call for different profiles of staff – such as community connectors, facilitators and development workers who will be likely to come from varied backgrounds outside health-related fields. There is concern that this feature may be drawn from the HIQA residential standards around health and care provision, whereas the aim of *New Directions* is around facilitating, enabling and creating opportunities to support inclusion. The implementation of this feature would instead take organisations back to a traditional model of supports. Sub352

5.4 Training Fund allocation required for service providers to meet this standard. Sub372

Feature 5.4.1

No data

Feature 5.4.2

No data

Feature 5.4.3

5.4.3 Have centres enough staff for all this? My son needs one to one as do many in his grouping even though they are a very disparate group. Sub100

Is the language clear? Yes language is very clear. Contemporaneous? – could it read “up to date?”. Language okay otherwise. Maybe more clarity around 5.4.3 – “Positive risk taking”, what is meant by this. Sub252

5.4.3 - What is meant by positive risk taking?. (Which is to be included in staff training). Sub252

The list of trainings that are considered key for staff does not include PBS (5.4.3). It seems that, while all people should have a PBS plan (3.2.8) according to the guidelines, not all staff should have training in PBS (5.4.3), and should staff seek training or specialist support in PBS, there are no standards set out for said training or for the competency levels required for practising at different levels of complexity within PBS (section 3). Sub280

Feature 5.4.3 state that training is tailored to specific members of the workforce in order to ensure the delivery of high quality person-centred services and supports. Staff training will also need to be tailored to the specific needs of the people accessing the service. It is recommended that a national training programme is developed to support providers in the training and retraining of staff. Emphasis will also have to be placed on developing the pre requisite Personal Attributes of staff. Sub355

Feature 5.4.3 state that training is tailored to specific members of the workforce in order to ensure the delivery of high quality person-centred services and supports. Staff training will also need to be tailored to the specific needs of the people accessing the service. Sub370

Feature 5.4.4

5.4.4 - On-going training - challenge for Provider. Sub252

5.4.4. - Training – Huge amount of necessary and obligatory training challenge as it leaves staff on ground low. Sub252

Feature 5.4.5

No data

Theme 6

General Comments

Theme 6: Use of Resources: Whilst objectives are desirable, with acute shortage of staff and funds the objectives cannot be implemented. Sub032

(Service Provider Name) provides our budget to our centre based on the requirement needed to provide an effective quality service, meeting our service user's needs. Sub040

Due to the current economic climate and cutbacks within the healthcare sector, it is important for staff to be encouraged to embrace a positive approach to achieving service users' goals and dreams by using creativity and initiative. Sub069

My assumption is that the appropriate competent management will be in place to ensure that all the staff will, with training where needed, have the required competencies to provide high quality, person-centred and reliable services and supports for all the special needs people with the many different levels of competencies. Sub073

Excellent standard. Sub094

I know my son's centre has been very creative (in a good sense) making use of the resources available with reducing funding each year but that cannot go on indefinitely. Standards will fall if centres are stretched too far and are expected to take on more people with disabilities without the necessary funding. Sub100

Many of the structures accommodating day services are not fit for purpose. Sub103

This explains well the need for person centred planning when using available resources. Sub107

We negotiate regional budgets in line with economic systems of work and also reflective of service users' choices & preferences. Sub113

With current funding restrictions it is not always possible to provide the level of service and support that may be necessary. Sub141

Theme 6: Use of Resources: To me you cannot function without resources, but to have resources you need to have a proper management who will plan to require resources needed for all individuals and their needs (you fail to plan, you plan to fail). Sub213

More money needed to have more staff to help us. Sub222

Theme 6: Use of Resources: Will Su's be contributing to the running of services they use in future! Sub226

Theme 6: Use of Resources: Ok. There is no reference to parents/guardians on Caring or insuring can't everything proper. Sub233

In the last number of years there has been a cutback of 1 million euros in our service. It is not possible to provide a viable service if there are any more cutbacks. Every possible resource is used very efficiently. With more service users entering the service there needs to be provision for extra funding. Sub239

Theme 6: Agree. General Comment: Community Based Programmes deliver better outcomes for the individual service users. From our experience to date, we have found that Community Based Programmes require higher staffing levels as you are working with smaller groups and supporting individuals to achieve their goals within the community/mainstream setting. In order to develop and sustain Community Based Programmes there must be a high level understanding of the resources required to deliver the service effectively. Families, also have an important role to play, there needs to be a change in culture where families move away from being over reliant on the service provider to provide all the supports. Sub245

Will proposed services in the local community be of a similar standard to those currently being provided by specialist disability organisations. If so, how will this be measured? Will staff engaged in the provision of these services have the same level of specialist training as currently available through disability service providers? Will individuals be required to assist by fundraising to enhance quality of services locally? Are there proposed fees for accessing future services to service users? Sub249

If all these standards are to be adhered to then Service Providers will need to have more finance made available to them. Sub252

I fully agree with this set of rules. Sub270

Themes 4-7: It would help our understanding of how services are run if we were included in these discussions. Repeat use of some pictures was confusing as they meant different things. Sub281

Clients have had to have some programmes cancelled when there is someone off – can be difficult then to continue with some very individual programmes. Sub282

Meaningful social Roles – Will there be extra funding given to support the resources. (more staff smaller ratios) for this to happen. Will a stronger link be created with Day Services, Respite and Residential Services? Sub253

Good Standard. Funding required to allow Services to hire qualified staff. Sub254

Specific Feedback on Themes 4-7: The ideals outlined in these sections are laudable but would be impossible to implement in their totality unless sufficient funding is made available by the government. Also what procedures will be put in place to ensure the standards outlined will be realized; staff to service user ratios need to be low enough for an effective differentiated programme to be put in place; managers need to be allocated time to ensure training is provided for staff in order to improve outcomes for people using services and supports. Sub261

Use of resources staff are deployed to areas which need their expertise to enable the service to give the best quality and person centred to each service user. Sub262

Notwithstanding the content of theme 6 which sets the expectation for the use of available resources, there is no indication of how delivery of these standards will be incrementally resourced. The aspirations of the standards will not be achieved without adequate additional resourcing. In particular, there will be significant incremental operational overhead in delivery of the standards and on-going monitoring. If additional headcount is not provided, then either the standards or service provision to users will suffer. A policy is required to guarantee required resourcing from government funding bodies. The absence of this resourcing represents a significant risk to the services provided to users and would undermine the goals of the standards.

Theme 6: Families: back to basics – resources for speech; literacy; dental; cookery and computers (other than games). Sub291

Agree with principles of this Standard – but it may take a lot of time and resources to engage and educate the wider community. Day service staff will need training to develop these skills on integration etc. It takes specialized skills to engage communities and keep it going to benefit people with ID. Sub297

Will the 'available resources ' be adequate to provide the individualised services and supports aspired to in the document report? We have already had major cutbacks in our service. There is a fear that the assessments may be made with priority to the availability of funds rather than the client's needs. To whom is the assessor accountable, is it to the resource provider or their agents.... It would be nice to think that 'Value for Money' is not a cost cutting exercise and that services will not become disjointed. Sub301

any areas that should be (a) included? Transport to + from services when family is no longer able to provide sane. Sub302

I think the standards are good but in the current climat I don't see how the standards will change my life, as there is a shortage of staff/ people to assist me go to places I want to go. No funding to move into a home that meets my needs, is more accessible for me as I use a wheelchair and has fewer people. Sub313

I would think its very hard to get full person-centred when there is not enough staff to support one person at a time. Sub319

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. Sub353

Theme 6: Use of Resources: Some Guidance should be provided on how available resources should be used to prioritise the most important Standards. Sub353

Will there be a standardised tool to assess levels of need? If current supports are meeting the needs of individuals will these continue to be funded and in the case that additional resources are required to meet the standards will these be provided. Sub359

Will there be a standardised tool to assess levels of need? If so how will the huge spectrum of needs be represented or will this be subjective assessment depending on the organisation being accessed. If current supports are meeting the needs of individuals will these continue to be funded and in the case that additional resources are required to meet the standards will these be provided? Again this will provide a more transparent process for organisations, there is a concern by families that in order to meet standards additional paperwork will be required and this will take form the time available to frontline supports. Sub378

Will there be a standardised tool to assess levels of need? If so how will the huge spectrum of will be represented or will this be subjective assessment depending on the organisation being accessed. If current supports are meeting the needs of individuals will these continue to be funded and in the case that additional resources are required to meet the standards will these be provided? Will geographical constraints of developing supports in line with the standards be taken into consideration? Again this will provide a more transparent process for organisations, there is a concern by families that in order to meet standards additional paperwork will be required and this will take form the time available to frontline supports. Sub379

Theme 6: parental consultation: Should be reworded to read “Provision and Use of Resources”. Sub369

Theme 6: There needs to a National Dependency tool made available rather than responsibility being passed to service providers in a manner that will result in service providers being underfunded to appropriately support their service users. It will not be good enough to say to service providers that you have a budget of X and a staffing level of Y to support an amount of service users. It will need to come from the ground up, a service users needs X amount of support that equates to Y amount of funding. Sub385

Not enough resources- need more to provide the high quality person centred individualised service that people deserve. Also parents spoke about the fact that resources are limited, family members who would choose to have a full 5 day service cannot get this service. Families expressed concerns that funding and budgets were the primary driver of HSE policy and that the standards were aspirational in many instances rather than achievable. Sub412

Theme 6: Use of Resources: Service users need their independence in the evenings too. If service providers are getting funding for service users who are out in the

community, money needs to be re-directed and made available to fund this lifestyle which require buying in courses like computers [sentence cut off at end of page]. Sub415

Theme 6: Use of Resources: Don't have it. Sub418

Standard 6.1

Standard 6.1 requires amendment to include: The use of available resources is planned and managed to provide high quality, person-centred and reliable services and supports. Detailed plans should be kept on future requirements and levels of support required. These should be provided to the proper funding authorities and written record of plans in progress kept. Sub004

My assumption is that the appropriate competent management will be in place to ensure that all the staff will, with training where needed, have the required competencies to provide high quality, person-centred and reliable services and supports for all the special needs people with the many different levels of competencies. Sub073

Standard 6.1: Resources are effectively deployed to meet the needs of the service users. Sub106

6.1 To provide services all services for each client as to fulfill all their requests without failure due to "unreliable services". This Services should have no excuses not to fulfill the requests of their clients Extra Fiance and extra Staff will make a service successful to meet the clients wishes to take a vital step in their lives to complete their missions while they are alive. A Client (my relation) would feel very confident if enough fiance and staff was put to run Service Providers Properly to fulfil everyone dreams . "Please follow through". Sub142

Will proposed services in the local community be of a similar standard to those currently being provided by specialist disability organisations. If so, how will this be measured? Will staff engaged in the provision of these services have the same level of specialist training as currently available through disability service providers? Sub249

Will individuals be required to assist by fundraising to enhance quality of services locally? Sub249

Are there proposed fees for accessing future services to service users? Sub249

If all these standards are to be adhered to then Service Providers will need to have more finance made available to them. Sub252

Meaningful social Roles – Will there be extra funding given to support the resources. (more staff smaller ratios) for this to happen. Sub253

All service providers strive to deploy resources effectively to meet the needs of people using their service. However, standard 6.1: this is a difficult task that needs

constant review and effective and imaginative planning to ensure we are using our resources to their best advantage. Sub296

Standard 6.1: (Service Provider Name) has had its budget reduced year on year since 2008. Funding is now around €600,000 less per year than it was then. Resources have been managed effectively to maintain services as they are but there are themes contained in the standards which will require allocation of extra funding. (Service Provider Name) is committed to implementing and delivering New Directions but like many organisations will struggle to do so under the current funding arrangements. Sub300

Resource issues around transport for people using our service could be more effectively deployed. 6.1 – Resources are effectively deployed to meet the needs of the service users. Sub342

Standard 6.1 should allow for and encourage individualised funding for people using day services. Sub353

Standard 6.1 The use of available resources is planned and managed to provide high quality, person-centred and reliable services and supports. Overall it is important that the available resources are not impacted excessively by increased administration and an increasing volume of recording, reviewing, monitoring and training. While records are very important they need to be balanced with the need to focus attention on the needs of the client. Sub355

Standard 6.1 puts the onus on the service provider to identify resource needs, this could be very subjective and a national approach to needs assessment would provide greater transparency and equity of service provision. Sub359

Standard 6.1 People should have access to the details of the funding agreement between their day service and funding bodies for their individualised funding, if they wish to see it. Sub367

Standard 6.1 Should allow for and encourage individualised funding for people using day services. Sub374

Standard 6.1 puts the onus on the service provider to identify resource needs, this could be very subjective and a national approach to needs assessment would provide greater transparency and equity of service provision. Sub380

Feature 6.1.1

6.1.1 Suggest direction on standardised tools that can be used for effective planning and allocation of resources. Sub372

Feature 6.1.2

6.1.2: Clear relevant information shared between the service at the right time to deliver high quality, person centred service. Sub348

Feature 6.1.3

Standard 6.1.3 should be needs and wishes rather than aspirations if the language is to be consistent throughout the document. Sub359

6.1.3 Suggest direction on evaluation of effective deployment of resources. Sub372

Standard 6.1.3 should be needs and wishes rather than aspirations if the language is to be consistent throughout the document. Sub380

Feature 6.1.4

6.1.4 suggest the published audited accounts of service provider is available to people who use the service and their families. Sub372

Theme 7: Use of Information

General comments about Theme 7

(Service Provider Name) as part of the HSE is governed by the Data Protection Act. All systems and processes to manage information is handled securely and efficiently in line with legislation. Sub040

Service users have a right to be informed of their rights and focus groups within (Service Provider Name) allows service users the freedom to learn about their rights as a person Sub069

General comment, this is as outlined is a must and should be achievable with appropriate management and process and procedures in place. Sub073

There is nothing sensitive in what I have said. It is my own opinion about New Directions having attended the various conferences since (Location Name). I am very anxious about those, like my son, who have no understanding of these changes and is not able to make choices in relation to his development needs. He is in a very good centre where he is understood and challenged. The Speech & Language Therapist has developed a system of communication for him and others and has trained families in its use. Going to a Broker for a S.& L. T for him would be a waste of time because they would not know him and what works for him. This kind of knowledge takes time to build up plus the rapport. Sub100

I would hate to see the diminution of the Training Centre and all the talent and commitment that is available there. Plus going there every day is a constant for my son who does not appreciate Bank Holidays because there is no work. He is up around 6 am every day waiting to “go to work”. And he is very happy there. Sub100

This is precise and clear. Sub107

This section is set out as per legislation Sub141

Theme 7: Good Standard Sub254

Specific Feedback on Themes 4-7: The ideals outlined in these sections are laudable but would be impossible to implement in their totality unless sufficient funding is made available by the government. Also what procedures will be put in place to ensure the standards outlined will be realized; staff to service user ratios need to be low enough for an effective differentiated programme to be put in place; managers need to be allocated time to ensure training is provided for staff in order to improve outcomes for people using services and supports. Sub261

Again this will provide a more transparent process for organisations, there is a concern by families that in order to meet standards additional paperwork will be required and this will take form the time available to frontline supports. Sub266

It would help our understanding of how services are run if we were included in these discussions. Sub281

Repeat use of some pictures was confusing as they meant different things ... Sub281

Theme 7: Families: The objectives are laudable but who will have the time to collate or effectively use it? Sub291

Theme 7: Information is very important to the planning and delivery of high quality person centred services .All staff need to up skill and update in this area. In order to support the service provider and service user deliver the service that's needed for each individual Sub296

Theme 7: General theme – this will provide further standards for the current legislation specific to this sector Sub359

Again this will provide a more transparent process for organisations, there is a concern by families that in order to meet standards additional paperwork will be required and this will take form the time available to frontline supports. Sub378 (Sub379 seems to be a repeat of Sub378)

General theme – this will provide further standards for the current legislation specific to this sector. Sub380

Theme 7: Individuals should have a clear choice as to what and if any information is held on them rather than a requirement being placed on the service provider to hold a service users information in what again is supposed to be a more normalised means of supporting individuals within their community. Sub385

Theme 7: In broad agreement with all stated standards. Sub419

Standard 7.1

Standard 7.1: A system is in place in the service such as multi disciplinary team meetings, family meetings and service users person centred planning meeting. Sub106

7.1 collates information from services-users and family members to develop an appropriate person centred plan to the best ability of the service. Sub262

7.1 – a system is in place in the service such as multi disciplinary team meetings, family meetings and service users person centred planning meetings. Sub342

Standard 7.1 (page 77) Last bullet point page 77 – amend to read ‘You can request to see any file which has reference to you in it and to get a copy of any information held about you by your service provider. Sub344

Feature 7.1.1

No data

Feature 7.1.2

No data

Feature 7.1.3

This standard is vital 7.1.3 to ensure that outcomes are achieved to enhance service provision developments. Sub094

Standard 7.1.3 needs to go further in identifying and mainstreaming this “system”. This is an extremely difficult task to deliver, and it will take some consideration in creating the system that is truly working effectively with positive outcomes. Sub291

Feature 7.1.4

7.1.4 I am sensitive over the fact that “People” is used: Where it should be stated: Clients family only or Clients family only gives permission on the intended use of personal information. Our “Clients” are humans and deserve “Respect” from all elements of society. Sub142

Feature 7.1.5

7.1.5 A family member only should have access to personal information. Family should be contacted if there is reason of concerns. This is an important feature, all through the client and Families (who use the Provider) using the service on day to day basis. Sub142

(7.1.5) where the client is unable (severe/ profound) to request personal information held will it be available to legal guardian or parent. Sub232

Feature 7.1.5 could be further enhanced through the following amendment “People have access to and are informed of their right to access their personal information in line with legislation and best practice. This section could be enhanced through the inclusion of features relating to a person’s confidentiality. In a day service, information about a person’s person-centred plan and their personal information must be managed in writing and verbally in a sensitive way. The person’s right to privacy and confidentiality should be explicitly referred to in the Standards. This theme could be further enhanced with mention of IT at a basic level for people with disabilities as a means of receiving information. Sub355

Feature 7.1.5 could be further enhanced through the following amendment “People have access to and are informed of their right to access their personal information in line with legislation and best practice. Sub370

Re: 7.1.5 Parents and guardians should have unrestricted access to their child’s personal information. Sub419

Standard 7.2

7.2 Standards outline clearly the reasonability of the service provider – all clients information is recorded in individual care plans which is placed in a secure press also P.C.P information which is updated on a daily basis. Sub348

Feature 7.2.1

No data

Feature 7.2.2

No data

Feature 7.2.3

7.2.3: It would be important to clarify any relevant statutory requirements for day services which may require the maintenance of a register. Sub424

Feature 7.2.4

No data

Feature 7.2.5

No data

Feature 7.2.6

No data