



Department of
**Health, Social Services
and Public Safety**
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LEARNING DISABILITY SERVICE FRAMEWORK

SUMMARY OF CONSULTATION RESPONSES

Working for a Healthier People



INVESTOR IN PEOPLE

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1. INTRODUCTION

1.1 The aim of the Learning Disability Service Framework is to improve the health and wellbeing of people with a learning disability, their carers and their families by promoting social inclusion, reducing inequalities in health and social wellbeing, and improving the quality of care.

1.2 The Learning Disability Service Framework sets standards in relation to:

- communication and involvement in the planning and delivery of services
- children and young people
- entering adulthood
- inclusion in community life
- meeting general physical and mental health needs
- meeting complex physical and mental health needs
- at home in the community
- ageing well
- palliative and end of life care

1.3 The framework also includes generic standards relating to communication, health promotion / disease prevention, and palliative care. These standards apply to all service frameworks, and were themselves subject to a recent review. All comments received in this consultation relating to generic standards were separated and informed that review. The updated generic standards have since been inserted into the Learning Disability Service Framework.

1.4 The core values outlined in the Equal Lives Review (2005) have been adopted in full in the development of the Learning Disability Service Framework. These core values when enshrined in practice will ensure that independence is promoted for all people with a learning disability.

2. CONSULTATION PROCESS

2.1 The Learning Disability Service Framework consultation document was launched by Ministerial Press Release on 12 December 2011.

2.2 A consultation team, made up of Departmental officials and Learning Disability Service Framework Project Board representatives oversaw the public consultation exercise. The launch was accompanied by the distribution of 420 hard copy invitations to the Department's Equality & Human Rights consultation list in line with best practice. In addition, targeted invitations were issued to key stakeholders encouraging organisations to seek and include the views of service users in their organisational response. The consultation was promoted, and participation encouraged, through Departmental/ HSC websites and membership schemes as well as the MENCAP Annual Conference.

2.3 In recognition that the service users' perspective is essential in getting this Framework "right" the consultation team actively sought to provide as many opportunities as possible for feedback, taking account of people's particular needs. In all, there were five consultation events facilitated by the Patient & Client Council (PCC) and the Association for Real Change (ARC(NI)) which brought together, and acquired the views of, learning disability service users (including carers and families) and providers.

2.4 The consultation closed 12 March 2012. A number of requests for extensions were accommodated.

3. SUMMARY OF RESPONSES

3.1 Respondents to the Learning Disability Service Framework consultation represented interests from a wide range of health and social care, community and voluntary organisations as well as from service users, carers and service user groups/ representatives.

3.2 A total of 75 responses to the consultation were received. This included 34 organisational responses and 41 individual responses. While many (25 respondents or 33% of overall respondents) provided their response using only the questions set out in the consultation questionnaire, others provided theirs in a more free format, for example, commenting on individual standards. In addition to the formal responses received, the views of approximately 65 service users (including carers, parents and support staff) expressed at the 5 consultation events, across Northern Ireland during the consultation process, were also taken into account.

3.3 Respondents were largely welcoming and supportive of the Framework and its associated Standards. Many valuable comments and suggestions have been received both concerning revisions to standards and indeed in some cases suggestions for additional standards and Key Performance Indicators. Respondents have also suggested possible gaps in evidence and reference material and have highlighted policy developments in other sectors regionally and nationally that may impact on the standards in the Framework, such as education. Other comments relate to the production of the final Framework document, implementation issues and the need for an “easy read” version as opposed to the “easy access” version (or “plain English” version) provided during the consultation to better meet the needs of the learning disability population.

3.4 All comments relating to the Framework were considered by the Project Team and Departmental Policy and Professional Leads and amendments to the

Framework and Policy Screening were carried out as appropriate. Comments received relating to the implementation of the Framework will be shared with the commissioning body. Other comments concerning generic standards and the needs of children and young people have been used to inform the further development of the Service Framework Programmes suite of generic standards and the Children and Young People Service Framework respectively.

3.5 A list of respondents is set out at Appendix 2.

3.6 Section 4 of this document provides a summary of the responses to the consultation questions as they appeared in Part A (general feedback) of the questionnaire. Under Q9, it includes general comments received under Part B and in free format. Section 5 provides a summary of the responses received in relation to Part B. Feedback relating to specific standards and comments received under Part A, Q9 or in free format relating to specific standards are recorded in tabular format at Appendix 1.

4. QUESTIONNAIRE - PART A RESPONSES

Q1. Please indicate (by sliding scale) your views on the following statement:

In general the language and organisation of the document is easy to follow

There were 24 responses to this question. 1 respondent strongly agreed with the statement, 22 agreed and 1 strongly disagreed.

Those who agreed and strongly agreed with the statement commented that they found the document to be well laid out, clear, concise, easy to follow and well referenced. Some commented that they found the colour coding and glossary of terms made it easier to follow and aided understanding. Others found the document easy to use and navigate particularly the easy access (web-based) version.

For some, the language is straightforward and user friendly and for others the wording and terminology used make it too complicated and difficult to understand. Whilst the easy access (web-based) version was welcomed, 20% of respondents called for the development of an 'easy read' version to meet the needs of the learning disability population. This call was reiterated at 3 of the 5 public consultation events.

It is noted that some respondents found the consultation questionnaire difficult to follow.

Q2. Please indicate (by sliding scale) your views on the following statement:

The standards covered by the service framework are important for people with a learning disability

There were 25 responses to this question. All 25 agreed (16 strongly agreed) that the standards covered by the Framework are important for people with a learning disability.

Respondents were of the opinion that the Framework is very comprehensive and covers the full lifecycle addressing the core services and life issues affecting people with a learning disability. Recognition within the Framework of issues, such as, health and ageing, parenting and relationships was welcomed. It was suggested that the generic health promotion/ improvement standards were no less important to the families, carers and health and social care professionals providing the services.

One respondent proposed the inclusion of an additional chapter to expand on draft Standard 13 (*meaningful relationships*). It was suggested that this draft standard placed little emphasis on sexuality, sexual health and issues, such as, consent relating to sexual relationships. There were also suggested gaps in standards including: dysphagia, autism, transition planning (for retirement and moving into adult services) and the management of vulnerability and risk.

There was some disappointment regarding the number of instances in which the anticipated performance levels for specific standards focus mainly on the establishment of baselines. In addition, some respondents would have preferred to have seen a greater focus on performance outcomes that relate directly to standards of care for people with a learning disability.

Q3. Please indicate (by sliding scale) your views on the following statement:

Overall this framework will provide an opportunity to help set priorities for commissioning learning disability services

There were 23 responses to this question. 6 respondents strongly agreed with the statement, 15 agreed, 1 strongly disagreed and 1 disagreed.

Whilst respondents were, in the main, in agreement there were concerns registered about funding, the need to prioritise standards, the delay caused by having to first establish baseline positions, how the Framework would link with other policies/ strategies and commissioning arrangements in their totality across the HSC.

One of the two respondents who disagreed (and strongly disagreed) with the statement felt there was insufficient detail provided within the Framework to facilitate commissioning. The other felt that the Framework should “*inform but not set the priorities for commissioning.*”

Q4. Which of these standards will have the greatest impact on the health and well being of people with a learning disability, and why?

There were 24 responses to this question.

Respondents (using the questionnaire) found it difficult to identify any one Standard that would have a greater impact on the health and well-being of people with a learning disability over all others. Other respondents indicated difficulties in identifying or prioritising the relative importance of all the standards. Broadly, all Standards were considered equally important. Respondents felt that the ability

to prioritise would depend on the needs and the perspective of a particular individual/ group.

Equality Implications

Q5. Having considered the outcome of the screening exercise do you think these standards will have any adverse impact(s) on any group of people in terms of the nine quality dimensions? If yes, please comment on how any adverse impact could be reduced.

There were 25 responses to this question. Of these, 3 respondents believe the standards will have an adverse impact(s) on particular groups of people in terms of the nine quality dimensions. These adverse impacts are as follows:

- people with learning disability will not have equal opportunity if they do not have equal access to the skills of occupational therapists;
- some people with a learning disability may not be able to access mainstream services by virtue of the degree of their intellectual and social functioning; and
- the Framework fails to consider the multi identities and communities that people with a learning disability are part of and consider the mitigating measures that need to be put in place to address the multiple disadvantage and exclusion they experience.

There were no suggestions provided on how these adverse impacts could be reduced.

Q6. Are you aware of any indication or evidence that the standards may have any adverse impact on equality of opportunity or good relations? If yes, please state the reasons why and suggest how these might be mitigated.

There were 25 responses to this question. Of these, 3 respondents said they are aware of indications or evidence that the standards may have any adverse impact on equality of opportunity or good relations. The reasons why are as follows:

- the Framework does not include information about the need to provide accessible information;
- the relationship between the psychiatrist and the person with a learning disability can be adversely affected by the same psychiatrist being involved in parenting assessments; and
- the lack of disaggregated data adversely impacts on the promotion of equality of opportunity and the avoidance of discrimination.

There were no suggestions provided on how these might be mitigated.

Q7. Do the proposed standards afford an opportunity to promote equality of opportunity and/or good relations? If yes, please outline your reasons.

There were 25 responses to this question. Of these, 20 agreed that the standards afford an opportunity to promote equality of opportunity and/or good relations.

The reasons given include:

- equality of opportunity is clearly woven throughout the Framework;
- the standards facilitate and promote the values contained in Equal Lives and support equality of opportunity and inclusiveness e.g. equitable access to generic services;
- the standards provide a clear accountable framework and a process with clear performance outcomes and measures of outcome(i.e. citizenship);

- there is real opportunity for multi-disciplinary, interagency, service user, family/carer working to improve the service user /stakeholder experience;
- the standards includes generic standards and the promotion of access to mainstream services;
- provides for more equity of services to a section of the community historically disadvantaged;
- each standard is person centred with performance measures that require monitoring regionally;
- the standards afford the opportunity for the person with a learning disability and their family to be actively involved in decision making about their individual health and social care needs; and
- the standards propose to provide increased choice, control and advocacy services in both community and hospital settings.

Q8. Are there any aspects of these standards where potential human rights violations may occur?

There were 25 responses to this question. Of these 4 respondents believed there was potential for human rights violations to occur. These include:

- access to appropriate services, such as, occupational therapy;
- a person-centred approach is excellent but it ignores the fact that some people with a learning disability cannot know what suits them;
- presents many challenges for HSC organisations in providing services to people with a learning disability; and
- the standards do not fully comply with the requirements outlined in UN Convention on the Rights of Persons with Disabilities (UNRPD) or the UN Convention on the Rights of the Child (UNCRC).

Q9. Any further comments, recommendations or suggestions

Respondents used this question to provide general comments many of which included comments on specific standards. Where this has occurred, the comment, recommendation or suggestion has been included in the Table at Appendix 1.

A sample of other comments, recommendations and suggestions received are as follows:

- in order to be effective and cohesive the Framework must be linked to all relevant strategies;
- funding needs to be allocated to vital front-line services; and
- needs more robust inclusion of the community and voluntary sector partners and a stronger emphasis on collaborative cross-departmental application.

General comments received under Part B of the questionnaire and in free format are summarised as follows:

Concerns were raised in relation to resources, specifically, affordability. While it was accepted that many of the standards could be achieved within existing resources it was felt that additional resources would be needed to deliver on others. Some felt that given the current economic climate this might not be possible.

A number of respondents felt that the achievement of many of the standards depended on the involvement of, and close partnership working with, other government departments and agencies, particularly in relation to housing, education, employment and benefits. It was also suggested that the importance of workforce development and effective leadership cannot be overestimated in

terms of achieving the aims of the Framework and, as such, requires monitoring to ensure these aspects of the out-workings of implementation are robust.

There were concerns raised about the relevance of key performance indicators and the need for these to effectively measure the achievement of the standards. For example, one respondent highlighted that the performance indicators attached to Standard 21 centre around access to mainstream services which they believe is inappropriate and unnecessary for many service users and should actually focus on screening, assessment therapeutic interventions and the skills and competence of staff.

5. QUESTIONNAIRE - PART B RESPONSES

Q(i). Please indicate (by sliding scale) your views on the following statement:

It was easy to locate my specific standard/ section of interest in the Framework

There were 18 responses to this question. Of those, 17 respondents agreed and strongly agreed (9 and 8) that it is easy to locate their specific standards/ section of interest in the Framework.

Respondents felt that the Framework was well structured and that the inclusion of the Table of Contents and the Summary of Standards at the outset assisted here. In addition, despite the length of the Framework, the colour coding and the use of Chapters eased navigation.

Q(ii). Are you aware of any key evidence or other information which is missing, and which would alter the nature of a particular section/ standard?

There were 18 responses to this question. Of those, 7 respondents stated they were aware of key evidence or other information missing from the Framework in their specific areas of interest which they consider should be included. These include the following:

- Occupational therapy and people with learning disabilities – findings from a research study (Lillywhite & Haines, 2010)
- The Autism Act NI, 2011
- UN Convention on the Rights of Persons with Disabilities (UNRPD)
- The NI Oral Health Strategy (DHSSPS, 2007)
- Early Diagnosis of Dementia for Individual with Down's Syndrome (SEHSCT)

- The draft Mental Capacity legislation
- The Strategy for the Development of Psychological Therapy Services (specifically, the stepped care model) (DHSSPS, 2010)
- NI Children's Strategy (OFMdfM, 2006)
- Review of Special Educational Needs (SEN) and Inclusion (DENI, 2012)

Q(iii). Please indicate (by sliding scale) your views on the following statement:

The performance indicators and the expected performance levels are reasonable, and they will help progress towards achieving the overarching standards

There were 18 responses to this question. A greater number of respondents agreed and strongly agreed (12 and 1) with the statement as it relates to specific standards. Two respondents provided mixed responses: one indicated that they agreed with the statement for some standards and disagreed with it for others and the other, whilst agreeing with the statement for some standards, neither agreed nor disagreed for others. Two other respondents neither agreed nor disagreed with the statement.

Those who disagreed and strongly disagreed (3 and 1) believed that the key performance indicators need to be more specific and more ambitious in order to bring about changes required. Comments about specific performance indicators are included in the table set out in Appendix 1.

Q(iv). Please indicate (by sliding scale) your views on the following statement:

I plan to use the/these standards to improve my practice, or services for people with a learning disability

There were 15 responses to this question. The majority of respondents agreed and strongly agreed (7 and 4) with the statement.

One respondent felt that the absence of any specific reference to their services made it difficult to see how these standards could be used to improve their practice or service. A number of respondents found that many of the standards set out in the Framework represented existing statutory requirements and best practice and therefore the formal publication for implementation would assist in further improving practice and/or services. Others believed the standards to be aspirational and that without funding were not achievable.

QUESTIONNAIRE - PART B RESPONSES TABLE (SPECIFIC STANDARDS)

STANDARD	RESPONSE
COMMUNICATION & INVOLVEMENT	
<p>Standard 1</p> <p>People with a learning disability should be involved as a matter of course in making choices or decisions about their individual health and social care needs. The views of their family, carers and advocates should be taken into account in the planning and delivery of services, unless there are explicit and valid reasons to the contrary agreed with the person.</p>	<p>Needs to be linked to citizenship and service user involvement</p> <p>Occupational therapists and other allied health professionals can be key in ensuring communication and involvement but there is no mention of this.</p> <p>Suggested rewording: People with a learning disability should as a matter of course make choices or decisions about their individual health and social care needs. This needs to be balanced with the individual's capacity to make such decisions and then the views of their family, carers and advocates should be taken into account in the planning and delivery of services; unless there are explicit and valid reasons to the contrary agreed with the person. It should also be noted that capacity should be treated as decision specific.</p> <p>Concerned at the narrow focus on HSC services when describing this standard. Suggest that it should reflect the reliance of people with a learning disability on HSC professionals, including social workers and GPs for information and support to access other services and rights including benefits, housing, education, transport etc. We suggest, too, that the key role played by HSC professionals in demonstrating need for support from other agencies such as Education and Library Boards in relation to statements of educational needs, DRD in relation to the half price smart pass for public transport or NIHE in relation to housing adaptations and housing need.</p>

<p>Standard 3</p> <p>People with a learning disability should be helped by HSC professionals to develop their capacity to give or refuse informed consent</p>	<p>Needs to include voluntary, community & independent sector delivery partners</p> <p>Suggest that explicit reference is made to both the requirement to pursue best-interests decision making when the service user lacks capacity, and the interim governance arrangements for individuals who are in the 'Bournewood gap' (European Court of Human Rights judgement in the 'Bournewood case' of HL VS UK, 2004. App no 45508/99; 40 EHRR 761).</p> <p>Would like further definitions of which HSC professionals should be helping people with learning disabilities develop their capacity to give or refuse consent. As the new capacity legislation is developed, it will be key to understand how this will relate to people with learning disabilities.</p> <p>The KPIs need to ensure they are measuring the Standard (e.g. evidence of consent or capacity assessment within documentation)</p> <p>Should be revised to reflect the requirements of Article 12, UNCPRD. Suggest that the standard and KPIs should reflect the extra help, including advocacy support, that people with learning disability need and should be provided with to develop and enhance their skills and ability to make informed decisions. We suggest, too, that this standard should reflect the important role played by education in supporting young people to develop their decision making skills whilst at school.</p>
<p>Standard 5</p> <p>People with a learning disability should receive information about</p>	<p>The delivery and implementation partners should include all central government departments and all other public authorities.</p>

<p>services and issues that affect their health and social wellbeing in a way that is meaningful to them and their family.</p>	<p>I would like a leaflet telling me about different services.</p> <p>.</p> <p>I like to know about what is available in easy read versions and big booklets for staff so that we can talk about it.</p> <p>Suggest that KPI2 needs to recognise that “signposting” by itself is unlikely to be sufficient to ensure equal access to mainstream services. In addition, we suggest that the KPIs should reflect the importance of HSC staff having access to up to date and accurate information and the necessary skills to help people with a learning disability find and understand information about public services that are available in their area as well as extra support to access them.</p>
<p>Standard 6</p> <p>People with a learning disability, or their carer, should be able to access self directed support in order to give them more control and choice over the type of care and support they receive.</p>	<p>Believe that an individual budget directive should be presumed as part of this standard.</p> <p>To increase the use of Direct Payments there is a need for additional staff resources. Professional’s concerns about how Direct Payments will work with duty of care, training issues, reviews and equipment and maintenance will need to be addressed.</p> <p>Suggested addition to Standard: People with a learning disability, or their carer, should be able to access self directed support in order to give them more control and choice over the type of care and support they receive and increased support from community learning disability multidisciplinary teams in order to be able to access such self directed support.</p> <p>It should be noted that self directed support such as Direct Payments can be difficult for people to deal with and so while it is self directed it is important that support in accessing such help is available to everyone as necessary.</p> <p>Suggest that there should be a KPI linked to the transition process, particularly in situations where a young person whose family carer manages their Direct Payments moves to adult services. In addition, there should be a KPI reflecting the extent to which people with a learning disability and family carers are supported to develop their skills and expertise on managing self directed support.</p>

<p>Standard 7</p> <p>People with a learning disability using learning disability services have access to advocacy services in both community and hospital settings.</p>	<p>Include KPIs on numbers of recipients of advocacy services, breakdown of case type and so on.</p> <p>There is lots of confusion around advocacy; this needs more than just representation. At present it appears to be an umbrella term with very few people having an in depth knowledge of what this exactly entails. There needs to be a clear identification of each type of advocacy. Self Advocacy, Peer advocacy, group advocacy and citizen advocacy (this kind of advocacy is probably the most complex; it is based on a very unique and special relationship. This kind of advocacy is extremely specialised and requires extensive training, and as a result requires heavily funded). Advocacy should be independent, therefore it should be provided by the independent/voluntary sector, and not by a member of the person's family.</p> <p>The words 'should' and 'independent' are inserted as follows: People with a learning disability using learning disability services should have access to independent advocacy services in both community and hospital settings. It should be noted that independent advocacy is required by both people with a learning disability and by their carers.</p>
<p>CHILDREN & YOUNG</p>	<p>PEOPLE</p>
<p>Standard 8</p> <p>From the point at which concerns are raised that a child or young person may have a learning disability, there is an action plan in place to determine the nature and impact of the learning disability.</p>	<p>Many young people in schools or units for children with moderate learning difficulties have an unrecognised/undiagnosed learning disability which impedes their ability to achieve a successful adult life. The issue of learning disability often only comes to the attention of services a number of years after the young person has left school and has at times engaged in risk-taking behaviour (Morrison <i>et al</i> 2010). It is therefore likely that many young people with moderate learning difficulties would, as part of their Transition Planning, benefit from referral for assessment to determine whether they met the criteria for diagnosis of a learning disability.</p> <p>Standards 8 – 11 (Children & Young People) The rights and best interests of children must be mainstreamed throughout other standards. For instance, where standards are coded as also applying to children, indicators and performance levels should detail child centred criteria.</p>

	<p>Examples of this include that advocacy provisions associated with standard 7 must provide dedicated support for children, that standard 21 in regard to those who experience mental health difficulties is applicable to child and adolescent mental health services and that access to appropriate support for those in the justice system includes protections for children across youth justice in standard 27.</p> <p>Standards 8 -11 (Children & Young People) would benefit from an acknowledgement of the role played by schools and ELBs in the assessment, intervention, support and onward referral of children & young people who may or do have a learning disability.</p> <p>Standards 8 – 11 should be amended to reflect UNCRC requirements and to monitor satisfaction with interventions put in place, as well as the assessments carried out, ensuring that are appropriate and suitable to children and young people with a learning disability and their families. In addition, KPIs are required to reflect the role played by HSC staff in facilitating equal access to and benefit from the range of public services, including education, available to others in their community. KPIs for each standard should measure the numbers of babies and children involved in the process of diagnosis, the percentage provided with early intervention support; the percentage of parents/family carers aware of the assessment and intervention processes and provided with a copy of the action plan and support plan; and the percentage of parents/family carers offered and satisfied with their key worker and the support they provide; the percentage of parents/family carers offered and provided with advocacy support and the percentage of parents/family carers offered and satisfied with their carers assessment. Disaggregated data should be produced for the numbers of children and young people with profound, multiple or complex health needs.</p> <p>We are particularly surprised that there are no KPIs around the role of HSC staff in supporting young people with a learning disability to become confident men and women, aware and supported to engage in strategies to respond to incidents of bullying and hate crime; supported, wherever possible, to understand the impact of their disability and the adjustments they should require public services to make to meet their needs and comply with equality, DDA, UNCRC and UNCRPD requirements.</p> <p>Standard should reflect the different terms used throughout the different stages and processes involved in the diagnosis of learning disability so that delays in diagnosis do not result in</p>
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	<p>delayed interventions when there is clear evidence of need.</p>
<p>Standard 9</p> <p>Children and young people should receive child-centred and co-ordinated services through assessment to ongoing care and support from the point at which a determination has been made that they have a learning disability.</p>	<p>Children with challenging behaviours should be offered early interventions to prevent difficulties escalating as they get older and move into adulthood.</p> <p>Suggested rewording: Children and young people should receive child-centred and coordinated services through assessment to ongoing care and support from the point at which a determination has been made that they have a learning disability. Such support should include age appropriate and timely respite care as required.</p> <p>A KPI re respite should also be included.</p>
<p>Standard 10</p> <p>HSC services should respond to the needs of children and young people who have a learning disability and complex physical health needs in a manner that is personalised, developmentally appropriate and which support access to appropriate care.</p>	<p>Who decides on the effectiveness of transition arrangements (KPI 2 refers)</p> <p>Multi-professional assessment should include occupational therapy & other AHPs</p> <p>Should KPI reference the level of contact with the key worker rather than whether or not the person's name is known?</p> <p>Further KPI suggested: 'Percentage of children and young people with a learning disability with complex physical health needs who have effective transition arrangements in place between children's and adult services including for school leavers' 'Entering Adulthood' is cited at Standard 15, however we feel it is very important that children and young people with a learning disability who also have complex physical health needs are</p>

	afforded a key performance indicator for their transition to adulthood in keeping with the Bamford principles.
Standard 11 Any child or young person who cannot live at home permanently should have their needs addressed in a way that takes full account of their learning disability.	Should state that people with a learning disability who can't live at home should have access to specialised placements within their local community if they or their family so wish. Suggest that KPIs should capture the range and accessibility of placements appropriate to children and young people with a learning disability, the numbers and percentage of children and young people with a learning disability who cannot live with their families and who are offered foster care arrangements and the duration and number of such arrangements.
ENTERING ADULthood	
Standard 12 Young people with a learning disability should have a transition plan in place before their 15 th birthday and arrangements made for their transition to adulthood by their 18th birthday.	This standard may need to be rewritten in light of the recent proposals to reform the Statementing Process. KPI 1 is not appropriate as there currently is a statutory duty to have a transition plan in place therefore this indicator is measuring failure to comply. Standard 12 – The transition plan will not be fully developed at 15 years however the process to deliver a plan should be activated. KPI 3 is misplaced and should not be included here. As this is the only standard relating to transition, it needs to be stronger and more inspirational. Feedback could be collated from service users and carers post transition in order to increase and develop more appropriate opportunities. School occupational therapists and physiotherapists have little involvement in later school years meaning that transition plans can be unrealistic for service users and are based mainly on an education report. There are unrealistic expectations of what level of support is available after school. There is a need for greater multidisciplinary team involvement in planning at all stages between 15 – 19 years of age. More AHP transition workers are needed with additional community alternatives to day

	<p>care, offering varying degrees of support and skill development.</p> <p>The document does indicate that Frameworks are evolutionary; we would have concern that a Transition Plan developed at age 15 would remain the same until aged 18. Surely this will also need to be evolutionary?</p> <p>Transition should extend from between 15 years old and 25 years old rather than 15 - 18 years old. A young person's transition between the ages of 15-18 will look very different as that of 18-25. Maybe looking at having a Transitions review between 18-25?</p> <p>Responsibility for delivery should also include DE and DEL</p> <p>Suggest that the involvement and satisfaction of young people with the plans produced, the arrangements put in place and their access to advocacy support should be reflected in the KPIs. We suggest, too that the involvement and satisfaction of family carers with the plans produced, the alternative arrangements put in place should also be reflected in the performance indicators.</p> <p>Suggest that the KPIs should include evidence that children and young people have moved into "real and fulfilling" options and that there is an unbroken continuity of support and intervention as the young person leaves school at 16 years, 18 years or 19 years. Suggest, too, that the role of HSC staff in facilitating and supporting access to mainstream further education, training or employment should also be reflected within the standard and performance indicators.</p>
<p>Standard 13</p> <p>Men and women with a learning disability should be supported to have meaningful relationships, which may include marriage and individual, unique,</p>	<p>KPI should reflect the development of regional guidelines on Human Rights, capacity and consent and self determination to ensure a consistent approach to this area. The KPI should also seek evidence of positive risk taking for people with LD.</p> <p>There is more clarity required around the current legislation. As far as we are aware it is currently illegal for people with a learning disability to engage in a sexual relationship and</p>

<p>sexual expression within the law, balancing their rights with responsibilities.</p>	<p>people especially in a professional environment shy away from this. This was a strong consensus within the group and it was felt that there needs to be a change in current legislation before staff are able to support people with a learning disability in relation to this standard. It was also identified that staff naturally adopt the caring role; they need additional training to learn how to support people with a learning disability who want to be in a sexual relationship. Professionals also felt that there was too much risk assessment around this area.</p> <p>As highlighted in the rationale, the standard and KPIs should reflect the need for appropriate and accessible education and support around personal relationships and personal safety for young people as well as adults with a learning disability.</p> <p>The Framework places very little emphasis on sexuality, sexual health and relationships & issues such as consent relating to sexual relationships. Suggested additional Chapter entitled “Relationships & Sexuality” – (see appendix A)</p>
<p>INCLUSION IN</p>	<p>COMMUNITY LIFE</p>
<p>Standard 14</p> <p>Adults with a learning disability should be able to access support in order that they can achieve and maintain employment opportunities in productive work.</p>	<p>The supported employment model should be specifically named in these performance measures.</p> <p>Requires interdepartmental working and are not the sole domain on Health and Social Care. In addition while health and well being can be improved by meaningful employment this needs to be facilitated across a range of agencies.</p> <p>The role of occupational therapist in assessing and developing skill levels to ensure successful work placements is very important.</p> <p>The criteria for day time opportunities can be unrealistic and excluding. In some areas clients must be totally independent with their personal care and as transport is not provided they need to be able to travel independently or be facilitated by their family. This means that people with good work skills may be rejected from the service on the basis of their personal care/ ability to</p>

	<p>access transport. Due to the limited resources currently available in day time opportunities clients may be moving on from day care to find that they have only got one or two days of activities and this may be for a time limited period. This gives both clients and family members less stability than they might have experienced within traditional day care. There is also a lack of suitable transport options and lack of continuity and reliability of community access officers that all vocational and road safety reports go to when any client is referred for day time opportunities/ alternatives to day care. Finally, it is well documented that there are increasing numbers of children coming through to adult services and the resulting pressure on day care.</p> <p>Standards 14 and 15 could be collapsed into one Standard as follows: All adults with a learning disability should be able to access support in order that they can achieve meaningful day opportunities which may or may not include employment opportunities and productive work.</p> <p>The reasoning behind this suggested change is in order that no distinction is made between adults with a learning disability and adults with a severe or profound learning disability all of whom should be able to access meaningful day opportunities of all kinds without assumptions being made which are potentially stigmatising and thus not in keeping with Bamford.</p> <p>Is this achievable given 1) lack of employment opportunities and 2) the current issue of benefits being cut when someone is working. People with a learning disability are very keen to work but do not want to lose their benefits</p> <p>Standards 14 – 16 - there should be specific reference within the KPIs to the role played by HSC services in supporting people with a learning disability to access meaningful, day opportunities over 5 days; as well as access to mainstream and specialist employment, training and further education opportunities. We suggest, too, that the standards and KPIs should reflect the proposed welfare reform changes.</p> <p>KPI1 refers to the percentage of school leavers with a learning disability accessing work placements or employment within 1 year of leaving school. We suggest that the data collection linked to the KPI should be repeated each year for 5 years after young people with a learning disability leave school, regardless of the school they attend and whether they leave school at 16 years, 18 years or 19 years.</p>
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<p>Standard 15</p> <p>All adults with a severe or profound learning disability should be able to access a range of meaningful day opportunities appropriate to their needs.</p>	<p>Requires interdepartmental working and are not the sole domain on Health and Social Care.</p> <p>. KPI 2 - people with profound and severe learning disability are provided for in Day Care settings and there may be some difficulty with provision for these people in Day Opportunity settings which will require further exploration and consideration.</p> <p>It is unclear why this standard relates only to individuals with severe and profound learning disability. We welcome the call for a radical reconfiguration of existing day service provision and recommend rewording this standard to read that all adults with learning disability should be able to access a range of meaningful day opportunities appropriate to their needs</p> <p>Service user feedback is needed to drive the cultural shift from reliance on day centres to meaningful day opportunities in non segregated settings. This will help to ensure that meaningful alternatives are developed based on service user choice.</p> <p>This Standard has positive recognition of early support but there is no PI on this. Is continuing education as a post-school option missing from this chapter?</p> <p>KPI 1 – wording creates a negative image of adult resource centres which will continue to provide a very necessary & much needed service for those with the most profound & complex needs. Is it necessary to use the wording “non-segregated”?</p> <p>Standards 14 and 15 could be collapsed into one Standard as follows: All adults with a learning disability should be able to access support in order that they can achieve meaningful day opportunities which may or may not include employment opportunities and productive work.</p> <p>The reasoning behind this suggested change is in order that no distinction is made between adults with a learning disability and adults with a severe or profound learning disability all of whom should be able to access meaningful day opportunities of all kinds without assumptions being made which are potentially stigmatising and thus not in keeping with Bamford.</p>
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<p>Standard 16</p> <p>All parents with a learning disability should be supported to carry out their parenting role effectively.</p>	<p>Many parents with learning disability do not have their learning disability diagnosed until they have been involved in Child Protection processes for extended periods of time and/or they are already subject to judicial processes (Tarlton <i>et al.</i>, 2006). Believe that emphasis should be placed upon identifying parents with learning disability at an early stage in their parenting role so that assessment, skills teaching and support have the optimum opportunity to be effective.</p> <p>Occupational therapists have a role in parenting assessments.</p> <p>Suggest that support for parents with a learning disability should reflect compliance with UNCRC and UNCRPD. Suggest that there should be an additional KPI checking the extent to which assessments and support arrangements are accessible, appropriate and tailored to meet the needs of parents with a learning disability. We draw attention to the limited research in this area and suggest a KPI on developing targeted interventions that will support parents with a learning disability in their parenting role. (See Bamford Rapid Review Research: http://www.publichealth.hscni.net/sites/default/files/Children&YoungPeople.pdf)</p> <p>KPI 1 - suggest that there should be KPIs on the adjustments made by social care services in supporting parents with a learning disability. We welcome the inclusion of the KPI on the provision of independent advocacy for parents with a learning disability and suggest that reference should also be made to social care services facilitating access to legal services.</p>
<p>MEETING GENERAL</p>	<p>PHYSICAL & MENTAL HEALTH NEEDS</p>
<p>Standard 17</p> <p>All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.</p>	<p>Would suggest stronger wording in relation to GAIN guidelines under 'KPIs' to underline a clearer commitment to GAIN: All acute hospitals should have an action plan for implementing the GAIN guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a GAIN action plan.</p> <p>Would suggest that further KPIs should be added as follows: All acute hospitals should have a planned admissions link with community teams.</p>

	<p>Percentage of acute hospitals which have a planned admissions link with community teams for people with a learning disability.</p> <p>and</p> <p>All HSC staff should receive mandatory rather than optional training in learning disability issues as a matter of course during their initial core professional training as indicated in Bamford.</p>
<p>Standard 20</p> <p>All people with a learning disability should be supported to achieve optimum physical and mental health.</p>	<p>None</p>
<p>Standard 21</p> <p>All people with a learning disability who experience mental ill health should be able to access appropriate support.</p>	<p>The timescale for KPI 2 is too lax.</p> <p>May prove quite challenging and perhaps a Regional protocol would provide some clarity to the current emerging issues re where a person's needs are best met. If a person is known to Learning Disability services then this programme is probably best placed to meet their particular needs. Co-working cases with mental health in a person-centred way may be appropriate but the lead should remain with LD as mental health fluctuates. The standard refers to accessing psychological therapies yet within mental health but there may be a training issue for therapists within mental health as I suspect a different approach would need to be taken with people with a LD. It seems a specialist role rather than an add-on.</p> <p>KPI 1 "a regional protocol....." would sit better as a KPI for standard 17.</p> <p>The regional protocol, if deemed appropriate needs to ensure people with a learning disability can access mainstream mental health service needs to consider which people would most benefit from this model versus current review via specific services provided by Consultant Psychiatry Learning Disability services. The protocol will need to ensure the clarity between</p>

	<p>services, joint working between services and identify the additional workload pressures placed upon mainstream mental health services. It will also need to consider admission to hospital and provision of relevant qualified professionals in meeting the needs of people with a learning disability in mainstream mental health hospitals.</p>
MEETING COMPLEX	PHYSICAL & MENTAL HEALTH NEEDS
<p>Standard 26</p> <p>All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services.</p>	<p>A KPI on advocacy services should be added.</p> <p>It is not currently possible to provide assessment within 24 hours. (see comment on P110 where 24/7 services are required)</p> <p>The key role of occupational therapy is omitted in regards to challenging behaviour despite other AHPs being acknowledged.</p> <p>This Standard has a positive KPI on challenging behaviour, however further emphasis should be given to the analysis of the communication needs of the person.</p> <p>Should there be direction on the use of "restrictive practices" ensuring that these maintain the safety, dignity and human rights of the individual? Recommend that the Framework includes a requirement for monitoring restrictive practices (i.e. use of physical restraints, psychotropic medication & exclusion from services) applied to people with a learning disability & challenging behaviour.</p> <p>May best read "a specialist assessment has been commenced within 24 hours" as the thorough assessment will most likely take longer than 24 hours when involving relevant stakeholders and different environments.</p> <p>Suggested addition to the end to the Standard as follows: All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services and other mainstream services as required based on assessed need.</p>

<p>Standard 27</p> <p>All people with a learning disability who come into contact with the Criminal Justice System should be able to access appropriate support.</p>	<p>The development of forensic services is required with the relevant staff training and development. Opportunity for interagency learning and development partnership for professionals involved across forensic casework.</p> <p>Suggest that there should be additional KPIs on the availability and success of preventative measures and interventions offered and provided to people with a learning disability who offend or are likely to offend. We suggest, too, that attention needs to be paid to the role played by HSC in supporting and facilitating access to justice by victims who have a learning disability.</p>
<p>AT HOME IN THE</p>	<p>COMMUNITY</p>
<p>Standard 28</p> <p>HSC professionals should work in partnership with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed.</p>	<p>Many individuals with learning disability live in shared tenancy or group living contexts. The BPS suggests that consideration is given to a requirement to complete compatibility assessments in such circumstances. This would be particularly important for individuals who lack the capacity to make decisions regarding accommodation options.</p> <p>The role of occupational therapy in housing adaptations, providing equipment for daily living and addressing support needs should be recognised in this standard.</p> <p>Need to monitor and improve two areas:</p> <ul style="list-style-type: none"> (i) number of and waiting lists for supported housing in every Trust area – this is a ridiculous post code lottery (ii) Staffing monitored in all supported housing – whether statutory or voluntary run. When the turn-over is high it is so disruptive to those in residence. Better pay, better supervision and incentives for good staff to stay need to be introduced. <p>This needs acknowledgement of specialised multi-professional teams to assess complex mental health and behavioural presentations.</p> <p>We believe, however, that, as the agency which the NIHE relies on to identify the housing needs of vulnerable populations, HSC services have a responsibility and a real opportunity to achieve change. We suggest that KPIs are required on the numbers of people with a learning</p>

	<p>disability who are able to choose who they live with and where they live; the numbers of people with a learning disability over 18 years and family carers that are supported to plan for the future and the percentage provided with the information and support they need to access the housing and extra support they need. KPIs are also needed on the protocols developed between the agencies involved in facilitating and providing accommodation and support and on the range and availability of short breaks close to where people live; and on the extent to which family carers and children and adults with a learning disability have control over when and how often they access short breaks.</p>
<p>Standard 29</p> <p>All family carers should be offered the opportunity to have their needs assessed and reviewed annually.</p>	<p>Concerned that the statutory rights of carers are being undermined by 2 performance indicators which presume that the statutory duty is not met.</p> <p>This standard should incorporate benefits advice.</p> <p>Suggested addition to the Standard as follows: All family carers should be offered the opportunity to have their needs assessed and reviewed annually. This should include any concerns regarding access to a full range of respite options.</p> <p>Would also suggest an addition to the Key Performance Indicators as follows: Percentage of carers' assessments completed and percentage of carers needs identified which are met.</p>
AGEING WELL	
<p>Standard 30</p> <p>All people with a learning disability aged 50 years and over should have the impact of ageing taken into account in having their future needs</p>	<p>While it is recognised that 50 is an age the standard should also include the words "or at a lower age if deemed clinically appropriate".</p> <p>KPI 2 would be better placed with Standard 29.</p>

assessed and proactively managed.	<p>We note the difficulties that some Trust partners have with the restrictive definition of what constitutes a “short break” and query whether this will impact on KPI 2. Will this Standard be enhanced by the inclusion of a KPI on “Emergency Plans” to support people to remain at home if their carer becomes suddenly ill?</p> <p>Suggested addition to the KPIs as follows: Percentage of people with a learning disability aged 50 years and over whose care plan has been reviewed taking into account of issues associated with ageing which may include accessing older peoples’ services and managing the interface between learning disability services and older peoples’ services.</p> <p>Aged 50 is too late. I would like to see that dropped to aged 40 to take into account the onset of menopause in women and the care plan reviewed REGULARLY.</p>
<p>Standard 31</p> <p>All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.</p>	<p>Should dementia screening for people with Down’s Syndrome be included in KPI?</p>
PALLIATIVE & END OF	LIFE CARE
<p>Standard 33</p> <p>All people with a learning disability being assessed for supportive and palliative care should have their learning disability taken into account in consultation with them and their carer.</p>	<p>Suggested addition should be made to the Standard as follows: All people with a learning disability being assessed for palliative care should have their learning disability taken into account in consultation with them, their carers and learning disability services when appropriate.</p>

GENERAL	
	<p>UN Convention on the Rights of Persons with Disabilities (UNCRPD) should be referenced (p36) and the UN Convention on the Rights of the Child (UNCRC) - including the general principles of the Convention such as article 12 which articulates the right of the children to express their view and have this taken account of in consideration of their age and maturity in any matter concerning them. For example, where the Service Framework standards note that the views or satisfaction rates of parents and carers will be documented, e.g. at Standard 8(1) the views of children should also be gathered and children with learning disabilities should be consulted in the development, monitoring and evaluation of the Framework.</p> <p>Framework requires a Standard on Dysphagia</p> <p>Framework has failed to consider the multi-identities and communities that people with a learning disability are part of and to consider the mitigating measures that need to be put in place to address the multiple disadvantage and exclusion they experience.</p> <p>Requires a Standard that focuses on the need for equipment and adaptations such as wheelchairs that can facilitate community access.</p> <p>The Glossary entry for AHPs should list the professions who have the most contact with people with a learning disability</p> <p>Transition plans are needed for older people who are making the transition to retirement</p> <p>Need to reconsider where standards are coded as applying only to adults but may also be relevant to young people with a learning disability. Illustrations of this include standard 13 relating to people with disabilities being supported to have meaningful relationships, standard 14 which is concerned with access to support in securing employment opportunities and standard 16 which relates to supporting people with learning disabilities who are parents.</p> <p>Suggested omissions of certain issues/standards that may have been expected to be included:</p> <ul style="list-style-type: none"> • For example, an increase in the number of people with complex, behavioural, mental

	<p>health, forensic needs cared for in non-hospital non-custodial settings.</p> <ul style="list-style-type: none"> • There are no standards centred around the assessment and treatment of individuals with a learning disability in specialist hospitals. • The delivery of care to young people with learning disabilities who may also have significant conduct, behavioural or mental health disorders. • The management of vulnerability and risk in the learning disabled population. <p>Chapter 3 – Would draw attention to the reference in the diagram (p38) to the need for reasonable adjustments at level 2. This fails to reflect the barriers experience by people with a learning disability in accessing mainstream level 1, HSC services and the reasonable adjustments that have to be made by level 1 services if children & adults are to enjoy equal access and benefit from such services including primary health care and accident and emergency services etc and the adjustments that have to be made to the other service frameworks, including cardiovascular disease, respiratory disease, cancer, children etc.</p> <p>Chapter 9 - suggest that a specific standard and accompanying KPIs are required on supporting people with profound and multiple learning disabilities, including the use of technology to facilitate their involvement in decisions made about the services and support they access and rely on.</p> <p>Chapter 11 - suggest that KPIs are required on a number of the points made in the section outlining the rationale and quality dimensions such as the numbers and percentage of older people with a learning disability who have access to a range of day and leisure opportunities, to advocacy support, and to plan for their future. We suggest, too, that an additional standard is required to reflect the fact that some people with a learning disability are also carers.</p>
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LIST OF RESPONDENTS

Organisations/ groups

Alliance Party of Northern Ireland
Ards Borough Council
Autism Northern Ireland
Autism Initiatives Northern Ireland
Belfast HSC Trust
British Association for Counselling & Psychotherapy
British Psychological Society
Camphill Community Clanabogan
College of Occupational Therapists
Cookstown District Council
Disability Action
Down District Council
Family Planning Association (FPA)
Forum of Podiatry Management NI Group
HSC Board/ Public Health Agency
MENCAP
Northern Ireland Commissioner for Children & Young People
Northern HSC Trust (Learning Disability Team)
Northern Ireland Board of the British Dietetic Association
Nursing & Midwifery Council
Positive Futures
Regulation & Quality Improvement Authority (RQIA)
Royal College of Nursing
Royal College of Psychiatrists
Society of Chiropodists & Podiatrists

South Eastern HSC Trust (Downshire Hospital)
South Easter HSC Trust (Ulster Hospital)
Southern & Western Education & Library Board
Southern HSC Trust
Southern HSC Trust (Community Dental Service)
Volunteer Now
Western Action Group for People with Learning Disability)
Western HSC Trust
Western HSC Trust (Regional Adult Learning Disability Group)

Individuals:

42 individual responses were received (representing 52 individual service users, carers, parents and support staff). These respondents were, in the main, members of groups, such as, Tell It Like It Is (TILII) Bangor and Lisburn and Muckamore Abbey Hospital Residents Group as well as recipients of Positive Futures' Supported Living Services.

Events:

23 February 2012	- Include Youth, Alpha House Belfast
5 March 2012	- Muckamore Abbey Hospital
6 March 2012	- Benbradagh Resource Centre, Limavady
8 March 2012	- ARC (NI), Belfast
12 March 2012	- Community Relations Council Office, Dungannon

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