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Findings from the public consultation on the draft interim standards for new directions, services and supports for adults with disabilities

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Údarás Náisiúnta Míchumais
National Disability Authority

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

IDS@UL

The National Disability Authority has commissioned and funded this research. Responsibility for the research (including any errors or omissions) remains with IDS@UL (University of Limerick). The views and opinions contained in this report are those of the authors and do not necessarily reflect the views of the National Disability Authority.

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Executive Summary

A public consultation on the Draft Interim Standards for New Directions, Services and Supports for Adults with Disabilities' was held from September 8, 2014 to October 17, 2014. The Draft Standards are built upon recommendations published in 2012, 'New Directions, the review of HSE Day Services and Implementation Plan.' This report presents the qualitative synthesis of 424 public submissions on the Draft Interim Standards for New Directions, Service and Supports for Adults with Disabilities. Submissions were primarily made by people who use services, families, and service providers.

A range of feedback was submitted including comments welcoming the Draft Standards and commenting on the clarity and content of Standards and Features. At the same time, a substantial volume of submissions expressed concerns regarding process, accessibility of the text, implementation and potential consequences of the Draft Standards. Thoughtful recommendations were also evident throughout the submissions. This feedback is summarised in the report, using quotes from respondents to demonstrate key points. The main report presents key issues that arose across all submissions. A supplementary report was also compiled, containing detailed comments from submissions that explicitly named specific Themes, Standards and Features.

The report opens with a description of the overarching concepts submitted across stakeholders that transcended all Themes and Standards. This includes issues of relevance of the Standards to all people who use services, particularly people with complex support needs. Family involvement in the Standards was identified as an area for development. Respondents noted the absence of important items in the Draft Standards—particularly the involvement of natural supporters and the acknowledgement of intimate relationships. Issues unique to rural regions and comments related to life stage are documented in this section of the report. Following on from this, the next sections of the report are organised under each of the 7 Themes:

1. Individualised Services and Supports
2. Effective Services and Supports
3. Safe Service and Supports
4. Leadership, Governance and Management
5. Responsive Workforce
6. Use of Resources
7. Use of Information

The report then turns to issues of implementation of the Draft Standards. Respondents noted the cultural change required to advance New Directions. The funding for services and supports was the central concern in many submissions. Linked to this was a call to establish an equitable assessment of support needs to ensure transparency in funding decisions. The costs of monitoring and compliance were a significant concern across stakeholders. Timeline for implementation was

raised as a point for critical reflection. The value of cross-sectoral collaboration and shared learning from exemplary practice within Ireland was highlighted.

The final section of the report summarises comments about the consultation process on the Draft Standards. Positive comments are followed by concerns expressed by respondents. The limited representation of service users and families was a primary issue identified by respondents. Lack of clarity within the Draft Standards also figured prominently in submissions. The process of sharing information and the overall timing of the process were a common focal point. A section outlining concerns expressed by respondents about the potential consequences of the Draft Standards closes the main report.

Background

This report summarises the key findings from the public consultation on the Draft Interim Standards for New Directions, Service and Supports for Adults with Disabilities. Following a competitive tender process, the research group Intellectual Disability Studies at University of Limerick (IDS@UL) was awarded the contract to complete this piece of qualitative analysis for the National Disability Authority. We began the analysis on Oct 22, 2014 and completed the first full draft of the findings on November 10, 2014. The final version of the report was completed on November 23, 2014.

Submission Formats

There were 2 distinct feedback forms provided which were structured with prompts followed by spaces for people to write or type in their answers. One was an easy to read document that focused on Themes 1 to 3 and included four key questions. The second feedback form was comprised of 5 main headings with spaces to respond to all 7 themes. Documents submitted included, but were not limited to, these formats. Alternative approaches to submissions included typed word documents, handwritten letters, emails, video, photos of writing on large papers, and easy read formats designed by service user groups. All handwritten responses were transcribed and pdfs were converted into word documents to facilitate efficient coding and retrieval within NVivo10 software.

Aims of Research

IDS@UL was contracted to complete qualitative content analysis of 424 public submissions on the Draft Interim Standards for New Directions. The analysis aimed to achieve the following:

- Provide an executive summary that is accessible to a wide audience
- Offer a balanced representation of the diverse perspectives of stakeholders with respect to each of the 7 key themes identified in the Draft Standards
- Present aspects that are unique to particular cohorts including people who use services (SU), Family Members (FM) and Service Providers (SP)
- Analyse and collate feedback relevant to the Draft Interim Standards
- Analyse and collate other feedback which was not directly related to the content of the Draft Interim Standards
- Identify key content areas that transcend the stakeholder groups
- Based on the feedback received, highlight issues for the Working Group to consider

Respondents

The response to this public consultation was impressive. The passion and commitment across stakeholders was palpable. The investment of time and resources to prepare the 424 submissions was evident. For purposes of this report respondents are classified into 3 cohorts:

1. People who use services
2. Family members
3. Service Providers (note that this cohort also includes staff members and umbrella organisations and statutory bodies)

Table 1. Respondent Type

Cohort	Number of Submissions
People who use services	238
Family members	71
Service providers (including 4 submissions from staff members; 1 umbrella organisation; 2 agencies)	54
Combination (e.g. people who use services/service provider; people who use services/family member/staff member)	16
Respondent type not evident	45
Total	424

Although it is straightforward to indicate the number of submissions, counting submissions does not accurately reflect the people behind these documents. It is crucial to note that although close to half of the submissions were from individual people, the rest were from groups ranging in size from 5 up to hundreds of people. Group responses from parents associations highlighted the commitment of natural supporters to engage in this process. Thus, any numbers presented in this report have little real-world meaning and cannot be used to make any statistical claims.

IDS@UL Research Team

The research group IDS@UL (Intellectual Disability Studies at University of Limerick) was founded in 2011 and now includes people from 10 different disciplines (nursing, occupational therapy, clinical psychology, health psychology, social care, speech language therapy, education, policy, disability studies, philosophy) , 4 Irish Higher Education Institutions, service providers, family members and over 20 self-advocates.

We aim to advance the rights of people with intellectual disability; to respect the individuality of each person within the context of families and allies; to create a forum for promoting social inclusion and citizenship and to promote inclusive research practices in Ireland. The IDS@UL research team is diverse. Members have engaged in applied research for up to 16 years and have worked together on a range of funded and community-based projects over the past 3 years. Our shared history of engaging in practice from a range of health and social care professions across 4 countries (Ireland, Canada, United States, Spain) firmly grounds us in the practical applications of research to policy and practice both nationally and internationally. Our capacity for critically engaging with evidence-based practice uniquely positions IDS@UL to produce relevant and timely research findings.

When we received the Request for Tenders from the NDA, a query went out to the group to identify what members could be available during the window of time required to complete the analysis. The people from IDS@UL who comprise this qualitative analysis panel include:

- Dr. Nancy Salmon is the lead researcher on this project. She has a PhD in Disability Studies and is Lecturer in Department of Clinical Therapies at University of Limerick. Dr. Salmon is Canadian, living in Ireland for 4 years. Dr. Salmon is currently engaged in a Marie Curie funded research project focused on the experiences of people with intellectual disabilities moving into community living in Republic of Ireland, Nova Scotia, and Northern Ireland.
- Ruth Ryan is a Lecturer in the Department of Nursing and Midwifery, University of Limerick. She is currently completing her doctoral studies.
- Jonathan Angus is a PhD candidate in disability & families studies. His background is in early years education. Mr. Angus is a US/Irish citizen living here for 13 years. He is the father of young adult with intellectual disability.
- Eleanor McSherry completed her MA at Mary Immaculate College with a focus on critical interpretations of intellectual disability in Ireland. She is the parent of a teen with a disability.
- Kathryn O'Shea is a parent advocate associated with the Clare Federation for People with Special Needs.
- Nicole O'Connell is a recent graduate from the MScOT (professional qualification) course at University of Limerick with experience in qualitative analysis.

Approach to Analysis

The IDS@UL team is committed to respectfully representing the diverse perspectives represented across these submissions. To that end we employed a collaborative approach to developing the coding framework, coding submissions and writing the report. Each stage of the analytical process is described below to explain our process. Strategies used to promote trustworthiness are then highlighted.

Stages of Analysis

The approach to qualitative content analysis used by IDS@UL consisted of four phases: (1) preparing data, (2) developing a coding framework, (3) coding submissions, (4) retrieving data to write up the final report. Each phase is briefly outlined below:

1. **Data preparation:** All submissions in pdf format were converted to word documents when possible. Any handwritten documents were transcribed into word documents to enable effective coding and retrieval within NVivo 10 software.
2. **Developing a coding framework:** In the first two days of the project an initial coding framework was developed. The coding structure has 4 key elements: Themes (274 codes); Type of feedback (29 codes), Stakeholder (18 codes), and Content (63 codes). The content codes were necessary given that over half of the respondents did not explicitly name the theme and standard they were commenting on. Additionally, numerous submissions were related to the process of consultation. Given the volume of comments made about the process, the IDS@UL team agreed that it was crucial to incorporate this into the findings.
3. **Coding submissions:** The lead researcher then divided the data up into sets of 20 submissions and distributed these to team members. Research assistants coded each submission in the software and wrote up an analytical memo after coding each set of 10 submissions. The final project file includes 424 coded submissions.
4. **Retrieving Data:** Because so many submissions did not incorporate comments under the identified Themes, the team identified code combinations that could be applied across the data set to retrieve information relevant to each Theme. The lead researcher allocated each submission to a particular 'classification' within NVivo 10—people who use services, family member, service provider, staff member, not provided (respondent type not evident in submission), and umbrella organisation. Extensive queries were run within the software specific to each theme and also connected to particular stakeholder groups. The data retrieved from each query was then compiled into a single 'report' for each theme. A supplementary document that includes all items coded explicitly under Themes, Standards or Features was prepared.

Storage and Data Protection

The management, storage and security of data was the responsibility of the lead researcher. All data was held on the lead researcher's password protected laptop. Each day the NDA project folder was backed up on an external hard drive that was stored in locked cabinet in lead researcher's office. Data Management and security measures employed during the analytical process were in line with standards of good practice guidelines.

Key Findings

In analysing the data from a public consultation the framework for this section of the report was designed to address each of the 7 Themes, Standard Statements, Features, and 'What it means to you' segments which are contained in the Draft Interim Standards for New Directions. The report synthesises data from across all submissions and is organised under the 7 Themes to inform the revisions to the Draft Interim Standards. It is important to note that more than half of the submissions did not explicitly comment on Themes or Standards. To ensure that these perspectives were drawn upon for the report, separate queries were run in the software by using combinations of 'content' codes. Specific quotes are included that clearly represent the main points made across submissions. These are all drawn from across the submissions. IDS@UL carefully considered the quotes to include, identifying quotes that

- reflected a core idea most effectively
- provided perspectives from across stakeholder groups.

Each section of the findings begins with a description of how relevant content was retrieved from across the dataset using NVivo 10 software. The sections are then organised under the following headings:

- General Comments on Theme (positive feedback and concerns)
- Comments on Specific Standards and Features

There are 10 main headings for the Findings in this report including:

1. Overarching Comments
2. Individualised Services and Supports
3. Effective Services and Supports
4. Safe Service and Supports
5. Leadership, Governance and Management
6. Responsive Workforce
7. Use of Resources
8. Use of Information
9. Implementation Issues
10. Feedback on Consultation Process
11. Concerns about Potential Consequences of the Standards

A large supplementary document itemises the comments made across submissions that explicitly identified Standards or Features. Reviewing both documents will provide a more comprehensive overview of the feedback received in response to this public consultation on the Draft Interim Standards for New Directions.

Overarching Comments

There were a number of over-arching comments that threaded through the commentary on the seven themes. Each of these will be considered in turn.

- Relevance
- Family Involvement
- Missing Content
- Rural Issues
- Life Stage

Comments on Relevance

Some respondents queried whether the Standards were relevant to particular cohorts of people with intellectual disabilities. “We feel that New Directions is directed towards people with higher ability than those that need greater supports and specialized day services i.e. nurse led services” (Sub295 SP). Another person added, “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 FM). Respondents felt that those with complex needs were not adequately considered during the drafting of the Standards. “I am here now trying to type up this message and my 20 year old son is upstairs on the toilet waiting for us to assist him to clean himself. This certainly has not been considered in the document, this is just one item in the 24 hour care that our son needs” (Sub350 FM). Similarly, Sub353 (SP) wrote, “there would appear to be insufficient attention given to people with significant support needs and how their participation can be optimised in terms of core concepts such as choice and individual planning and the actions required to ensure that their needs are fully met.”

Families expressed a range of recommendations, many of which were linked to equity of service provision and were specifically focused on people with complex support needs and/or people with communication difficulties. One family group (Sub266 Family Group) wrote, “Families felt that these Standards are too wide ranging. They felt that the overall population being covered by one set of Standards was so wide ranging that it made it difficult to cover every individual’s needs. Families felt that having Standards which encompassed all day services did not accurately reflect the specific needs of individuals with an intellectual disability. They strongly felt that specific Standards were required. The inclusion of all adults should be more specific in relation to individuals with high support needs, the families did not feel that this was accurately reflected throughout the Standards.” Assuring equity among people with varying complexity of support needs will be a critical consideration.

“Some thought also needs to be given to existing mental health programmes which are funded from adult day service disability funding and don’t come under the Mental Health Commission. e.g. a number of RT Programmes, Clubhouse’s, other mental health recovery initiatives. They would fall under the scope of the standard now in

certain areas but decisions need to be made around where they would be best located in the future" (Sub 110 SP).

Connected to comments of relevance were points made that all of the Standards may not be relevant to all people who use services. For example, Sub291 (SP) wrote, "The twelve supports that are identified are excellent, however it should be highlighted that not all the supports will be applicable to all individuals at all times. Therefore efforts must be explored to prioritize specific supports and the concentration on them is time measured."

Family Involvement Requires Consideration in Standards

A strong sentiment that family involvement was not acknowledged enough was evident in the data (Sub266 FM, Sub273 FM, Sub275 FM), with "a danger of some service providers using this omission from the Standards to suit themselves and exclude the input of family" (Sub273 FM). Consideration and recognition of the role of families was highlighted by several families. "Staff will come and go different staff members will have different ideas and will influence and help the service user in various ways, but family are there all the time and are constant in the service users lives" (Sub256 FM). While the "vast majority of people in society do not have a personal centred plan" (Sub256 FM), as "the constant" support the majority of families expressed eagerness and desire to be involved in service delivery recognising the "client belongs to a family and they play a very important role in the clients life within the service that they are using" (Sub142 FM). Based on these comments, there is an inferred reliance on natural supporters within the Draft Standards, yet little information is provided in the Standards about how these natural supports will be activated and sustained.

Lack of recognition of the pivotal role of families was also central to comments on the Draft Standards document. "Throughout the document it was felt that family involvement and support of individuals was not acknowledged enough. Where advocates were mentioned it was felt that families should also be referred to as they felt that they would often assume this role when an independent advocate was not available" (Sub266 FM Group). Another respondent added, "We accept that family may not always be available, interested or aligned to the best for the person, but their exclusion misses a chance for balance and betterment of the service provided" (Sub273 FM). The same sentiment was echoed by Sub275 (FM Group), "Many parent and sibling voices have been heard on the consultation Roadshow process. It is surely not beyond reason or practicality to develop those voices into a Consultative Resource, comprising of a wide cross section of people, who are capable of engaging in meaningful conversation."

Content Missing from Draft Standards

Definition of Positive Risk-Taking

There is mention of 'positive risk-taking' in the Standards; however, the meaning of this phrase was unclear for many stakeholders. For example, Sub252 (SU/SP) wrote, "What is meant by positive risk-taking?" "Positive risk taking, personal responsibility

versus service responsibility...is an area which requires a lot of work when it comes down to implementation, interpretation and monitoring” (Sub110 SP).

Respondents noted that the recognition of rights and levels of supports requires further dialogue including a discussion about how positive risk-taking can become a mechanism to support personal planning to be implemented ‘philosophically and operationalized.’ The notion of ‘positive risk-taking’ was well-received by people who use services, some families and service providers. Conversely, it was a flashpoint for many families and service providers. Underneath the reservations expressed by the cohort contesting ‘positive risk-taking’ was an implied concern about intimate relationships. This appears to be a substantial oversight within this theme and across the whole document.

Intimate Relationships

Questions arose regarding responsibility, particularly when considering the right to intimate relationships. Sub291 (SP) mentioned “the dramatic changes which are proposed to take place within law with regard to the law pertaining to capacity, consent and sexual relationships. These proposed changes amend the existing law outlined in the Criminal Law Sexual Offences Act 1993 which makes it illegal for a person with a disability to have a sexual relationship. This proposed amendment removes this restriction and in doing so places a legal obligation on services to offer a range of service to people with disabilities in matters relating to education on such matters as sexuality and relationships.” Another service provider wrote, “There should have been information about Relationships/Sexuality” (Sub261 SP). Intimate relationships could be understood as an aspect of positive risk taking and were identified as an area requiring further development in the Standards. Sub367 (SP/SU) commented, ‘The Standards only brief mention of sexuality and romantic relationships is in relation to health.’ This notion threaded through comments made by people who use services. The same respondent further substantiated this. “I want the right to have a family... I’d like to have a boyfriend (girlfriend) and maybe have a baby’ (Sub367 SP/SU).

Bullying

People who use services were keen to learn, “more about the standing up for yourself and safety” (Sub178 SU) as outlined in Feature 1.4.6. There was a clear emphasis on the need to reduce the experience of being bullied (Sub018 SU). This topic appears to be missing from the current Draft Standards. Bullying and fear of not being accepted appeared as real concerns for services users in their response to this consultation. People who use services explained that “I want to feel safe and not to be bullied” (Sub014 SU). Some had previously experienced negative responses from the community, such as “some people are rude and ignorant to us in the community – bully or ignore us” (Sub355 SU). Instances of not being “accepted in the community” (Sub141 SU) were described. Respondents suggested that the Standards inform and educate community partners around anti-bullying strategies.

Lack of Detail on Person-Centred Planning

The language of person-centred planning is embedded throughout the Standards, yet Sub353 (SP) pointed out that further clarification is needed around expectations for practice. “We have concerns at the lack of detailed description of good person centred planning practice. Person centred planning can vary from selecting from a prescriptive service options menu approach to the detailed practice reinforced in the Genio Endeavour for Excellence and Enabling Excellence programmes which focuses on the person’s interests and abilities using the Discovery approaches within a Socially Valued Role framework. We consider this a priority area for attention, the key cornerstone to ensure that the Standards have the potential impact on the lives of people who use support services.”

Rural Issues

Access to transportation and access to opportunities were core concerns expressed in relation to rural areas. Establishing links with Department of Transport was recommended, with specific attention to “Transport between rural to urban areas is also causing many barriers to service users and hindering their independence... The need for many disability issues to become part of the agendas of different government departments is also causing concerns around the transference of funds from HSE to the departments concerned” (Sub226 SP). People who use services shared this concern writing, “The ideas are good but things often don’t happen. I’m not always listened to and there is often no transport or support worker to bring me places so I do lots of things with my family. It would be nice to have support to be independent” (Sub298 SU). Families strongly expressed reservations about potential implications of New Directions on transportation in rural areas. For example, Sub411 (FM) stated, “Transportation is a key issue for those in rural areas, how can this be sustained and funded in the future.” Similarly Sub397 (SP) wrote, “the challenges of the lack of public transport in rural areas needs to be addressed. If not, they will continue to rely on arrangements provided by Day Services. Specialist transport accommodation for those with physical disability, behaviour that challenges, health conditions such as epilepsy has to be factored notwithstanding the issue of rural isolation and lack of public transport.”

Access to opportunities in rural areas was specifically mentioned by Service Providers and families. Sub282 (SP) wrote, “Very few clients are able to meet up outside Day Centre hours – live too far away – nobody to support them to do so.” A family member added, “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” (Sub073 FM). Building on this another family raised concerns about the lack of opportunities in their local communities. “I don’t detect any compassion, good will/understanding of their fellow humans. Come down the country which has been destroyed. In our village we have lost our school, Garda station, post office, shop & now our Priest. We do have a graveyard. Never had a Bus service. Nearest town 8 miles” (Sub411 FM). This comment highlights the challenges uniquely located in rural communities across Ireland.

Life Stage

Concerns about life stage ranged from parents expressing anxieties about aging themselves and what the implications would be for their adult children and also what impact these life stages have on the understanding of 'community' as used in the Standards. "The issue of a fuller life in the community is not an easy one to crack. People on our road are ageing and dying. The younger parents – both work- and have no free time. Is the community the ageing parents who are already caring? Siblings either live a long distance away or have emigrated. At least at present when our children with ID go to a day centre they are mixing with their peer group who are the only friends they know from 9 to 3.30. We, the carers have time to catch up with other things and are re-energised by the time 4pm arrives" (Sub239 FM).

Aging of people with disabilities was also clearly identified by respondents. For example Sub093 stated, "No one in Ireland is disabled once they reach 65. D.A. switches to O.A.P. and no service provision appears to have been made for these clients". Attention to end of life care was raised by a few respondents. Although numbers were small, this seems a crucial issue to consider.

Theme I Individualised Services and Supports

Introduction to Theme I

To explore the data related to 'Individualised Services and Supports' the research team ran a set of queries within each of the three main submissions classifications: People who use services, Service Provider (including Staff Member and Umbrella Organisation submissions) and Family Member. The content of submissions coded as Theme I or any of its constituent Standards and Features was then identified. Dataset queries were also run combining the codes 'people with disabilities' and 'rights' or 'advocacy' to ensure that relevant comments were drawn forward in the analytical process.

General Comments on Theme

"I like this book as it explains all the support and help I'm entitled to [original spelling retained]" (Sub218 SU). This comment succinctly expressed the response of people who use services to the Standards included in Theme I. People who use services appreciated the language in this theme "respects your right to make choices" (sub278 SU) and were pleased to know that "people have to listen to you" (Sub018 SU). The Standards within this theme afford people the opportunity to choose how to spend time during the day and sets up the supports they need to do so. One group of people who use services commented that "through their own goals they choose their work and activities and this is good" (Sub390 SU). People who use services agreed that they should be involved in all planning meetings about them "nothing about us without us" (Sub093 SU group). Another group commented, "Person centred plan is a good idea. Being safe and feeling safe is important. Important to be part of the community and have help to be in the community. Having good health is important and getting help when I need it or ask for it. It all sounds good" (Sub236 SU group). One group of people who use services (Sub383 SU Group) summed up the response to this theme clearly in the following list:

1. Being able to pick the keyworker we want to work with. This person would help us choose the services that we want to get involved in
2. Opportunities outside our centre, so that we can make new friends and build on relationships with other organisations
3. To help us build confidence and skills to be involved with other people in our community to get to know our neighbours
4. Trying courses outside the [service]
5. Living alone, discuss with family and staff. Get help to organise this and also provide support when living alone
6. Getting help with things like health
7. Getting work experience

Many service providers also welcomed this theme given that, "it recognises the central role that people should play in decisions that are made about their lives" (Sub355 SP). Another service provider agreed, stating, "New Directions Standards are very welcome. Standards are extremely positive. There is a strong emphasis on

person centeredness, rights and community integration. The Leadership and Governance is strong also and we feel it is an excellent document that promotes high quality person centred supports for people with disability. A really excellent document and most welcome!" (Sub291 SP). Family members concurred, with one stating that "The Standards included are well thought out" (Sub103 FM).

Many service providers, families and people who use services highlighted examples of good practice already evident across Ireland. For example, Sub069 (SP) stated, "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."

Comments on Specific Standards

Advocacy, rights and respect were all featured prominently in submissions that connect to Individualised Services and Supports; however, when they considered in more depth, they all appear to be subject to the issue of how capacity is interpreted. This is further considered under the relevant Standards headings.

Standard I.1: The rights and diversity of each person are respected and promoted

Citizenship was highlighted as central to this Standard. A service provider wrote, "rights and empowerment ensure 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" (Sub353 SP). Yet, there was concern that rights had been interpreted too narrowly within the Standards. For example Sub355(SP) commented, "In the what this means for you section of Standard I.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."

It was noted that people with disabilities in Ireland are currently in a difficult position with respect to rights, "Irish people with disabilities are not yet in a position to assert their rights under this International Convention [referring to UN Convention on the Rights of Persons with Disabilities]" (Sub355 SP). Yet the unique opportunity to centralise human rights was commented upon. "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 SP).

The process of reviewing the Standards facilitated conversations and dialogue around 'rights'. This was reflected in comments such as "good ideas - good to have choices" (Sub222 SU), "talking about your rights" (Sub320 SU, Sub188 SU, Sub171 SU, Sub390 SU) and having "your rights respected" (Sub363 SU).

The responsibility that comes with enacting one's rights was commented upon. "Giving service users a list of rights is great but nowhere do I see that service users also have responsibilities. You cannot just inform service users that they can have anything and everything they want. Life is about give and take. Life is about responsibility. Life is about not having everything you think you want. These Standards in their simplest form for service users read like a menu of all the things you ever wanted must be provided" (Sub293 FM).

Living a life of dignity (Feature 1.1.3) that is free from discrimination was highlighted as a recommendation by one group of respondents. Sub 291 (SU/FM/SP) wrote, "In outlining what this means for a person using a service it is recommended that the Standards should clearly state that you have the right to live your life free from discrimination. This means that any disability you may experience should in no way hinder your opportunities to achieve your goals. You have a right to achieve your goals on an equal basis as all other citizens. You have a right to supports that will enable you to reach your goals in areas of employment, health, education, political and public and private life. Such supports are called reasonable accommodation measures and entitles the person to such accommodations as: Employment-supported to commence your work at a time that facilitates your needs best. Health – your health care intervention explained to you in a way that supports you to make an informed decision. Political – supported to become involved in political life. Supported to exercise your right to vote."

Standard 1.2: the dignity, privacy and autonomy of each person are respected and promoted

There was broad agreement with the principle of treating everyone with dignity and respect. Respecting privacy was of utmost importance to many people who use services. Sub093 (SU group) "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." The same group also expressed concerns about inspection of day services and whether this "would mean more things written down about them... and staff spending more time on paperwork."

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

It was suggested that additional guidance should be provided for within the Standards to avoid a power imbalance. "I would suggest there needs to be a specific set of Standards about communication. I have seen that the power imbalance that adults with ID experience often stems from communication difficulty. Standards need to reference not just putting information into understandable language but actually checking what people have understood. Otherwise it is a paper exercise" (Sub074 SM).

Recommendations from respondents included practical suggestions about communication within services. For example, Sub096 (SU) wrote, "Some people

recommended that it is also important to give information regularly (more than once) to help people understand and remember it.” “Some SU’s feel that a structured timetable 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 SU). Some respondents advocated for transparency within service provider organisations, with one writing, “service level agreements should be publicly available to all clients with detailed explanations of what is happening in their organisation. This should also be in easy to read format” (Sub097 SU/SM). In contrast other organisations appeared to be very cautious around access to communication technologies. For example, email communication was an area of mixed opinion with Sub097 (SU/SM) writing, “I am aware of clients that are not allowed to use the in-house email system because the company feels it would inherit a liability. The equally will not allow an email account to be set up for cyber bullying purposes.”

While many respondents were in favour of this standard, there were a few who questioned the ability of people with intellectual disabilities to make informed decisions. For example, Sub073 (FM) stated, “I don’t see how this is possible for many people (clients/users) as from my experience they seldom will be capable of making well informed decisions.” Another wrote, “For ID people to understand and make decisions is grossly and dangerously over stated” (Sub095 NP). A service provider also questioned the issue of access to personal information (feature 1.3.8) where a person who uses services has complex needs; “where the client is unable (severe/ profound) to request personal information held will it be available to legal guardian or parent?” (Sub232 SP).

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 services

In general, there was very little connection made by respondents between the Draft Standards and the UNCRPD. That said, there were a small number of submissions that demonstrated strong alignment with UNCRPD. For example, Sub291 (SP) cited Articles 1,3 and 5 in relation to this theme, specifically advising 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.”

A clear need to connect with the forthcoming Assisted Decision Making (Capacity) Bill (2013) was evident within multiple submissions. Sub291 (SP) stated, “This is a legal requirement that people with disabilities should be afforded the option of supported/ assisted decision making to have their decisions legally recognised. This is a clear opportunity for the Standards to promote the Bill and support people with disabilities to be legally recognised decision makers in matters relating to health, welfare and lifestyle, all of which are part of the New Direction Standards.” At the same time there were concerns expressed about the issue of capacity by some

respondents, many of whom were family members of people who were described as having severe or profound intellectual disabilities. For example, Sub379 (FM) wrote, “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.” Other concerns regarding capacity were primarily connected to how this concept is understood or applied when a person has complex support needs. For example when reflecting on decision making, a family member noted, “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 FM).

How capacity will be determined was central to many concerns documented from families and service providers. “These Interim Standards involve people with disabilities in the design, delivery, monitoring and evaluation of the services and supports provided. However this raises issues in relation to people’s capacity and assessment of same. There is no standard framework in relation to assessing capacity” (Sub295 SP).

When a person with disabilities experiences difficulty with verbal communication, respondents sought clarification about how this scenario would be managed. “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 FM). Another family member explained, “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 FM).

People who use services expressed concern about having limited choices. For example, Sub096 (SU) wrote, “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.” Another group of people who use services commented “that they do not have enough choices and they cannot remain in their own houses when day centres are closed due to financial costs. (This would be people in HSE houses) The document says that supports should be person centred but this does not always happen for some people” (Sub029 SU).

Advocacy

Advocacy was understood as multi-dimensional, including self-advocacy, informal advocacy and accessing formal advocacy services. “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” (Sub370 SP).

Connected to this is the need to facilitate effective involvement of advocates. One service provider commented, “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 SP).

Access to advocacy services was raised as a key concern both by people who use services and by service providers. “Some service users did not know they could avail of an advocate” (Sub368 SU). A provider stated, “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 SP).

Standard 1.5: Each person has a personal plan that outlines the services and supports to be provided to them to achieve a good quality of life and to realise their goals

Concerns were expressed about the limited description available in New Directions about the process and practice of developing and implementing the person-centred plan. “We have concerns at the lack of detailed description of good Person Centred Planning practice as it is generally acknowledged that there are significant variations in how it is practiced. Person Centred Planning can vary from selecting from a prescriptive service options menu approach to the detailed practice reinforced in the Genio Endeavour for Excellence and Enabling Excellence programmes which focuses on the person's interests and abilities using the Discovery approaches within a Socially Valued Role framework. We consider this is a priority area for attention, the key cornerstone to ensure that the Standards have the potential to impact on the lives of people who use support services” (Sub353 SP).

Respondents sought clarity about how personal plans will function. This was in part related to who owns the plan and also how the plan would be communicated or shared across different provider organisations that a person might be connected with under New Directions. Sub343 wrote, “the person has ownership of their personal plan, while the service provider keeps a copy of it.” There was some confusion around the types of personal plans already in place and how these would link with the person-centred plans outlined in the Standards. “The service users feel they have a lot of folders already. They have an Individual personal plan and a profile folder they do not want or feel they need another one” (Sub093). Service provider (Sub372) added, “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 SP).

It was clear however, that a plan for a good life did not necessarily equate to accessing services from the same provider for life. Sub355 (SP) stated “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.”

Many respondents were concerned about how people with communication difficulties will participate in the person-centred planning process. Several approaches were offered to address this. For example Sub74 (SM) suggested that staff be provided with training in a range of communication strategies. The same respondent went on to write “Staff will review all goals, plans, information with the person. This will involve checking if the person can explain their own goals on more than one occasion to a familiar person. The person’s communication needs including supportive communication strategies should be clearly identified.”

Conflict of interest was raised when provider is involved in both the development and delivery of the Personal 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” (Sub273 FM).

Standard 1.6: Each person is supported to use local community facilities and to develop a range of relationships in their community, in line with their choices, needs and abilities

Concerns relating to the feasibility of the extent of the role of the community were raised, particularly in reference to standard 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 NP).

Concern was also raised regarding physical environments that require upgrading since “many of the structures accommodating day services are not fit for purpose” (Sub103 FM). Another family group echoed this worry, noting 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 FM).

The pivotal role some day services play in the local community was raised by some

respondents. “Given the demands that community based services will inevitably make on existing resources, the Standards as currently presented are causing genuine fear on the part of service users that the centre based services that they desire will be diminished or lost. For many service users the centre is their chosen community. Please remember that the centre is an integral part of the wider community as well. The standard should be updated to reflect the true reality of the lives of people with a disability by giving force to the protection of services as currently provided and the protection of the rights of individuals to receive the support and help they need within a well-run services centre” (Sub067 NP).

Clear connections were made between Theme 1 and Theme 3 with respect to balancing rights with risks. Some respondents highlighted potential conflict between an individual’s right to choose to make decisions and the implementation of New Directions within services and in the community. For example a Service Provider noted, “The issue of rights and personal choice versus risk may need to be developed a bit more in the standard” (Sub110 SP). They later added, “General discussion took place in our feedback group in relation to concerns in situations where an individual’s choice of service activity cannot be met due to the risk they may potentially pose to other service users in a particular setting” (Sub110 SP). Another respondent was concerned about some people who use services may indicate a, “choice of community placement in which they may potentially pose a risk to others” (Sub252 SP).

People who use services, families and service providers all raised concerns about how receptive communities would be to people with intellectual disabilities. Sub040 (SP) wrote, “while a lot of our service users have an active role in the community some feel that acceptance in the community is limited.” While some worried that people would not be welcome others were concerned that particular activities would become magnets for other people with intellectual disabilities, inadvertently reproducing segregation in the community setting. For example Sub 412 (FM) wrote, “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” (Sub412 FM).

Standard 1.7: Each person is supported to make transitions between supports provided by a specialist and mainstream services and tries new experiences on an ongoing basis, in line with their choices, needs and abilities

This standard received many positive comments given the support mentioned during transitions. Sub278 (SU) submitted, “We agree on helping people. Important because people may not be able to adapt to change or new environment without a proper support structure in place.” Many service providers also endorsed this Standard. Sub355 (SP) wrote, “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 service to be constantly supporting people to progress to the next stage whether that is

outside the disability services or in taking up a new activity within their disability service.” A tension between individualised services and the needs of service providers was described by Sub353 (SP) “the focus is still on the ‘service’ and not on the provision of supports around the person to live the life of their choosing.”

Connecting Standards to those present in other agencies was advised. “This standard must be amended to reflect changing objectives for both schools and service providers and the HSE. The National Council for Special Education (NCSE) would assist with the wording of this standard. We note that the NDA 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 SP).

Standard I.8: Each person makes progress toward achieving their goals and aspirations

This standard was supported across submissions. Sub278 (SU) wrote that this is “a 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.” Monitoring was recommended with Sub066 (SU) stating, “inspectors should check all progress made on each service users’ goals and dreams.” Some concerns were raised about the Standard with Sub261 (SP) noting that it “should be explained further” and Sub266 (FM) writing “again no mention of the role of families.”

Standard I.9: Each person’s complaints and concerns are listened to and acted upon in a timely, supportive and effective manner

There was support from across stakeholders for this Standard. Sub297 (SP) wrote, “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.” Specifically commenting on the complaints process, one service provider noted, “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 SP). A useful recommendation was offered by one service provider to incorporate additional content: “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” (Sub352 SP). A person who uses services commented, “Even when I complained about something I was not happy with the answer I got” (Sub237 SU). Sub097 (SU/SM) provided a recommendation to address this concern, “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.”

Timeliness of response to people with complex support needs was also raised. For example, Sub412 (FM) wrote, “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.”

Theme 2: Effective Services and Supports

Introduction to Theme 2

To explore the data related to 'Effective Services and Supports' the research team ran a set of queries within each of the three main submissions classifications: People who use services, Service Provider (including Staff Member and Umbrella Organisation submissions) and Family Member. Any content of submissions coded as Theme 2 or any of its constituent Standards or Features was then retrieved from NVivo10. Dataset queries were also run combining the codes 'choice' and 'participation' followed by another query using the codes 'people with disabilities', 'access' and 'choice.' Finally, the contents of the code 'person-centred' were also gathered to ensure that relevant comments were drawn forward in the analytical process.

General Comments

There was a broad appreciation of the content of Theme 2. "I am a parent of two adults with a disability. I have been asking for this kind of service for them for years. I was encouraged to bring them through main stream so you can imagine how it felt to have them segregated when they came to adults. So I was happy to see this New Directions Services" (Sub354 FM). Another respondent submitted, "This explains well what we can expect from our service. Pictures matched well with the writing" (Sub107 SU/SP). Some concern was also expressed with Sub263 (SP) writing, "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."

Comments on Standards

Standard 2.1: Each person receives services and supports that are responsive to their individual choices, needs and abilities, in line with the service provider's statement of purpose

The notion of a 'statement of purpose' appeared to confuse a number of respondents. Sub109 (SU) submitted that "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... could organisation be used in place of 'service provider'?" Sub351 (SP) also sought clarification, "Need clarity around statement of purpose, is this envisaged as a general statement of purpose across the service or individual statement of purpose and function for each person supported."

Many service providers and families were concerned about timetabling services and supports outside traditional hours. "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 lose this" (Sub297 SP).

In contrast people who use services commented specifically on Feature 2.1.3 writing "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 SU). A number of families also supported more flexibility in timetabling. For example, Sub247 commented, "We love the idea of involving the clients in more social events, perhaps in the evenings and at weekends" (Sub247 FM).

Standard 2.2: People are involved in the planning, design, delivery, monitoring and evaluation of services

Many service providers noted that they are already meeting this Standard in their submissions. For example Sub095 (SP) wrote, "every summer, there is an individual plan review when service users have the opportunity to review their choices." Involving people with disabilities in the design of services could be considered in relation to questions raised by respondents about how capacity would be understood in relation to New Directions. "These Interim Standards involve people with disabilities in the design, delivery, monitoring and evaluation of the services and supports provided. However this raises issues in relation to people's capacity and assessment of same. There is no standard framework in relation to assessing capacity" (Sub295 SP).

One service provided added that "Standard 2.2.2 very positive and powerful statement. The user is a partner in service rather than a recipient" (Sub263 SP). Direct requests to include people who use services in management discussions across service provider organisations surfaced several times from across stakeholders. "It would help our understanding of how services are run if we were included in these discussions" (Sub281 SU). Some service provider organisations appeared to be reluctant to enact this significant culture change within services, noting that timing made this an aspiration that would be difficult to put into practice. For example Sub141 (SP) wrote, "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." In contrast Sub263 (SP) noted, "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 areas of staff recruitment, service location, staff training and development are totally new concepts and will require a significant change in organisational culture and approach."

Standard 2.3: Each person's access to services and supports is determined on the basis of fair and transparent criteria

Some people who use services pointed out existing inequities in the system with Sub081 (NP) writing, "some people think some individuals get more support and attention than others at times. Some people are not sure about this Standard." Sub296 (SP) agreed, "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 information to all."

Families wanted New Directions to include: “A comprehensive assessment of [service user’s] needs. A plan for meeting these needs and transparency on the methodologies used” (Sub108 FM). This comment specifically connects with Feature 2.3.6. Questions were raised by Sub114 (NP) including, “Who is responsible for determining the fair and transparent criteria? What are the criteria for determining individual needs? When and by whom will the assessment of individual needs to completed?”

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

Timetabling was raised as a shared concern across all stakeholders. Sub297 (SP) wrote, “Welcome this standard. Can be difficult for day service staff to link with residential/respite staff with the differences in shift patters/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. Day service supports/centre not always in people’s local community.” Specifically commenting on Standard 2.4.3 a respondent noted, “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” (Sub077 FM).

Communication is crucial to establishing and maintaining effective services and supports in line with individual choices, needs and abilities. People who use services were quoted by Sub355 (SP) stating, “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.” Sub281 (SU) commented that the easy to read guide ‘should have pictures of i-pads and smart phones.’ People who use services felt this standard could help with communication. “We like this standard... happy and think it’s important as it will help with emailing and telephone use. It’s an essential standard. Communication is key to helping service users develop” (Sub278 SU).

An important critique of this Standard was offered by Sub367 (SP): “This Standard must include access to free social time with peers. Many adults with disability talk of loneliness or feelings of isolation, in relation to peers more than local community or supporters. Community based and community focused social activity must be complemented by opportunities to meet and socialise with peers and make friends with peers beyond their own community/day services. This social development opportunity could be facilitated between families, day service providers, and communities or possibly independent networks.”

Standard 2.5: People develop skills to manage their own lives and maximise their independence in line with their choices, needs and abilities

This was acknowledged as an important Standard by many respondents. Sub367 (SU) wrote, “I depend on my family too much. I need to know on my own about money, food, job, bills for living.” Responsibility for effective services was raised as a key question within this Standard. “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 FM). Some respondents questioned how realistic it is to expect people to manage their own lives with Sub095 writing, “independent living unfortunately is outside the scope of many service users and this must be taken into account in any plans.” Sub096 agreed stating, “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.” These concerns connect back to the different perspectives on capacity outlined under Standard 1.4 above.

Positive risk taking as an aspect of managing one’s own life was commented on by many families and service providers. For example Sub110 (SP) wrote, “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.” Sub412 (FM) added, “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.”

Standard 2.6: People explore, identify and are supported to develop valued social roles in their community, in lines with their choices, needs and abilities

This Standard received mixed reviews with some families expressing serious reservations about how people who use services might be received in the community. The time needed to address this standard was highlighted by Sub297 (SP): “Developing social roles for an 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.” In contrast, there were many submissions that viewed this Standard positively with Sub255 (NP) stating, “I am pleased to see this included. I think for a person with a disability who does not work outside the resource centre this would greatly improve their mental health and self esteem.” Sub353 (SP) pointed out that ‘Standard 2.6 needs more development on Socially Valued Roles and what this means, based on the key interests of the person.’

Standard 2.7: People explore their own creativity and find their own means of self-expression, in line with their choices, needs and abilities

People who use services and Service Providers were generally positive about the values underpinning this theme. “We think facilitating a person’s creative expression is vital in a person reaching their full potential” (Sub094 SP). Sub370 (SP) added that

people “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: signing, cooking, acting should be allowed to be developed. You could use supports to give back to the community.’” Clarification was requested by Sub109 (SU), “the concept of ‘creative roles’ was not clear to some people, although it was explained some people still didn’t grasp the concept.”

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

Concerns were raised around who is responsibility for access to healthcare. People who use services 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.” People who use services posed the question “Who will look after health services, the house or Day Services” (Sub368 SU). Service Providers meanwhile wondered if their role under the new Standards much broader than it currently is. “This Feature [2.8.6] 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 SP).

Service providers expressed concern about whose remit it is to support people who use services to access to healthcare services. “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 SP). Equally, people who use services felt they had restricted choice when accessing healthcare, ‘People don’t feel that they always have choice about what health care providers they can use’ (Sub093 SU).

Clear and open communication relating to relevant health information and advice was desired. A family member specifically requested “Active participation and consultation in the delivery of care” (Sub108 FM). Self-management/health care was a particular concern of the families who disputed the notion that people who use services can be responsible to manage their own healthcare needs. Feature “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 FM). “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 FM).

A family group had a concern that the document did not address mental health issues. “If a family member with an intellectual disability developed mental health issues—most people in the group wouldn’t know where to turn. Some thought G.P.

would organise a psychiatrist or if necessary get admitted to the psychiatric hospital. Overall not enough information on this topic. Others noted that there are no psychiatric services in the Community for anyone with a moderate ID and mental health issues” (Sub384 FM).

Standard 2.9: People access formal education programmes, in line with their choices, needs and abilities

In order to have access to education, opportunities need to be pitched at the right level for people with intellectual disabilities. Sub040 (SU) pointed out that “some service users felt limited because of their poor reading and writing skills. They felt education providers cater for the more able.” Sub281 (SU) wrote, “Access to education is important but there are very few courses for us such as VETAC levels 1 & 2 and 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.” Sub066 (SU) went further stating, “Need to inspect mainstream education providers as they often stop people with disabilities attending course with excuses such as ‘we are too full’ or ‘we don’t cater for people with disabilities.’” The connection between education and employment was highlighted by Sub263 (SP), “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?”

Standard 2.10: People accessing bridging programmes to vocational training, in line with their choices, needs and abilities

The bridging programme proposed in standard 2.10 was raised as a particular concern both to people who use services and to providers. Sub261 (SP) wrote, “2.10 is also confusing- ‘bridging programme’ should be explained with examples.” People who use services commented, that the entire standard should be removed noting, “The standard is not necessary. People should be able to learn on the job, in college but not in training programmes based on centres only for people with disabilities” (Sub066 SU). In contrast, another group of people who use services indicated they were “Happy, it is an important standard. Courses like catering, computers etc. helps to prepare people for work. Everyone can do a programme to get ready for vocational training if they need it” (Sub278 SU).

Standard 2.11: People access vocational training and employment, in line with their choices, needs and abilities

Although the UNCRPD specifically comments on right to employment, the Standards were criticised for focusing too heavily on recreational activities. “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” (Sub374). Another example demonstrating this concern was evident in comments from Sub249 (SU). “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.”

The value of paid work was clearly stated, “Need pay to promote self-worth” (Sub061 SU). One respondent convened multiple focus groups and emphasised the importance of work to people who use services. They wrote, “all focus groups spoke about the importance of having a job. 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. 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. Day services should be about helping people who want work, to get work (paid or otherwise). Some service users want to work in the centre, they have worked hard in developing enterprises within their centres” (Sub093 SU Group). A family group queried, “Will people be retained in full time employment? Will they get paid for their work? If employment is terminated for whatever reasons what support will then be provided to the service user?” (Sub411 FM).

At the same time respondents were acutely aware of how the current economic situation impacts upon employment opportunities for people with disabilities in Ireland. “There is a general frustration around lack of employment opportunities for all people in society at present however to add to our problems people with disabilities are competing with a skilled workforce. The government need to bring in policies incentives to mobilise people with disabilities. There is also a fear that if people work or earn a certain amount they will lose their benefits. There needs to be more clear inform circulated in relation to benefits. One of the strands of new directions focuses on independence. Many of our service users wish to live independently however due to finances they are not in the position to do this. If a SU moves into independent living they either need to work to supplement their income or increased benefit. There are currently no statutory provisions to enable this” (Sub 226 SP).

Families and Service providers expressed concern about the availability of both education and employment opportunities given Ireland’s current economic situation. Sub263 noted that, “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 SP). This was reiterated by Sub252 (SP) who wrote, “Difficulty envisaged around Supported Employment and Vocational Training. Individuals competing in a highly competitive environment for jobs and opportunities” (Sub252 SP).

Standard 2.12: Premises and facilities are designed to support the delivery of community-focussed, high-quality, person-centred, and safe services and supports

Community Hubs were welcomed by many, but perceived as a threat by others. Sub095 (NP) wrote, “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 services 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.” In contrast Sub263 (SP) pointed out, “all staff agreed with 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.” Sub291 (SP) added, “additional resources and capital development plans will need to be resourced to make this feasible.”

Physical access of Community Hubs was raised as a concern. For example, Sub317 (SU) wrote, ‘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.’ Physical access to existing buildings was raised by a few service providers as well, with Sub291 (SP) stating, “Concern now is how to implement it given current resource constraints – both staffing and non-staffing (particularly environmental given the poor condition of some buildings).” Another respondent made a practical suggestion, “check if day services are located close to public transport and make it easy for people to access their communities” (Sub066 SU).

Standard 2.13: The effectiveness of services is systematically monitored, evaluated and continuously improved

This Standard was generally supported. For example Sub370 (SP) wrote, “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.” Clarification on this Standard was sought by a number of respondents. For example Sub073 wondered, “Who would systematically monitor the effectiveness of services?” While Sub093 (SU) queried, “Who checks the plan, the service users? The manager? An inspector? Generally groups felt it was about time that someone was going to keep a check on Day Services form outside of the (service).” Sub066 (SU) advocated for “service user involvement in this area.” Sub263 (SP) documented a specific concern “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?”

Theme 3: Safe Services and Supports

Introduction to Theme 3

Safety featured as a prominent concern for respondents. Provision of safe services and supports was referred to by Sub291 (SU/FM/SM) as the “umbrella standard” and the “golden thread” in the realisation of individual goals. Overall more concerns were expressed than positive comments and suggestions.

Data related to ‘Safe Services and Supports’ was gathered by retrieving all comments that explicitly identified Theme 3 or any of its constituent Standards and Features across stakeholders. This data was then expanded by searching for all content of submissions that was coded under ‘risk and safety’, ‘rights’, and ‘responsibilities to ensure that the whole dataset was accessed.

General Comments

People who use services noted the “Standards are good” (Sub014 SU, Sub235 SU, Sub070 SU). There was a sense that the Standards promote a sense of people who use services “being safe and feeling safe. It all sounds good” (Sub236 SU) and that people who use services were “happy we are safe” (Sub011 SU). Although New Directions is new approach to service provision, people who use services reported satisfaction with existing person-centred approaches, reflected in comments such as “I liked New Directions. I also like Person-Centred Plan and always been given a choice in everyday living” (Sub009 SU).

Family members were positive about the Standards around safe supports and services, describing them as “very good proposals” (Sub270 FM) that “sound positive” (Sub240 FM). Others noted that “it is difficult to argue with any of the proposed Standards in themselves” (Sub272 FM) because “in theory, yes” (Sub032 FM) the Standards should protect people who use services. Families described services in which “users feel safe and appreciated” (Sub350 FM). Another family member was more restrained in praise, suggesting that “safe services and supports is an expected outcome of any service provider” (Sub103 FM).

Many service providers were in agreement with all of the Standards in this Theme. They described existing roles in relation to safe and appropriate support service and their commitment to treating everyone with dignity and respect (e.g. Sub300 SP, Sub355 SP, Sub104 SP). Service providers reported that staff had received training with regard to appropriate policies and procedures e.g. health and safety, recording, and documentation. Safety was viewed as “a priority in service delivery” (e.g. Sub069 SP, Sub106 SP, Sub262 SP, Sub342 SP, Sub348 SP). The perception that services presently provide safe and effective support was evident in the three cohorts, as was the expectation that a service provider would provide a safe service. The right to feel safe and secure in a service was valued by people who use services, family members and service providers. Respondents acknowledged that there are different levels of safety supports required by people who use services.

Presenting an alternative perspective, Sub374 (SP) recommended a substantial revision to this Theme. “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.”

Comments on Standards

Standard 3.1: Each person is protected from abuse and their safety and welfare is promoted, while using services and supports

All stakeholders identified safety and the right to be free from abuse as a key concern. Procedures by which abuse or welfare concerns could be reported and followed up were not always clear. It was requested that “the service provider should issue policies and procedures statements to all clients’ families, so it’s very clear to a family member to follow in the event of allegation of Abuse and support is given to the client” (Sub255 SP). Additionally, it was felt that “a facility whereby a person outside the service provider can report abuse or a concern on behalf of a person using the service” was necessary (Sub255 SP). Accessing public and private amenities in the local community was a shared concern of both service providers and people who use services, particularly relating to respect and the challenges faced by people with disabilities in the community at large. An example was given of a local bowling alley where it could not be guaranteed that staff or customers would refrain from bullying (Sub355 SP). Thus, it would be useful to present a clear and transparent reporting process for lodging and following up concerns around incidences of alleged abuse. The concern for safety was noted by people who use services, families and service providers as multifaceted and requiring a complex response. It was felt that reporting procedures around abuse, recognition of the importance of family involvement, vetting procedures and limits on positive risk-taking were elements requiring further attention.

Standard 3.2: Each person receives services and supports that promote positive behaviour and emotional well-being

Concerns in relation to Standard 3.2 and the use and consequences of positive behaviour supports were raised. “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” (Sub353 SP). Some concern was expressed that the language used in the accessible summary at the end of standard 3.2 demonstrated a framing of people rather than situations as problematic. It was suggested by respondents that this section be rewritten in person-centred, rights-based language to ensure there can be no misinterpretation of the standard.

A few submissions made by professional bodies advocated for provision of specialist services. For example Sub372 (SP) wrote, “The Organisation Name welcomes the recommendation in 3.2.10 that staff should be trained in the provision of Positive Behavioural Support. However, it is the opinion of Organisation Name that the quality of training sought by services should reach a recognised standard... unfortunately, the Draft Standards do not stipulate who should provide training, advice and supervision. This is an area that falls within the expertise of Organisation Name... it is strongly recommended that only those with appropriate qualifications should provide PBS services that involve independently designing, implementing and supervising interventions. All others assisting the provision of PBS services who do not meet these requirements should do so under the supervision of a qualified Board Certified Behaviour Analyst.” In contrast, Sub386 commented that although an in-depth assessment from a PBS specialist may be warranted at times, “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.” A multidisciplinary approach was recommended by Sub386 (SP). “Organisation Name would also like to highlight the importance of well-coordinated multi-disciplinary supports as positive behaviour support requires an integrated assessment formulation and support plan. It is difficult to achieve such coordination when mental health supports are provided by separate services.” This group went on to advise that references to ‘inappropriate behaviours’ within the Standards be replaced by alternative phrases that are currently used in practice including ‘behaviour of concern’ or ‘behaviours that challenge’ (Sub386). To conclude Sub386 wrote, “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 qualifications and experience.”

Based on a review of submissions, IDS@UL queries if there are perhaps two concepts at odds within the Standards around communication and behaviour. Some respondents appear to retain a medicalised approach that positions the problem with the person while other submissions demonstrate an understanding that the problem is in the situation. This was specifically raised by Sub374 (SP). “There is a general

imbalance of power throughout the Standards making the person the problem, particularly evident in standard 3.2.”

Standard 3.3: Adverse events and incidents are managed and reviewed in a timely manner and outcomes inform practice at all levels

Positive risk-taking was identified as an area that required clarification (Sub278 SU, Sub266 FM) and additional emphasis (Sub355 SP, Sub359 SP and Sub I 10 SP). This was underpinned by the question of where responsibility and accountability for adverse events lay, and how the desire to minimise adverse risk should be weighed against creating opportunities for personal development through positive risk-taking.

Balancing responsibility and risk was highlighted. “Do not block the way ahead for people who are gradually gaining back their independence” (Sub355 SP). One respondent warned of the risk of becoming overly demanding about responsibility. “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” (Sub369 SP).

Theme 4 Leadership, Governance and Management

Introduction to Theme 4

Data related to 'Leadership, Governance and Management' was gathered in the first instance by gathering all comments from all stakeholder groups explicitly related to Theme 4 using NVivo10. To deepen the analysis, data was also retrieved in NVivo10 using the code for 'service provider' (in contrast the type of submission being from a service provider) combined with 'funding', 'measurement', 'policy and law', 'responsibility' and 'change management' in turn.

General Comments

This theme was well-received in the consultation. The need and recognition for leadership and governance in this area was consistently acknowledged by people who use services, providers and families. This positivity relates to the values of "person centeredness, rights and community integration. The Leadership and Governance is strong also and we feel it is an excellent document that promotes high quality person centred supports for people with disability" (Sub291 SP). Similarly Sub007 (SP) wrote, "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."

Contribution of people who use services in the management of centres' services was welcome. For example Sub097 commented, "Clients on boards of management—amazing. Service users developing policies—brilliant" (Sub097 SU/SM). This was described as "the most positive approach that I have experienced in my 22 years in the services" (Sub097 SU/SM). Similarly Sub073 (FM) agreed, "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?" A recommendation was made to support the implementation of this Standard by Sub344 (SP), "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."

A family member summed up the overall comments well, writing, "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 FM). Similarly Sub385 (FM) commented, “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 of 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. “

Comments on Standards

Standard 4.1: The service provider develops and promotes the culture of quality, person-centredness, community inclusion and active citizenship throughout the service

Sub341 (SP) provided an in-depth reflection on this Standard, offering strategies to support implementation. “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 the 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 the community and 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; publicly inform and actively involve the community in 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.”

Standard 4.2: The service provider performs its functions as outlined in relevant legislation, regulations, national policies and standards to protect each person and promote their welfare

There was general support for this Standard, with Sub370 (SP) writing, “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.” However, Sub291 (FM) queried, “where is the staff and money to ensure this?” and Sub081 (NP) stated, “too much bookkeeping involved” in this Standard.

A service provider commented, “This is such an important start to theme 4, where governance is highlighted with clear defined lines of responsibility” (Sub291). Clarity was requested on Features within this Standard. For example, Sub279 (SP) noted, “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.” Sub353 (SP) suggested, “that a demonstration of implementation would be useful.”

Standard 4.3: The service provider has effective leadership, governance and management arrangements in place and clear lines of accountability

To promote accountability within the governance arrangements suggestions were made about including parents and people who use services. Sub097 (SU/FM) commented, “Including a parent advocate committee within the service provider structure was one suggested strategy for enhancing accountability.”

The distinction between Standards for day services and residential services with respect to responsibility of staff is worth consideration by the Working Group. For example, “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 SP).

A number of service providers noted that they already have this documentation in place (e.g. Sub106, Sub 342, Sub370). Families wondered if Features in this standard, specifically 4.3.7 might enable service providers to “cherry pick the type of service they provide by putting profit before people” (Sub232 SP). Organisation Name queried if Feature 4.3.1 and 4.3.5 were quite similar as were 4.3.11 and 4.3.12. The responsibility of auditing was raised by several respondents (e.g. Sub424, Sub263, Sub359).

Standard 4.4: The service provider has a publicly available statement of purpose that accurately and clearly describes the services and supports provided

As in Standard 2.1, many respondents commented on the ‘Statement of Purpose.’ For example Sub351 (SP) wrote, “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?” An Organisation provided a succinct comment on this standard. “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 SP Umbrella). Building on these comments Sub359 (SP) wrote, “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.”

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

There was general concern expressed regarding what this standard would mean to service providers and could inadvertently restrict flexibility. For example Sub355 wrote, “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 supports needs and therefore funding levels for the service.” Sub384 (SM) worried that too much responsibility remained with service providers writing, “Family/person/advocate need involved in this. What happens if the service provider doesn’t fulfil its contractual agreement? What’s the penalty? What’s the come back? The contracts are too high level and more fit for a company. It’s not about people. Contracts have nothing to do with the service provider and service user. They agreement is only between the service provider and funder. Needs to drill down further. This is all too generic. Families need to be fully involved in a real way. Again needs to be written as SMART. Contracts need to be documented/evidence based/ tangible/measurable and signed off by all stakeholders.”

Theme 5: Responsive Services

Introduction to Theme 5

Theme 5 focuses on aspects of a Responsive Workforce. The search strategy within NVivo10 started with a search of all text that specifically named Theme 5 or its constituent Standards and Features. This search strategy was supported by additional queries that focused on combining content codes, including all items coded as 'unions.' All segments of submissions that were coded both as 'training and competency' and 'staff' were retrieved within the software as were all items coded as both 'relationships' and 'supports.'

General Comments

The contradiction between Standards that appear to endorse professionalising services and Standards that promote individualised supports was commented upon repeatedly. Sub359 (SP) named this problem clearly, "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)." Many submissions advocated for professional supports; yet there was little evidence across submissions that respondents were balancing out the costs of people perceived to be experts in terms of value for money.

The human interaction provided by services is considered paramount to the success of the organisation and to the quality of care provided. The importance of supportive relationships between people who use services, staff and families was raised regularly. Particular emphasis was placed on allowing time for these supportive relationships to develop. "We are given enough time to develop relationships to help with support" (Sub131 SU). This was reflected in comments from families who commented on "the dedication of staff members on the ground, despite being under severe pressure, and that competent staff and in particular the manager are vital to the success and atmosphere of a centre" (Sub100 FM).

The contribution of the Standards to accountability was also reflected in comments, "this will provide a more transparent process for organisations" (Sub266 FM). The positive approach to recruitment, induction, training and retention of staff was appreciated. For example a service provider commented, "It is positive to see recommendations for services to have strategies for the retention of staff" (Sub353 SP). In contrast, others described the process of writing and reviewing the Standards as 'much easier' than implementation and this relates to having appropriate skilled personnel to operationalise them (Sub095 NP).

Comments on Standards

Standard 5.1: Safe and effective recruitment practices are in place to recruit staff

Hiring processes outlined in the Standards received mixed feedback. Although the involvement of people who use services in hiring staff was viewed favourably by many respondents, some concern was expressed by some respondents. For example, Sub141 (SP) argued that “the recruitment practice has to be in line 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.”

A small, but significant comment was made regarding gender imbalance in support staff, where few men in Ireland are employed as carers. “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 SP). A Service Provider pointed out that “Many men using day services report that they would like to have more men working in the service” (Sub355 SP). Although it may be outside the scope of setting the Standards for New Directions, this was a comment is worth documenting. Based on this comment, in the longer term it could be useful to engage in creative approaches to attract more men into careers connected to individualised services and supports.

A clear critique of some hiring practices in the HSE was raised, specifically the approach of hiring staff from a panel (Feature 5.1.2). Sub245 (SP) commented, “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 SP). Linked to this is a concern about the skills of support staff. Sub385 (FM) wrote, “What will be seen as a recognised qualification for a day service instructor, programme facilitator, community mentor? How will a person’s skills and fit for a job be judged?” These will be important considerations going forward with the Draft Standards.

Recruitment and vetting practices (Feature 5.1.4) were discussed with the recommendation that employees should be vetted prior to the commencement of and regularly throughout their employment. It was also suggested that all employers of persons with disabilities should be subject to Garda Vetting to reduce any risk to people with disabilities in workplace settings. “Garda Vetting [should be] 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 vetting to keep our disability clients safe. Note: On-going vetting throughout the employee’s employment” (Sub142 FM). Thus, it would be useful for the Standards to ensure that vetting procedures are standardised and implemented across all stakeholders in service provision

The term 'positive risk taking' (Feature 5.1.8) requires an explicit definition and perhaps examples to support better understanding of the concept across stakeholder groups. Please refer to feedback presented in other sections of this report related to positive risk taking (definition requested p.10; intimate relationships p.10; Standard 2.5 p.25; Standard 3.1 p.31; Standard 3.3 p.31).

It may be important to consider whether there are any potential conflict between Standards and requirements of professional bodies and identifying a mechanism for resolving any issues that arise (Feature 5.1.9). One service provider group Sub372 wrote, "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?"

Standard 5.2: Staff have the required competencies to manage and deliver high quality, person-centred and reliable services and supports

Standards that addressed management and human resources were well-received by respondents. One family member summarised this sentiment stating, "Competent managers are vital to the success and atmosphere of a centre" (Sub100 FM). Another commented, "We very much welcome identification of Accredited Management Training for Front –line staff" (Sub291 SU/FM/SM).

In relation to Feature 5.2.1, an Organisation commented, "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 SP). Some respondents questioned whether others who are involved in meeting the person's needs and ensuring their safety have been overlooked in such as family members and natural supports. Here again an Organisation summarised this concern effectively stating, "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" (Sub352 SP).

Standard 5.3: Staff are supported and supervised to carry out their duties to deliver high quality, person-centred and reliable services and supports

This Standard was generally well-received by stakeholders. An Organisation commented, "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." Sub291 (SU/FM/SM) wrote, "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." Delving more deeply into the implications of Features within the Standard Sub370 (SP) commented, "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.

Standard 5.4: Training is provided to staff to improve outcomes for people using services and supports

Training of support staff was a popular topic for respondents. For example, positive behavioural supports (PBS) was raised in different ways across the dataset. Sub280 (NP) provided a thoughtful reflection in this regard. “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).”

It was recommended that a broader menu of professional development opportunities include training staff to engage in supported decision-making and to use a range of strategies to understand the will and preferences of people with complex support needs. “Training to ensure that staff members have the necessary skills to communicate with service users and parents/carers was identified as being especially important” (Sub103 FM). A range of training areas were also identified, including learning how to support people to make decisions. In particular Sub282 (SP) queried, “How do we improve decision making/access to local communities for clients with more complex needs?” In a related comment, a staff member encouraged more attention be given to the communication approaches used by people with disabilities, “Advocates and staff need to be trained in a variety of supportive communicative methods to include LAMH, Talking Mats, Blank Comprehension Levels, Key word Identification’ to elicit choice with service users” (Sub074 SM). This was reiterated by Sub353 (SP) “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.” Many respondents were concerned about how people with communication difficulties will participate in the person-centred planning process. Several approaches were offered to address this. For example Sub74 (SM) suggested that staff be provided with training in a range of communication strategies. The same respondent went on to write “Staff will review all goals, plans, information with the person. This will involve checking if the person can explain their own goals on more than one occasion to a familiar person. The person’s communication needs including supportive communication strategies should be clearly identified.”

Communication and technology are often linked, particularly when people with disabilities use alternative or augmentative forms of communication. “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 SP).

Education and training resources were identified to ensure “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 FM). Some respondents argued that all staff need to be trained to ‘the highest level’; however, others expressed significant concern that too many resources were being put into training staff at the cost of direct services and supports to people with disabilities. Based on respondents comments it seems that there is a need to strike a balance between a sufficient level of training for supporters while simultaneously centralising the support needs of people with disabilities will be a critical factor to the success of implementing the Standards.

An Organisation summarised key concerns around this Standard given that “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 U).

Theme 6: Use of Resources

Introduction to Theme 6

To review the data coded under 'Use of Resources' all segments of text coded specifically under 'Theme 6' and its constituent Standards and Features were retrieved initially. This query was followed by an additional search within NVivo10 for comments that were coded as 'timetabling', 'human resources' and 'change management.'

General Comments

Many positive comments about resources were balanced with an expression of concern in the same sentence. These comments were often structured as a statement endorsing the Theme or Standard, followed by a concern about the realities of implementation. For example, Sub313 (SU) wrote, "I think the Standards are good but in the current climate 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...as I use a wheelchair." Similarly a Sub353 (SP) contributed this balanced comment, "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." Thoughtful comments were also submitted by families, with Sub273 stating, "We welcome the overall thrust of New Directions and these Draft Interim Standards. These ambitions are laudable. Their success will require a well-resourced, skilled and supported monitoring/enforcement body."

A number of respondents used this opportunity to highlight good practice already evident in services despite what is perceived as an extensive reduction in funding by the HSE in recent years. "I know my son's centre has been very creative (in a good sense) making use of the resources available with reducing funding (Sub100 FM). Equally, service providers presented themselves as already demonstrating alignment with this Theme in their current practice. "We negotiate regional budgets in line with economic systems of work and also reflective of service users' choices and preferences" (Sub113 SP).

Comments on Standard

Standard 6.1: The use of available resources is planned and managed to provide high quality, person-centred and reliable services and supports

Remarking on Standard 6.1 Sub073 (FM) wrote, "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." Sub249 (SU) appeared to be less certain and asked, "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?”

Future Planning was recommended with emphasis placed on the necessity of effective management systems “you fail to plan, you plan to fail. A proper manager who will plan to require resources needed for all individuals and their needs” (Sub 213 NP). “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 NP). There was a clear need identified to strike a balance between a sufficient level of training—both for paid and natural supporters—and the overall costs associated with meeting the support needs of people with disabilities. In other words, supporters need enough training to provide effective services without taking too much HSE funding away from the provision of direct services.

Most comments connected with Theme 6 related to concerns about how resources would be deployed during the implementation of New Directions. This information is embedded in the upcoming section on ‘Implementation Issues.’

Theme 7 Use of Information

Introduction to Theme 7

To gather information across the dataset related to 'Use of Information' the research team initially ran a query to collect all sections of submissions coded specifically under Theme 5 or any of its constituent Standards or Features. This search was then followed by a query where all data coded as either 'access to information' or 'access to documents' was gathered from across the entire dataset.

General Comments

Family groups viewed this theme as achievable if appropriate management structures and procedures in place to support its implementation (Sub073 FM). The contents of the theme reassured respondents that a more transparent process for documenting information would be in place for organisations (Sub266 FM). Family groups demonstrated a willingness to be involved in planning and "work together" (Sub103 FM). People who use services added that "It would help our understanding of how services are run if we were included in these discussions" (Sub281 SU)

Comments on Standards

Standard 7.1: Information is used to plan and deliver high quality, person-centred and reliable services and supports

"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 SP). Suggestions were made to extend the Features. Sub370 wrote, 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." Similarly two service providers (355 and 370) felt that 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." Note that aspects of this comment may also apply to Feature 1.2.3.

Standard 7.2: Information governance arrangements ensure secure record-keeping and file-management systems are in place to deliver high quality, person-centred and reliable services and supports

Families also expressed concerns regarding the confidentiality of the personal information people who use services' and about who has access to said information (Feature 7.2.1). These concerns ranged from families alone having access to information "A family member only should have access to personal information. Family should be contacted if there is reason of concerns" (Sub142 FM).

Information documented about a person was raised in relation to Feature 7.2.3. A family member wrote, "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).

In many submissions people who use services linked the concepts of rights to the use of their personal information (Feature 7.2.6). For example in reference to Standard 1.2 The dignity, privacy and autonomy of each person are respected and promoted. Keeping information private was of utmost concern to many people who use services. “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 SU).

Service providers also indicated this was an important standard. For example, Sub385 wrote, “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.” Another Service Provider felt that the system outlined in Standard 7.1 “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” (Sub 291 SP). It would be useful to provide guidance on what and how much information must be held by service providers and who legally ‘owns’ this personal information about people with disabilities.

Implementation Issues

All stakeholder groups raised issues in relation to the implementation of the Standards, throughout their commentary on the different Themes in the Draft Standards, which related to:

- Cultural change
- Funding (including comments on individualised funding and human resources)
- Equitable assessment of support need
- Monitoring
- Unions and staff contracts
- Implementation timeframe
- Cross-sectoral collaboration
- Shared learning

Cultural Change

Underpinning many comments across stakeholder groups was the recognition that a change in culture is required within services, in communities and also in families. Sub245 (SU/SM/FM) reflected this in a profound way writing, “Community based programmes deliver better outcomes for the individual service users. From our experience to date, we have found that community based service 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 of 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 supports.” It was unclear to respondents to what extent the Draft Standards could effectively measure a ‘change in culture’ within day services.

Culture change within the community was also highlighted as pivotal to the success of New Directions. Sub275 (FM) commented, “We are all aware of the very significant policy development over the years affecting the lives of people with disabilities in Ireland. The policies were aimed at changing societal attitudes and developing our culture to be more inclusive, affecting all sectors and Services. We recognise this concentration of effort was needed to change a society where many people with disabilities grew up in institutions, disconnected from their families and the rest of the Community. This view was captured by one of the parent’s comments: It took generations to change from living in institutions to community-based Centres. It will probably take another generation to make the changes in New Directions”

There were suggestions that a national programme be developed to promote the philosophy underpinning New Directions. One family member expressed their concern this way. “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” (Sub412 FM). Respondents highlighted the need to build capacity among providers and community members to create individualised services and supports. Sub142 (FM) noted, “Assistance and support must be provided to all staff and clients of the service. This will make communication in the community work successfully” (Sub142 FM). Educating the community was identified as a priority by Sub097 (SP).

A similar point of view was voiced by a service provider, who stated, “Perhaps there needs to be a co-ordinated effort to promote New Directions with mainstream services. Local ETB’s, community development organisations etc. need to be made aware of the coming changes in the provision of services for adults with disabilities. Although services are promoting the philosophy, support on a national level would speed up the process” (Sub300 SP). Leadership in relation to national and community education was suggested to highlight the role New Directions would play in supporting community inclusion. Thus, it could be useful to connect with national initiatives that promote positive attitudes toward people with disabilities. Building on this, a family member noted that mechanisms need to be put into place to evaluate the effectiveness of initiatives to support community inclusion stating, “It would be useful to include a periodic review of how a person with a disability is engaging with the community” (Sub392 FM).

Funding

Funding was the central concern that threaded through almost every submission across all stakeholder groups. General concerns around funding will be presented first, followed by comments specific to individualised funding. Attention then turns to funding human resources.

“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 being used efficiently. With more service users entering the service there needs to be provision for extra funding” (Sub239 SP). Family members voiced a lack of confidence in the Draft Standards based on past experience. One family member expressed this plainly, saying “I have little confidence in execution capability (because adequate funding from Government/HSE will not be provided)” (Sub272 FM). The additional costings connected with monitoring the implementation of the Standards was raised by many as a significant issue and cut across all Standards. “The will need to be an injection of funds for this theme to be really successful” (Sub077 SP). It will be important to directly respond to this uncertainty. The current financial context was a focal point in many submissions. For example an Organisation wrote, “There were many concerns amongst service providers in relation to this standard [5.2] given the experience over recent years of budget cuts, the moratorium on recruitment and reductions in employment ceilings. There were many submissions where the extensive funding cuts and subsequent reductions in staffing levels were centralised. When this is combined with changing demographics of people who use services concerns deepened.

“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 SP). And a reality gained from experience “They will not work unless there is further funding which we all know is not available” (Sub293 FM). In a related concern, families wondered if in an effort to manage costs, “will service providers be able to ‘cherry pick’ the type of services they provide by putting profit ahead of people” (Sub232 FM). Families extended their concerns to services stating that there was “too much bookkeeping involved” (Sub081 FM) for people to live an ordinary life. Families were also noted that “the scope (of the consultation) too narrow” (Sub301 FM) and queried about where the funding for implementation would come from (Sub350 FM). People who use services also expressed hope that the Standards would mean a “return of our money [and] more staff in centre” (Sub064 SU). A clear desire for any inspection of services to centralise the perspectives of people who use services. “We hope that when the Standards are rolled out and inspections begin that service users will be met with and interviewed to make sure their choices are being recorded and worked toward”(Sub066 SU).

The need for financial resources to support identified plans was highlighted (Sub 249 SU Group). The direct costs of training raised concern for many respondents. “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 SP). Similarly Sub289 (SP) wrote, “The aspirations of the Standards will not be achieved without adequate additional resourcing. In particular, there will be a significant incremental operational overhead in delivery of the Standards and ongoing 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” (Sub289 SP). This was echoed by Sub275 (FM) commenting, “We believe it is quite irresponsible that the New Directions policy and Draft Interim Standards have not included realistic costings, taking account of all of the aspects outlined here. This is a job yet to be done. The roll-out of New Directions must include an investment package over the next decade which is adequate to support the development of the Centres and the activities which are identified and fostered in the Community. This latest policy development is no less a task than that of the policy/proposals of the Commission on the Status of People with Disabilities twenty years ago which was supported by a decade of investment.” Sub285 echoed these sentiments noting, “Overall, we welcome Standards for Day Service Provision they are long overdue. However, in the absence of a cohesive

approach to funding based on appropriately assessed need as a National Baseline its very difficult to apply standards when the resource allocation differs significantly from County to County up and down the Country.”

Access to Individualised Funding

‘I want to know where my money goes to? I’d like to be more involved in my funding’ (sub367 SU). The desire to actively engage in financial decision-making was raised by many people who use services. Individualised funding was raised as one option for people with disabilities and families to assume more control over budgets. “I believe that an applicant should have the right to apply for individual funding to give parents and their child what they believe is the best possible care, and what they believe they require the most. We believe that social workers should play a key role in aiding with any documentation regarding individual funding and should be knowledgeable in signposting to relevant services that parents and children with disabilities may want to partake in” (Sub108 FM). A few service providers also commented on individualised budgets with Sub291 (SP) writing, “Overall this is a good document, but the government now need a mechanism for individualised funding so we can follow this through for individuals, so they can do ordinary things in ordinary places!!” An Organisation noted, “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 Value for Money report” (Sub352 SP Umbrella).

Another related option presented was for people with disabilities to access day services from a range of providers and discontinue these if not satisfied. “People should be able to work with multiple services. People should control their own money. People should be able to move from one place to another without losing their services. People should be able to fire their services and shop for something else if they are unhappy with them. Services should be reviewed annually by the service users. These reviews should be conducted externally. People should own their own individual plan, and share them with services, rather than services owning the plans, and sharing a copy of them with the people they are about” (Sub 365 NP).

Human Resources

The main concern evident throughout the data and common to all stakeholders is “acute shortage of staff and funds” (Sub032 FM). This encompasses the moratorium on recruitment of staff and also training and up-skilling of current staff. “With current funding restrictions it is not always possible to provide the level of service and support that may be necessary” (Sub141 SP).

Human resources were a pivotal concern across all respondents, with people who use services making some of the strongest statements about the real-world implications. Many people who use services noted that in the past few years their opportunities are reduced because staff members who are on sick leave are not replaced. When staff shortages are covered by temporary agency staff, person-centred plans are rarely followed through. Service providers noted safety concerns related to resource issues and the current moratorium on recruitment of staff and future training needs of staff (Sub263 SP, Sub355 SP, Sub242 SP, Sub393 SP).

The perception of people who use services was that the HSE was responsible for the subsequent reduction in opportunities. For example Sub080 (SU) wrote, “We don’t have enough staff in adult services so New Directions will not work in our centres and you can’t blame the staff. The HSE are saying that we can’t have the staff. The HSE won’t let us replace staff when they retire, or get another job or if they get sick.” Many family submissions endorsed this position. For example Sub290 (FM) wrote, “My brother is being cared for through a Service Provider and they have been extremely professional, supportive and helpful in his daily care; however, with all the HSE financial and staffing cut-backs over recent years, the implementation of these Standards seems unrealistic and impossible for the Service Provider to deliver. Speaking as a family member and on behalf of my brother, I see the pressure of understaffing, lack of funding and resources has put on the ground staff and support teams who care for adults with disabilities. Despite their genuine commitment and dedication to their work, it is getting more and more difficult for them to do their job.”

Engaging in community-based activities and employment are long-awaited for many people with disabilities. At the same time, people who use services wondered how staffing would be managed. “We would like to know how this lovely new and exciting programme “New Directions” is going to be managed and staffed. Us as a group can see the need for more support workers in order for this to be a success – if one staff is supporting an individual in the community and they would normally be supporting six in the centre in a group, who supports the other five. Its sounds great on paper, but how is it going to be put into practice? Will it be practical?” (Sub111 SU Group).

Staffing resources for people with complex support needs was raised from a range of stakeholders. For example Sub291 (SP) wrote, “New Directions must be tailored to suit individual needs, and indeed the supports of specific groupings, which require specialised supports in specialised settings. More emphasis must be made for identifying supports for individuals who require these opportunities, and the Standards must not forget these individuals. This group of people require supports from a highly trained staff team, who have been trained in specific systems that have been identified, as both modern & conventional.”

Equitable Assessment of Support Needs

The concern around funding directly extended to the assessment of need. Many respondents queried about whether a standardised tool would be made available to promote equitable allocation of resources across all regions of the Republic of Ireland. “Standard 1.6 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 SP). Another Service Provider went on to state, “There needs to be 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 user needs x amount of support that equates to y amount of funding” (Sub385 FM).

“How will it be ensured that each service users' needs are met considering that there is a vast spectrum of individuals with varying levels of ability? How are people going to be assessed and by who? If from the assessment people can't work in the community, what happens to them and how will they be provided for? How will assessments be funded? How will users be classified according to their abilities and what actions will be taken for each level? How will people get day services if needed?” (Sub411 FM). Respondents asked for a clear response to queries about resource allocation, with the possibility of introducing national guidelines to promote equitable assessment of support needs.

Monitoring and Compliance

Respondents asked that careful consideration be given to where responsibility lies for monitoring implementation of the Standards. Families called for a demonstration of accountability that doesn't “pass the buck to others” (Sub108 FM) or “turn into a box-ticking excuse for consultation and an utterly useless waste of resources in an area where so many families are stretched to breaking point” (Sub 104 FM).

The power differential described between service providers and families/people who use services is noteworthy. One organisation suggested addressing this issue by establishing “an independent body separate from the HSE funder to address duty of care issue. Managers say they are our funders, we won't go against them despite how wrong they think it is” (Sub097 SU/SM).

The approach in these Standards provides a framework for the delivery of individualised services for people going forward that for success “will require a well-resourced, skilled and supported monitoring/ enforcement body” (Sub273 FM). It is not surprising that overseeing and measuring value for money arose in the data. For example, Sub261 (SP) noted that monitoring needed to be enacted “to ensure the Standards outlined will be realized. Staff to service user ratios need to be low enough for effectiveness” (Sub261 SP). Many others wondered whose responsibility it would be to conduct ongoing monitoring and evaluation within services. Sub359 wrote, “who will complete these audits? Is this a requirement that internal audits occur or will an external body be tasked?” Another Service Provider commented on the change in culture that New Directions could create if it is properly monitored during implementation: “I think it is the application and monitoring of the standard which will be important in making sure that the standard promotes the change in culture that New Directions articulates and does not promote the development of the existing systems and structures, albeit in a nice quality framework” (Sub 110 SP).

Respondents pointed out the need to allocate sufficient resources to document compliance with the Standards while not disadvantaging people who use services in the process. “Overall it is important that the available resources are not impacted excessively by increased administration and 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 SP). A family group reiterated this concern writing that “in order to meet Standards additional paperwork will be required and this will take form the time available to frontline supports” (Sub266 FM).

Unions and Staff Contracts

Although rarely mentioned explicitly within the dataset, issues related to unions were common. For example one respondent wrote, “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 NP). In a rare example, Sub038 (SM) unions were commented on directly. This respondent noted that Standards “discuss 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.”

Similarly, employment contracts were raised as a point for consideration. Sub355 (SP) wrote, “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.” This concern about timetabling of services was oft-mentioned by families and service providers alike, and no doubt has implications for unions as well.

It will be important to respond to extensive concerns regarding human resources. There was a clear perception across stakeholders that implementation of New Directions will require significant increases in paid support staff and also personnel to monitor implementation of Standards that the funding structure cannot support.

Implementation Timeline

One person who uses services captured the tension between many people with disabilities who are eager to follow through with New Directions and Service providers who are concerned about the implications for their organisations. “There is an order and a structure to the document but stated rights can be overwritten by bureaucrats who use fear of consequence as a means of disabling service users. For example person with a disability who independently uses services in their community at weekends are not allowed practice such independent living skills while in the services because of the fears of the O.G.A. He uses Duty of Care as his defence. The difficulty I think you face in its implementation is not from the service user or the staff. On paper it is perfect (with maybe a few additions listed below). From observation and discussion I get the impression that managers are worried while staff and clients appear excited and are looking forward to its implementation. I wish you the best in its implementation. Clients on boards of management. Amazing. Service

users developing policies. Brilliant. As a person with a disability who availed of the services and later also a Senior Instructor with a service provider I believe this to be the most positive approach that I have experienced in my 22 years in the services” (Sub097 SU).

“The content of this book doesn’t demonstrate how we can implement all of the Standards. On page 8 it makes reference to Monitoring and Implementing, from reading this section, it will take a very long time for this structure to be developed and implemented. How real and achievable are the Standards? Each person has the right to services based on the principles of person-centeredness, community inclusion, active citizenship and high-quality service provision. As a large programme area we welcome and look forward to the implementation of the New Direction Standards equally across all areas of the service” (Sub 291 SU/SP).

“Whilst the intention is good... for 60% totally aspirational and completely unrealistic” (sub 291 SP/FM). A family group submission added to this by stating, “The families were clear that timeframes for achievement of each of the Standards should be included.” (Sub266 Family Group).

A graded transition to the new model outlined in New Directions was suggested by family members. “We strongly believe that the elements that are valued by service users and carers in the existing day centres should be preserved and developed. Over a period of time progress can be made on migrating to the new vision which combines the best of the centres and community experience”(Sub275 FM). It may be useful to respond to query about the possibility of ‘phased compliance’ as an option for implementing the Standards.

Cross-Sectoral Collaboration

Although many respondents focused on individualised concerns, a number of submissions highlighted the need for cross-sectoral collaboration. For example, Sub372 (SP) wrote, “The difficulty people are having is the road map, evidence of the joined up thinking across all Government Departments in particular like Education, Environment, Health, Social protection and Finance. There is concern also about having the necessary legislative drivers to enforce the Standards when you see that Government has not fully ratified the UN convention on the Rights of People with Disabilities and still hasn’t passed the Assisted Decision Making (Capacity) legislation/bill” (Sub 372 SP).

Connections with other government departments was raised again under this Theme. “Clarification on the role of each government department in mobilising new directions” (Sub226 SP/SU/SM). A family group succinctly stated, “Above all there is a major resource issue which needs to be addressed to establish parallel systems, working together” (Sub275 FM Group).

A problem was identified regarding cooperation between departments, for example Department of Environment, Department of Health, HSE, Department of Education. For example, concern was expressed about people with disabilities not being able to

access community-based employment or volunteering schemes: “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” (Sub252 SP).

Shared Learning

Respondents noted that sharing good and creative practice regarding resource allocation across services could benefit people who use services, families and service providers across the country. It was recommended that the HSE draw upon examples of good practice from demonstration projects within Ireland. One submission highlighted this well, “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 SU/SM).

Closing Comments

“Please follow through” (Sub142 FM). This respondent highlighted how important it is to fulfil expectations by following through with implementing the Standards.

Feedback on Consultation Process

A substantial number of submissions documented comments about the consultation process itself, thus it is important to present this as a key finding in the report. While it is evident that the consultation occurred on a large scale, many respondents noted concerns with the process related to content and language within the document, timing of consultation, delivery of information and finally the active involvement of people with disabilities and families as outlined below.

Positive Comments

The multiplicity of approaches taken in disseminating the Standards to increase understanding was appreciated by people who use services. For example, people who use services noted that to ensure understanding “the video was helpful” (Sub044 SU), “focus groups” were completed (Sub390 SU) and “staff read the book to me” (Sub320 SU). Many people found the language in the easy read version of the Draft Standards was accessible. Sub107 (SU/SP) summarised the recurrent positive comments well when they wrote, “good layout; easy to understand; writing is a good size; it is good that it mentions person-centred... the pictures are clear and easy to see; pictures should be in colour; this explain well what we can expect from our service; pictures matched well with the writing.”

Concerns Expressed

Respondents expressed concerns around the consultation process itself. These are outlined below under four main headings: representation of people who use services and families; clarity and content; process of sharing information about Draft Standards; and timing.

Representation of people who use services families

The composition of the Working Group was raised as a concern by families, people who use services and service providers. The lack of representation of people who use services and of families in the Working Group repeated surfaced across the dataset. One family member requested directly to be involved in the implementation process. "I believe that parents should be on any committee generated by New Directions. I would also like to formally request to join the local branch of the New Directions, and would like to be informed in full of how to complete this process. I cannot emphasise enough the importance of having a parent on this committee is" (Sub108 FM).

Although most comments made about membership of the Working Group were raised by families, a few significant submissions highlighted the need to include people who use services in the Working Group as well. One respondent summarised this point effectively. “While it is noted that a consultation process was undertaken with people who use current adult day services in the formation of the Interim Standards it is highly regrettable that such persons have not formed part of either the National Implementation Group or the Sub-group established by the National Implementation group. As outlined in theme 2 the requirement of an effective service is that ‘People are involved in the planning, design, delivery and monitoring and evaluation of

services.’ It is proposed that such Standards should be applied from the outset so that people with disabilities are the central driving force instead as a group only to be consulted” (Sub 291 SU/FM/SM).

Concerns were also expressed about the lack of balance between urban and rural regions of the country in the Working Group. For example Sub411 (Family Group) wrote, “From looking at the membership of 'Sub Group 2', all of these people seem to be based in Dublin. Why is there not a mix of people from all over the country rural and urban?”

Clarity and Content

The length of the documents—both easy read and full versions—were commented on by many respondents, noting that it was ‘too much information’ to review in a short timeframe. That said there were very few submissions that suggested any of the Standards be reduced or merged. The intent appeared to be using fewer words overall. Linked to this is the use of complex language.

The use of legalistic and professional jargon within the document raised the issue of clarity from a number of respondents. This was evidenced by comments such as, “You would need a lot of time to decode it. It could have been written in ten short simple pages instead of 87 pages of legal/political jargon” (Sub291 FM/SP). The same respondent went on to say, “the easy read document was very informative for the service user but there was a lot to take in and staff had to break it down to simpler terminology in order for the service user to understand” (Sub291 FM/SP).

The use of images was well-received overall; however, it seemed that particular images within the easy read consultation sheet were taken literally. This distracted people who use services from the meaning of the Standard. For example, one group of service users commented that the wheelchair in one picture could not possibly get through the doorway in the building. They commented on the image without reflecting on the intent of the standard. Others expressed concern about the images being difficult to interpret, while others reported that the pictures were childish (referring to the happy/sad faces on the easy read response sheet). Hearing a message and understanding was challenging for a large number of people who use services, even with the pictures. For example, Sub284 (SU Group) reported that there was ‘too much writing, [we] don’t understand the pictures.’ To make the easy read document more reader-friendly, a group of service users suggested a maximum of 3 images per page. A service provider added, “The group think that the document should be addressed to them personally so change ‘they’ to ‘you’. Did not understand all the words; some need to simplified so anyone can understand” (Sub291 SP).

The heavy reliance on text was raised by others, with one person commenting, “couldn’t focus on book due to visual impairment, but listened to staff discuss book and how it will help my life” (Sub313 SU). Recognising that Ireland is a country where many languages are represented, queries were raised regarding whether the Draft Standards could be available in other languages. For example, Sub311 (SU) wrote, “I

speak Polish at home with my parents, so did not understand most of the spoken word, but used gestures when staff pointed to the photos. Could it be written in Polish so my parents could explain it to me, and so they could understand it too?" Another respondent commented that it is necessary to provide each person "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 FM).

Language emerged from the data challenging at times primarily for people who use services and family members. This appeared to be related to promoting understanding of the document as opposed to the Standards themselves. Clarity regarding terms while outlined in the glossary, appeared at odds with language used on the ground for example "the word 'Service provider' is very confusing for people supported, none in fact understood it. [They] suggested 'organisation' could be used in place of 'service provider'?" (Sub109 SU).

Support staff commented on the need to translate complete sections of the easy read Standards and the Powerpoint slides that were made available online. "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 SU/SP).

Process of sharing information the Standards

There were numerous expressions of discomfort regarding the public information meetings made regarding the Draft Standards. One respondent's comments created a vivid image. "I attended a meeting on the 10th September at Radisson Blu Hotel. I was as well informed coming out as I was going in. 'New Directions' sound very nice but why change if people are satisfied with the present situation? No names introduced. Gents in their suits holding folders tightly to their chests and young ladies smiling happily holding documents with HSE logos on their headings" (Sub 411 FM). Criticism on the information meetings was widespread in the submissions, particularly in relation to causing significant alarm for people who use services, families and service providers alike. A parent wrote, "My son has great difficulty making decisions. He gets upset. I'm afraid that it's likely that individuals will be overlooked in implementing this strategy. We all want their lives to be as normal as possible but that does not necessarily mean independence. I would not like to see him cut adrift" (Sub275 FM). "Many families are unsure about the New Directions and appear nervous to embrace change...They do not see it as a change coming from the HSE and spreading throughout all of the disability services. We need to educate and tackle this misconception" (Sub226 SP). Another family member commented, "While the meeting and the lady who called it, were both very good. I found it all very involved, very drawn out and the language quite unclear, both meeting-wise and

in your lay-out which we were given on the night and which I have it got through yet” (Sub206 FM).

The information chain was complex in this public consultation. The public presentations attracted many service providers and families and people who use services. Service providers were asked to go back to their organisations and share the Themes and Draft Standards with others. Many submissions from people who use services were written by supporters—whether natural supports or paid staff. The feedback forms asked for the respondent’s name (optional) but did not ask whether the respondent was completing the form on their own or with support, as an individual or as a group. This information would be very useful when interpreting the comments made. Additionally, it was apparent in many responses from people who use services that they were answering different questions than the ones in the feedback form. As with any consultation, the extent to which this translating of information is accurate and represents the intention of the consultation would be useful to acknowledge as a limitation of the process.

Timing

Six weeks may appear to be a substantial period of time to seek engagement from the public, however respondents disagreed. “This rushed processed was not designed to communicate effectively with people themselves in a format the majority could understand without an intermediary facilitator” (Sub281 SU). Another noted, “I think it is an on-going thing I need to understand and have this booklet explained over a long period of time not just in a day” (Sub340 SU).

For some people, due the complexity of the Standards and in-depth nature time presented an additional challenge. “Standards were not discussed in depth. We have only had time to examine 25 Standards in Themes 1-3” (Sub242 SP). Considering the importance of such changes questions arose in relation to the “number of people who are aware, never mind understand, what ‘New Directions’ is about is relatively very small. There has been no attempt at national level to communicate in simple terms what the Value for Money Report, and now the New Directions Report, are all about” (Sub272 FM). Given that New Directions is grounded in effective communication, it was argued that future consultations may require more creative and longer consultation periods.

Concerns about Potential Consequences of Standards

Standards were viewed as a threat to many respondents who do not want things to change. There was evidence of mistrust from some families in the data regarding the motivation for these changes. "It seems to me a mechanism for cost cutting by keeping individuals away from day services with them operating primarily from home for an increasing number of activities" (Sub272 FM) and also of the true implications, with fear that the move toward less centre-based supported services will result in less time where their family member is meaningfully engaged away from home (Sub275 FM). People who use services and parents were concerned that the current arrangement will be taken away from them, without a suitable and freely chosen alternative provided. "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 NP).

A substantial number of people who use services were concerned that their friendships would be disrupted when the Standards are implemented. They wondered if services being community based and more individualised would mean that they wouldn't get to spend as much time with the people that have become central in their lives. Sub111 (SU) wrote, "Some of us had a concern that if New Directions were to become so individualised would certain individuals become or feel isolated from their peers, therefore find it hard to build new relationships with new peers they may not see on a regular basis as they would do whilst attending at a regular day centre." Respondents sought reassurance that their friendships would not be in jeopardy.

Others expressed concerns about how the Draft Standards would impact current day services and employment opportunities. For example, Sub048 (SU) wrote, "I would be worried that being out away from my centre would lead to it being closed down. This I would hate because I would not have the security of knowing that I have somewhere to go if everything falls apart. I would also miss meeting up with my like-minded friends which would make me feel lonely and isolated. I would also worry about changes leading to cuts in my wages, allowances etc. I would have liked a bit more detail about what information they were looking for from us and the repercussions of these new directions."

'Falling through the cracks' came up as an unintended consequence for many families, particularly when people who use day services also experience mental health difficulties. Sub071 (FM) summarised these concerns effectively, "I am the parent of an adult with I.D. Reading through the document I cannot see how it would suit my daughter. The saying 'one shoe fits all' cannot apply to all adults with I.D. My daughter has epilepsy and Bi-polar affective disorder... There is no way your model would fit into her life as is it now. Not only does she need 24hour supervision. Her Bi-polar can affect her on a daily basis. For her to have any connection with the

community would be impossible. My fear with your documents is that people like my daughter would fall between the cracks.”

Concerns were also expressed about the conflation of day services and respite care. This was highlighted in the following quote, “Many families viewed day services as an extension of Respite” (Sub412 FM), hence the focus on having consistent 9-5 access. This insight raises questions about the tension between family-centred services and individualised or person-centred services. This is a key issue that will need to be resolved as New Directions moves forward.

Resistance to the changes within New Directions was evident in the alternative interpretation of choice was presented by Sub067 (NP), one that sought to endorse maintaining existing day service structures. “As acknowledged by the Standards, the community of adults with disabilities in Ireland is one made up of individuals with a wide, wide range of capabilities, desires and dreams. And whilst they hold out the hope of new opportunities for some, and refer to the right of individuals to refuse a service or some element of a service and to exit a particular service in favour of another one, the Standards needs to say more about the protection of existing centre based services for those who choose to avail of them.” Many respondents emphasised how integral families and natural supports are to the success of New Directions, yet these supports are not mentioned. For example, Sub397 wrote, “the Draft Interim Standards put the onus on the Service Provider to support the individual in all aspects of their life, with no requirements placed on natural supports, the wider community or the appropriate mainstream providers.”

It was also noted that people who use services and families will need to be supported throughout the change process. Sub397 (SP) commented, “the fears and anxieties arising from these proposed changes to people’s current service are acknowledged and responded to by the HSE and the Department of Health, in order to build the much sought after trust and confidence in future service changes to come.” Sub393 (SP) provided a thoughtful recommendation writing, “Families are looking for reassurance that the implementation of these standards does not mean less service/supports for their son/daughter/sibling. We all have a role to play in reassuring families in this area. There is fear and anxiety that centres will be shut and services closed. We need to do a better job around assuring people that this will be an evolution of services person by person, rather than a cutting back or rationalising of supports. Perhaps some reassuring words to this effect could be embedded into the introduction/principles section, as well as carefully crafting that message in the roll out once the standards are finalised.”