



(a): Respondent Information Form (RIF)

Please Note this form **must** be returned with your response.

Consultation on the National Health and Social Care Standards

Are you responding as an individual or an organisation?

Individual (See Part (i) below) Organisation (See Part (ii) below)

Full name or organisation's name:

Scottish Commission for Learning Disability (SCLD)

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The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

- Publish response with your name / name of organisation
 Publish response only (anonymous) – Individuals only
 Do not publish response

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Government to contact you again in relation to this consultation exercise?

Yes No Date Completed: **20/1/2017**

Background

The Scottish Commission for Learning Disability (SCLD) is an independent charitable organisation and strategic partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The keys to life*. The strategy defines learning disability as a significant, lifelong, condition that started before adulthood, which affects development and means individuals need help to: understand information; learn skills; and cope independently.

We are committed to finding new and better ways to improve the lives of people with learning disabilities and are focussed on sharing innovation and good practice so that those providing services and interventions can learn from each other. We also aim to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

In December and January, we held two events on behalf of the Care Inspectorate to support the involvement of people with learning disabilities in the consultation process for the new national standards for health and social care. The first event took place in Inverness and the second was held in Inverurie in partnership with ARC Scotland. The feedback from these events was mostly qualitative in nature but also gathered some quantitative data using the live voting software tool Clikipad which allowed participants to respond to a series of questions. A full report from the two events is included as an appendix to this response and is representative of the views expressed by the individuals who attended.

In compiling this response, we have drawn on what we consider to be the most salient points to emerge from the consultation events as well as on our considerable expertise and experience in the field of learning disabilities. This has been developed through extensive engagement with a wide range of stakeholders including: people who commission and provide services for people with learning disabilities; those who act as advocates or are working in research; as well as people with learning disabilities and carers. Our involvement in the Scottish National Action Plan Health and Social Care Action Group has also informed our thinking. SCLD welcomes the opportunity to respond to the Scottish Government's consultation on the new national Health and Social Care Standards.

To what extent do you think the Standards will be relevant and can be applied across all health, care and social work settings?

SCLD welcomes the new National Health and Social Care Standards and considers them to be timely given the number of recent policy and practice developments including the integration of health and social care. People with learning disabilities often rely on care and support from health, care and social services to live independently and to maintain their wellbeing. However, historically they have been more likely than the wider population to be denied choice and autonomy, to face

discrimination and even to experience cruel, inhuman and degrading treatment in health and social care settings.

Stigma and discrimination remain part of everyday life for many people with learning disabilities. Within health, care and social work settings, despite the existence of law, guidelines and good practice, there is still inadequate redress when rights are infringed. Organisations can be unaware that they are infringing individual's rights, while at the same time people are generally not well informed about what rights they have and how they can access them. In our view, the new standards present a positive statement of what people should expect when receiving care and support across a diverse range of settings.

We welcome the human rights approach underpinning the standard's principles of dignity and respect, compassion, being included, responsive care and support, and wellbeing. It is vital that these principles are fully reflected within the standards to provide a set of practical statements that can be easily understood and applied by service providers and service users. In our view, there is scope for a human rights perspective to be further embedded within some of the statements contained within the standards. Considering each statement with reference to the PANEL principles (Participation, Accountability, Non-discrimination and equality, Empowerment and Legality) provides a basis for achieving this.

Effective application of the standards across all health, care and social work settings will require commitment and action from all stakeholders. It is crucial that stakeholders view the standards as a basis from which to build rather than the default minimum for service provision. For provider organisations, it is crucial that leaders, managers and staff understand and incorporate the standards at every stage in service the design, delivery and improvement of services. Equally, commissioners of care services need to use the standards to set out how high-quality care should be planned, commissioned, delivered and assessed. For local authorities and NHS boards, application of standards will help in assessing people's holistic needs and establishing care packages and pathways. For people who use services and carers, the standards provide an important reference point for redress if they are unhappy about any aspect of their care and treatment.

To what extent do you agree these new Standards will help support improvement in care services?

The true impact and value of the new standards will be dependent on their effective implementation. Ensuring these principles become a reality will require health, care and social work support and services to be fair, consistent and respectful and individuals to know who they can appeal to when standards fall below this. It will also require that individuals enjoy autonomy, self-determination and the opportunity to actively participate in decision making that affects their lives. If developed and

delivered in a rights-based way we believe the standards can support people with learning disabilities in Scotland to live healthy, active and independent lives.

In our view, a legitimate criticism of the existing National Care Standards is that they have not been appropriately communicated to front line staff or people who use support and services. Additional resources are required to support the skills and capacity of health and social care services to realise the new standards which should include direct training for all staff working with people with learning disabilities. Without this there is a risk that the standards will be little more than statements of aspiration and will not achieve the desired transformational change.

Effective implementation will also be dependent on the development of methodologies of inspection and scrutiny to enable proper monitoring and evaluation of the standards and to hold organisations and individuals to account. Individuals who use services should feel they have ownership and knowledge of the standards and know who they can approach if they are unhappy about an aspect of their care and whether there is an independent authority to which they can appeal. Equally it is vital that all stakeholders are clear as to what action will be taken when standards are not met and with whom responsibility for doing so resides.

SCLD is in favour of a relational approach to inspection and scrutiny which is human rights based in ethos and approach. We believe inspection ought to be a continuous process of review which is orientated towards improvement and quality in delivery. In this sense, we would like to see less emphasis on the mechanics and processes of the system. Rather, it needs to be more collaborative and co-produced and orientated towards capacity building to achieve human rights outcomes whilst still retaining a link to regulation and compliance. This will require services to be examined with greater reference to the experience of the person rather than through the lens of overall delivery.

The Scottish Human Rights Commission has developed the 'FAIR' approach to help embed a human rights approach to inspection and scrutiny, and improvement methodology. It is both person centred and recognises the rights of all engaged. The basic steps of the FAIR approach are:

- **Facts:** What is the experience of the individuals involved and what are the important facts to understand?
- **Analyse rights:** Develop an analysis of the human rights at stake or which are being engaged.
- **Identify responsibilities:** Identify what needs to be done to ensure the upholding of rights and who is responsible for doing it.
- **Review actions:** Make recommendation for action and later recall and evaluate what has happened.

The FAIR model recognises the complexity of the inter-relationships of rights and responsibilities, and fits well with the complex multi-stakeholder dynamic that occurs within a social care or health context. The rights of one person can be balanced against and held in relationship to those of others, including other patients or users of the service, the rights of staff and the rights of family members and carers. By being solution focussed and allowing for an understanding of proportionality, the FAIR approach to human rights in health and social care can assist in balancing risk and quality of life considerations and can provide a common framework of rights and responsibilities for everybody.

To what extent do these Standards reflect the experience of people experiencing care and support?

In our experience people with learning disabilities still experience obstacles to their full, meaningful and active participation in decisions that affect them. This extends not just to their own care, but more widely in relation to decision making on the design, delivery and resourcing of services and support. The feedback from the consultation events suggested that there is still some way to go to ensure that people with learning disabilities consistently enjoy their right to care, treatment as set out in the new standards. In relation to the statement “I get support to make good choices that make me healthy, happy and safe” in the easy read version it was noted at the consultation events that staff often “tell” people what they should do rather than supporting individuals to find a way to do it themselves. It was felt that staff need to work in a more supportive and encouraging way. In relation to “Staff listen to me because I know what I want and need” people felt that in their experience this was not always the reality particularly in relation health services. It was also noted that issues around funding and availability of housing can mean that the easy read statement “I can live in my own home if possible” is not always a reality for people. Therefore, while the standards clearly promote and support the health, wellbeing, independence and active participation of people who use support and services, there remains challenges for staff, providers and commissioners to put this into practice.

Standard 1: I experience high quality care and support that is right for me. To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?

At our consultation events people with learning disabilities agreed with the easy read version of Standard 1: I get good care and support that is right for me and felt that the statements included under this standard generally described what they should expect to receive. SCLD considers the statements under Standard 1 in the full version to be well grounded in the principles of dignity, fairness, equality, respect and autonomy.

Statement 1.8 reads “I get the most out of life because the people and organisation who support and care for me have an enabling attitude and believe in my potential. We think the use of “an enabling attitude” here is unclear. We suggest that this

statement is amended to make explicit reference to individuals' concerns being listened to and acted upon and being able to exercise some autonomy in who supports them and how. We also think that statement 1.9 should be revised to "...my wishes and choices are both respected *and safeguarded.*'

Statement 1.12 says "I am encouraged to take part in everyday tasks to help the running of the service if I choose". In our view this does not incorporate the level co-production and involvement people with learning disabilities and others should expect in health and social care services in Scotland. We believe that genuine involvement this must go beyond 'everyday' tasks and include opportunities to influence service design and delivery. We would like to see statement 1.13 amended to read "My emotional, psychological and physical needs are assessed *and discussed fully with me* by a qualified professional at an early stage, regularly and when my needs change." Individuals have the right to be fully informed and involved in all aspects of their care and support. For people with learning disabilities this includes being provided with accessible information. Standard 1 would benefit from an additional statement which clearly outlines individuals' right to equitable and accessible information about their care and support.

At our consultation events the meaning of the easy read statement "I can get things to help me look after myself. Like computers or other things that help me look after my health" was unclear for some people. The full standards refer to 'technology and other specialist equipment' rather than computers. There is a danger that using generic language such as this could lead to people with learning disabilities having unrealistic hopes about what they can expect to receive. We suggest that the wording in the easy read version is revised to convey a more precise meaning. People also felt that a fuller description of what is meant by 'support' was required in the easy read statement "If I can't get the support I want staff tell me why".

At our consultation events people agreed that support and opportunity to exercise and eat well are important to them in terms of looking after their health and for their well-being more generally. It was felt that particularly in residential settings it is important for staff to know how to support people to prepare and cook fresh food. We do not feel statement 1.34 in the full standards "If I experience care and support in a group, I can choose to make my own meals, snacks and drinks, with support if I need it" is adequate. We suggest rewording this statement to include people having the choice to prepare and cook fresh and healthy meals and receiving the appropriate support to do so. We would also like to see explicit reference to this in the easy read version. We would like to see statement 1.39 revised to "I am supported to participate fully as a citizen in my local community, *including the opportunity to pursue employment and education.*" SCLD believes this is a crucial component for ensuring that people with learning disabilities live full and independent lives as active citizens and enjoy healthier lives.

**Standard 2: I am at the heart of decisions about my care and support.
To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?**

SCLD believes that Standard 2 is crucial for empowering people with learning disabilities to exercise autonomy and self-determination giving them greater choice and control over their lives. This is a key strategic outcome in *The keys to life* implementation framework. Everyone, no matter what level of impairment, is capable of exercising some choice and control in their living, whether that choice and control is supported by others or not. With regards to health, care and social work settings ensuring that care is person-centred and person-led is critical to empowering people with learning disabilities to achieve independent living and to be in the driving seat around decision-making.

The availability of appropriate support to make informed decisions about treatment or care or getting support to make decisions is critical for people with learning disabilities. At the consultation event people generally agreed with the easy read version of Standard 2: “I have a big say in the care and support I get”. They felt it was important that they are involved in decisions surrounding their care and support so. Co-produced solutions in health and social care involving the participation and empowerment of people with learning disabilities is important here. We believe that further emphasis could be placed on the importance of co-production within the standards.

Statement 2.3 reads “I am involved as I can be in agreeing any restriction to my independence, control and choice and these are justified, uphold my human rights and are kept to a minimum.” SCLD thinks it is important that any restrictions to independence, control and choice are reviewed at regular intervals with a view to removing them wherever possible. We propose that the following additional statement be considered “if restrictions apply to me, they will be regularly reviewed to decide whether they are still necessary”.

At the consultation events people with learning disabilities drew attention to resource issues such as lack of staff and limited budgets. They said that it was important that if they are not eligible for a certain level of support that the reason for this is clearly explained to them. People said that having support to be involved in the local area and participate in activities is important to them but they were aware that this type of support is often reduced when budgets are tight. The statement in the easy read version: “Staff help me do new things if I want to. They help me know if things may be safe or unsafe” was welcomed by those who attended the consultation events. People felt that social care was overly risk adverse with too much emphasis on protecting people rather than enabling people to enjoy a full and active life. We think that statement 2.5 which refers to “translation services and communication tools” should be extended to include alternative information formats including easy

read. Some participants at the events said they require guidance around aspects of organising their day to day life, for example managing their money. We would like to see statement 2.15 amended to “I make choices and decisions about all day to day aspects of my life, including managing my own money, how I dress, what I eat and how I spend my time *with support to make healthy and safe choices.*” This will also address concerns regarding choice about healthy eating/weight and the need to balance this with a duty of care regarding adequate nutrition.

**Standard 3: I am confident in the people who support and care for me.
To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?**

Participants at the consultation events agreed with the statements included under Standard 3 in the easy read version. Some people expressed concern around adequate training for personal assistants and suggested that minimum training standards are required and that there should be more expectation on training bodies and increased regulation. People said they would like some reference to this included in the standards.

We think statement 3.1 should refer to people’s understanding of what is being said to them rather than it just being said in a courteous or respectful manner. Certain information may be inaccessible to people with learning disabilities despite being conveyed in a courteous and respectful manner. We would also like to see statement 3.3 strengthened by through acknowledgement that individuals should be supported to stand up against discrimination and bullying too.

**Standard 4: I am confident in the organisation providing my care and support.
To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?**

Participants at the consultation events agreed with the easy read statements included under Standard 4 and felt that they met the principles. However, some people said that, in practice, organisations can be reluctant to apologise when things go wrong for fear of being held culpable. Some people were also of the view that while being able to say you are unhappy about something is fine but what matters more is that organisations respond appropriately and timeously. There was a feeling that financial constraints sometimes mean that little is done.

We welcome the reference to human rights in statement 4.1. However, we believe the standards would benefit from making reference to empowering people to understand what their rights are and how they apply to their health or social care setting. We think statement 4.6 could be strengthened by acknowledging the responsibility of the support or service to seek and act upon feedback not solely the responsibility of the person who uses the support or service. We would also like to

see an additional statement included in this section referring to integrated services e.g. “My health and social care service is well integrated, resulting in my health and social care needs being met promptly and in a way that promotes my human rights and access to the best appropriate services in a timely way”.

**Standard 5: And if the organisation also provides the premises I use.
To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?**

Standard 5 is concerned with the environment someone may get care and support in but mainly regarding physical aspects of the building. People at the consultation events thought there is more to environment than just having a clean, well maintained building. It was suggested that the atmosphere and ambiance also needs to be considered.

The choice of being able to share a room with someone they know well or who looks after them was welcomed by most participants. This was something that many people felt they did not have an option to do at present. Most participants said this was not something they would choose to do all the time but that it was important to have the option, for example when they are on holiday, or if they are in a new residence or temporarily in an acute setting. It was also felt that the easy read version should include the proviso “if I live in a care home” where statements only apply to care homes. This is included in the full version of the standards but not in the easy read version. It was also felt the wording and rationale behind the statement “If I get care all hours of the day I can use a TV, radio, phone and the internet” was unclear and would benefit from being revised.

The inclusion of the statement about the use of CCTV cameras was met with some reservation by all participants. People felt strongly that CCTV should only be used where there is a very good justification for doing so. They felt this should involve choice and discussion about the use of CCTV rather than people just being informed its use. It was considered essential that individuals understand why CCTV is being used and that staff fully discuss and explain how people can ensure that their privacy is protected and respected. In the full version of the standards we think that statement 5.6 which refers specifically to the use of CCTV should refer to monitoring devices more generally. Moreover, there are significant human rights implications arising from the use of CCTV, which require careful consideration of proportionality to be justified. The standard does not cover assessment of proportionality or people’s right to access the information held about them, and should be revised to do so.

**Standard 6: And where my liberty is restricted by law.
To what extent do you think this Standard describes what people should expect to experience from health, care and social work services?**

We welcome the strong focus on human rights in this section. The standards would be strengthened by clear and explicit reference to human rights throughout the document. Human rights may be restricted in circumstances where a person is not necessarily deprived of their liberty. In our view, this is not adequately reflected outside of the standards where liberty is restricted.

Human rights can provide a framework for communication between professionals, individuals using services and family members, helping to resolve tensions in the way in which care is delivered. Bringing these considerations front and centre helps to increase the understanding and positive acceptance of a human rights based approach and its applicability. A human rights approach can assist in balancing issues of risk, for example, the use of restraints, door locking, allowing people to leave the care home setting, the use of medication or restricted diets, against the rights of the individual to choice, control and autonomy.

We suggest amending statement 6.1 to “I experience my human rights being protected where my *independence, choice or control* is restricted and this complies with relevant legislation”. An understanding of the reasons for any restrictions is key to participation in decision-making. The Convention on the Rights of Persons with Disabilities requires that a person must be supported to make decisions, rather than those decisions being made on their behalf by others. It is important to focus on the concept of support rather than on capacity to make decisions. We think statement 6.2 should be revised from “I am helped...” to “I am supported to understand how and why my behaviour affects my rights, including the use of any physical intervention, sanctions or incentives”.

In our view, statement 6.3 should outline that people should understand the circumstances under which restraint may be used. It should also take account of, and make specific reference to, medication and treatment given against the person's will. We do not believe that the reference to “sensitivity” in statement 6.5 is clear enough about the need to use the least restrictive means of searching. We suggest that this statement should be revised to: “If I am restrained or searched, this will be carried out with sensitivity. *It will be carried out in the least restrictive way necessary to deal with the problem.*” We also think that statement 6.7 should be more strongly worded to reflect the need for ongoing review and the right to live independently and be included in the community.

Is there anything else that you think needs to be included in the Standards?

We think that greater reference could be made within the standards to the right to a private and family life. This should include stronger emphasis on the right of everyone, including people with learning disabilities, to have relationships and partners regardless of care setting. We also feel the standards could be stronger

around the right to personal privacy at home or in care home and around the use of personal information.

Is there anything you think we need to be aware of in the implementation of the Standards that is not already covered?

Ensuring that individual communication needs are met will be central to enabling people who use support and services, their carers and families to use the new national care standards effectively and empower them to make informed decisions and play an active role at the centre of their care. It is therefore paramount that the standards must be made available in a range of formats, including; via online platforms; hard copy; large print; spoken word audio; braille; multilingual formats and easy read. Some participants at the consultation events felt that the existing easy read version of the standards could be improved as at present too many of the statements are misleading or could be misconstrued. Some said that the easy read version felt rushed and that revision was required to ensure that it conveys precise meaning but in sufficiently clear and simple terms.

The standards would also benefit from being accompanied by some practical examples and illustrations to help make the standards as tangible and accessible as possible. Without this there is a danger that the standards appear abstract and inaccessible to some. Furthermore, everyone who accesses health and social care should also be given information about where and how they can access the standards and how they should be used. An important starting point for individuals when considering the standards may be 'what matters to me?' In communicating and implementing the standards it is therefore important to be clear whether the statements are intended to have universal application or whether individuals have some autonomy to determine which elements of the standards they feel are relevant to them. This may be particularly relevant where people are commissioning their own support through Self-Directed Support.

We would also encourage the Scottish Government to consider how it will work directly with Health and Social Care Partnerships and providers in the third and independent sectors to make sure that all support staff are aware of, and embody the spirit, the standards. This will require significant investment but will be critical to ensuring that people who use support and services feel confident that their expectations of the new standards are being upheld.

What should the new Standards be called?

National Health and Social Care Standards.

Appendix - SCLD and ARC National Care Standards Consultations Events Report

Introduction

The Scottish Commission for Learning Disability (SCLD) is an independent charitable organisation for the learning disability sector. We are ambitious for change - our vision is for a Scotland where people with learning disabilities are included and respected as equal citizens.

We are a strategic partner to our principal funders, the Scottish Government and work with them to support and evaluate interventions and delivery projects and drive improvement.

We are committed to ensuring that people with learning disabilities have an opportunity to express their views and share their experiences on issues that have an effect on their lives.

The Care Inspectorate approached both SCLD and ARC Scotland to support the involvement of people with learning disabilities in the consultation process for the new national standards for health and social care.

SCLD ran one event in Inverness and joined with ARC Scotland to host an additional consultation event in Inverurie in Aberdeenshire.

ARC Scotland are an organisation that support a number of activities across Scotland. This includes the National Involvement Network, Local Provider Forums and Self-advocacy groups. ARC Scotland seek to ensure that people with learning disabilities are involved and represented in discussions at a national level.

The consultation is looking to seek the views of members of the public about the proposed new single set of standards for health and care services in Scotland. This will replace the previous care standards which applied only to social care services. The previous standards were written to apply separately to different types of service. The version of the standards that is being consulted on is now written so that one set of standards applied to all types of social care service as well as to health services. This is to ensure that they are in line with changes to the law that means that health and social care services are now operating as integrated joint boards.

The consultation events

We held two events, one in Inverness which SCLD hosted alone and an additional event in Inverurie, Aberdeenshire which was co-hosted with ARC Scotland.

We focussed only on standards 1 – 5 as 6 and 7 are not applicable to the wider group of people.

After presenting attendees with some back ground to the consultation and to Health and Social Care Integration we ran a short session using Clikapad. Clikapad is a live voting software tool that participants can use to answer questions presented to them on a screen. The answers can be shown live and it is a great way to both engage with participants but also to gathering some quantitative data from people in attendance at events.

Following this we split attendees into groups, two in Inverness and three in Inverurie. Groups then used the descriptions of each standard given in the Easy Read consultation document to look in more depth at the suggested standards. In groups, participants were asked to sort the statements given in the descriptions into lists. Each group had three sets of list headings, the statements were then sorted into lists using the two choices in each set.

These were;

- We agree this should be a standard or We do not agree this should be a standard
- This standard meets the principles or This standard does not meet the principles
- This standard applies to both health and social care or This standard does not apply to both health and social care

Each group looked at three standards, sorting a different standard into each list. Between the groups at each event standards 1 – 5 were considered.

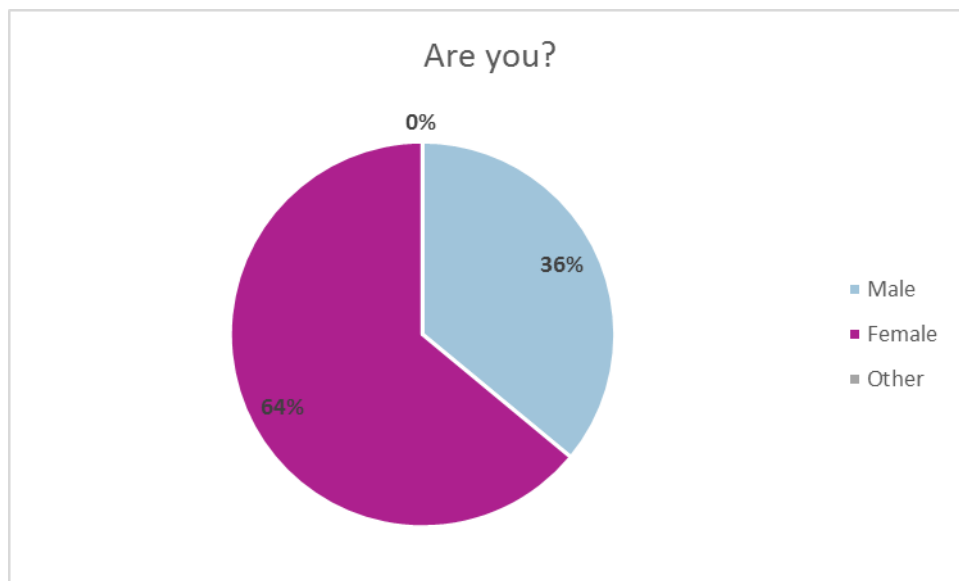
Who we spoke to

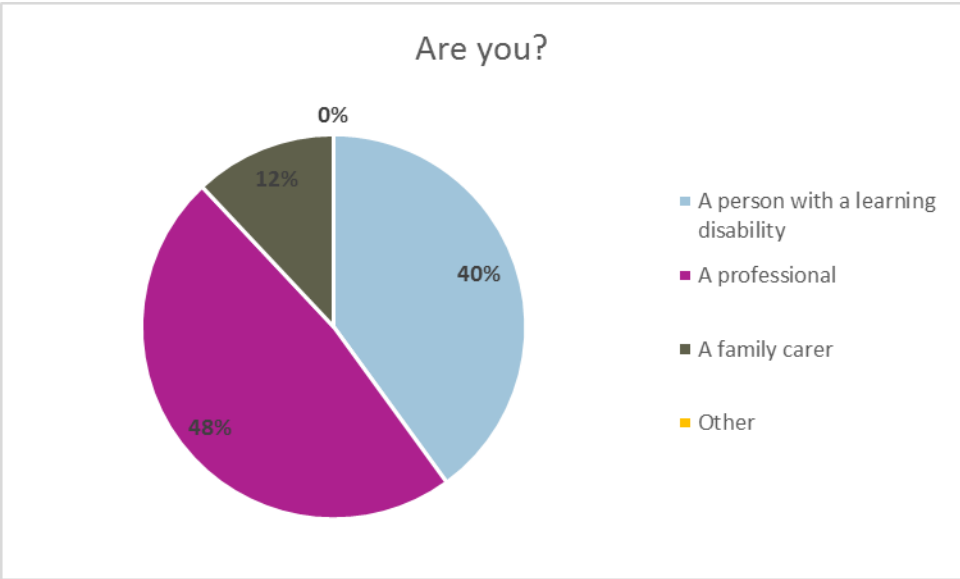
A total of 28 people attended between the two events. At each event there were late comers who arrived after the initial Clikapad session had begun, in the case of the Inverness event, one participant arrived after the Clikapad session has ended. In Inverurie two people were called out during the session. For these reasons the numbers recorded by Clikapad for each question do not all add up to the same amount of responses for each question.

The responses given as being recorded by Clikapad are the totals given across the two events and include the responses given by the participants who were present during the 'voting' for that question.

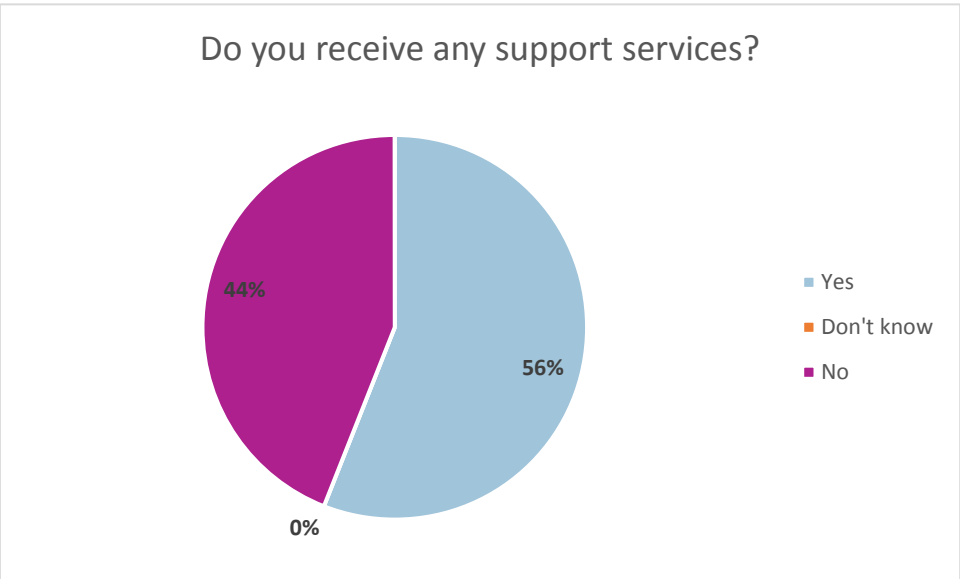
The phrasing of the questions on the Clikapad vote were intended to be answered by people with learning disabilities, other attendees were asked to answer with the people they support, either as a family member or a professional in mind.

Of the people we spoke to at the two events the following graphs give the breakdowns as percentages based on the number of responses given.





A large percentage 40% of all participants were people with learning disabilities. The largest group of people represented at the events was 'professionals' these were professionals who work with people who have learning disabilities many of them were supporting people to attend the events.



Staff who work in support services were asked to select 'yes' for this as their experience of learning disability services will relate to support services.

What we found out

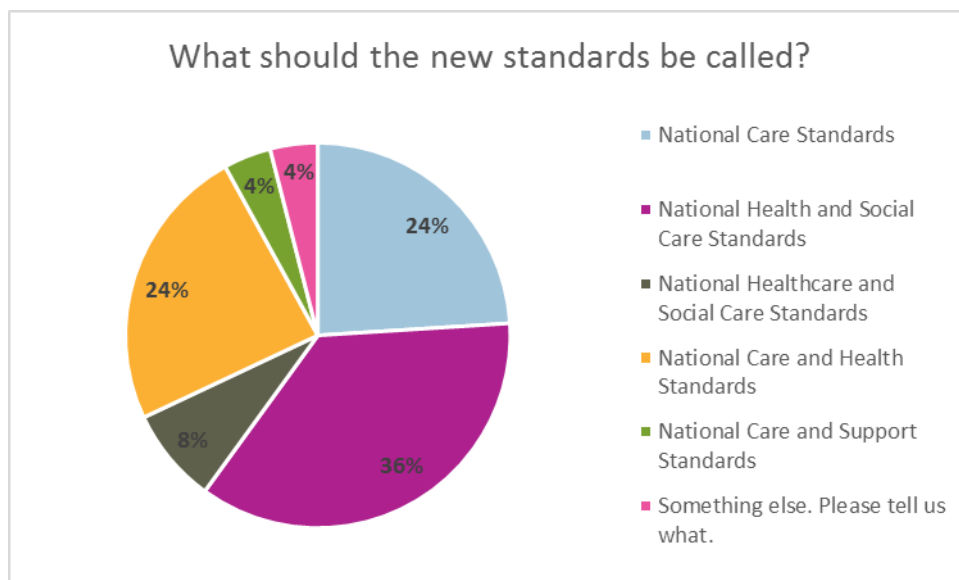
We used the Clikapad to ask attendees at the events to rate statements depending on how important they consider them to be. These statements relate directly to the proposed new care standards.

We then asked attendees to indicate if this is how they currently experience their care service.

In Inverness the answers were unanimous that everyone agreed that the suggested standards were things that people thought were very important. The only exception being if the building is important. Which differed only because for some people this was not applicable as they do not get support that would be covered by this standard (Standard 5)

There was some more variation in the answers given in Inverurie.

There was less consensus around whether people currently experienced care that would meet the standard. The following pie charts show the answers given at the events as a percentage. Answers have been combined for the two events.



Participants were asked for their views on what the new standards should be called. Although there was not a clear preference recorded, National Health and Social Care Standards received the highest single percentage of the votes with 36%. National

Care Standards received 24% of the votes and was the second most popular choice offered.

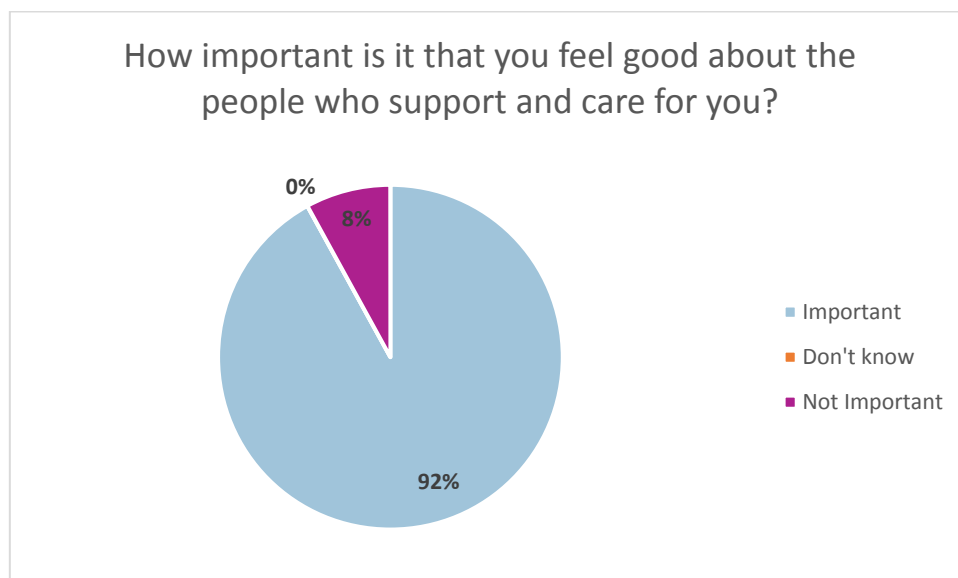
One person came up with an alternative “Scottish Support Standards”. Following this suggestion there was some agreement that it would be a good idea for the name to reflect that the standards do not apply to England and Wales and that the term ‘National’ may mislead some people.

The answers that people gave suggest that the suggested care standards are based on elements of care that people consider to be important. In Inverness, all attendees were unanimous that the suggested standards focussed on what was important. There was a little more variation when the Inverurie event was included.

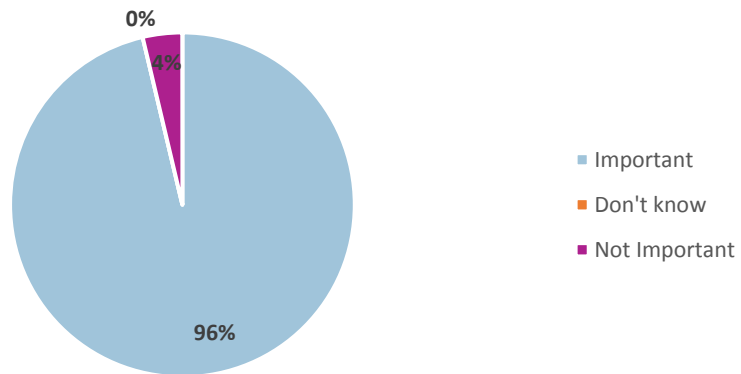
100% of responses to the following questions were that it was important.

- How important is it that you get good care and support that is right for you?
- How important is it that you have a big say in your care and support?

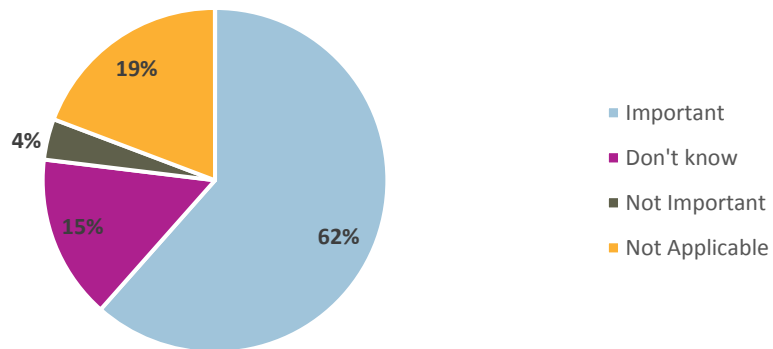
The more varied answers are shown in the graphs below.



How important is it that you feel good about the organisation that you get care and support from?



How important is the building that you get care and support in?



People who do not currently get any services that are based in a building that is owned by the support provider chose to answer 'not applicable' There was a lack of clarity surrounding this at the event in Inverurie which took place in a sheltered housing complex where people receive support to live independently. We were unclear if this sort of service would be covered by standard 5.

More about the standards

At our events people looked at the Easy Read version of the standards so most of the comments made refer directly to these. Some specific comments were made about the way the Easy Read document has been phrased but in general it was not thought that this was very well written. Comments were made that the whole of the easy read standards document needs to be written more carefully as the wording is not clear and it could be a waste of time writing them if the non-easy read version says something different.

There was general agreement that all of the suggested headings should be included as standards and that all of the statements included under these were relevant.

It was agreed that the standards meet the principles as agreed by the Scottish Government. More specifically it was agreed that all of the standards could and should meet these principles. A comment was made that “If a service is working well then it should be meeting the principles”. Services should be inspected on the principles separately from inspecting them on the standards.

Standard 1 “I experience high quality care and support that is right for me”

General Comments about this standard

"This standard is very important. especially the fairly part. Everyone should be treated the same"

"I have my own opinion so listen to me"

Staff helping me get the healthcare I need is "one of the most important standards"

"If staff believe in you people would try harder. It builds confidence"

"You also need to acknowledge how much the person can do. Be realistic. Don't set someone up to fail."

Comments about the relevance to both Health and Social Care

One group looked at if this standard can be applied to both health and social care they thought that this standard should apply to both but there were a number of comments made that suggest that health services in particular will need to make a number of changes to their current practices in order to be able to meet this standard. One example of this is that in order to meet the point “I get support to make good choices that make me healthy, happy and safe” a lot of people working in health services would have to change their approach. It was noted that health staff tend to “tell” people what they should do but do not support individuals to find a way to do it. They need to encourage more. It was felt that more staff who are able to work in a supportive and encouraging way would be helpful.

“Staff listen to me because I know what I want and need” It was thought that this point should apply to both health and social care services but people currently feel

that their experience in relation to health services is mixed as to whether this happens.

Comments about the practical difficulties in meeting this standard

It was noted that there are problems with meeting some of the points. Housing shortages make it difficult to meet the standard “I can live in my own home if possible”

The point “I have a big say in the care and support I get, to make sure it is right for me” does not allow provision for the voice of family members who are carers. This was raised as an issue of concern for a family member who was present.

Recruitment issues are a real concern for some people. Particularly when people are employing their own support. This was highlighted as a difficulty when it comes to meeting the standard “If I can’t get the support I want staff tell me why”

There was a concern raised about meeting the point under this standard of “I get support to be part of my local area and join in with things” when people need support to this it is important that the support is provided. Support for this kind of stuff is often not prioritised particularly when budgets are tight.

Comments about the way the standards are written

A number of different groups commented on the standard “I can get things to help me look after myself. Like computers or other things that help me look after my health”

In the non-easy read it refers to telecare but using the term ‘computers’ in the easy read version is misleading. This could lead to people having false hope about what they should expect to receive.

The word “computer” makes you think of a laptop, not equipment, such as apps or telecare to help. Someone said “an easy ready booklet is easier to follow than a computer screen”

The focus of this section in the non-easy read is on living independently but the focus is on health in the easy read version. People felt strongly that they should have support for their wants as well as for their needs.

One group said that exercise and eating well are important to look after your health, not computers. They could not see how computers would help. Again this may be the fault of the terminology used. People who need support to do these things should be assured they will get the support they need. Staff need to know how to support people with their health and how to prepare and help people to cook fresh food.

The point “If I can’t get the support I want staff tell me why, they help me find other support” needs some clarity. It is unclear if it applies only to staff or to activities as well. Does it refer to things like staff sickness preventing a member of staff from supporting a person that day or wider than this in terms of choosing specific staff members to provide support?

Standard 2 “I am at the heart of decisions about my care and support”

General Comments about this standard

“It is also important to have guidance when offering choices. Informed choices”

“Some people don’t have concept of money. As staff we have duty of care”

“to have choice there has to be an alternative. There was no other option for my child”

“Ask people who has known me for a long time. Some new staff don’t know we well yet”.

“Need to have a history of people”.

“I want to feel safe, but it is nice to try something different so long as it is still safe”

One of the most important statements was being able to tell people what I want in a way that feels right. “I have my own opinion”

Comments about the relevance to both Health and Social Care

Participants in the two events did not think that all of the statements connected to this standard could fit equally well with health services as with social care services.

It was thought that the following statements did not apply to health services

- I can choose who gives me care and support and what it will be like if possible, If possible I can visit first
- I can choose what I want to do, like how I spend my money, what to wear and what to do each day
- I get support to do things that make me happy and more confident

The statement 'Staff help me do new things if I want to. They help me know if things may be safe or unsafe' was considered as being more relevant to social care than to health services. The statement was welcomed by a number of participants who think that recent culture has become very risk-averse and tends to over protect people for their safety and therefore stopping them from having full enjoyment of life.

Comments about putting this standard into practice

At both events the need for accessible, easy to understand information was raised. The statement 'staff give me information and advice in way that feels right for me' brought comments such as "important, but only if accessible." It was felt by all that there needs to be more easy read information available, "but it is getting better".

In particular there was noted to be a need for more easy read information about health issues and treatments.

There was a comment made that some additional guidance might be needed, in particular around managing money for others and taking account of the individual's capacity to do this.

Standard 3 “I am confident in the people who support and care for me”

Fewer comments were made about this standard, some people called for regulation to look at training for social care staff, in particular personal assistants where people are employing their own staff using their Self- Directed support budgets.

People called for a minimum training standard to be set, SVQ level 2 or 3 was deemed adequate. Some reference to training standards should be included in the care standards and these should apply to all staff working in health and social care.

Standard 4 “I am confident in the organisation providing my care and support”

Comments given during discussion of this standard focussed on some of the difficulties associated with putting the standards into practice. It was noted that organisations fear admitting they have done anything wrong and as a result sorry is not said often enough, it can also prevent organisations from making improvements as in order to do so they would first need to admit fault. One participant asked the question “Being able to say you are unhappy is fine. But is anything done?” Sometimes limited finances can prevent change and improvements from happening. It may be hard for organisations to meet the standards if their financial situation limits them.

A number of comments were made regarding the Easy Read version of the standards used for the consultation exercise. Some people said that it feels rushed and that some of the statements are misleading or can be misconstrued. This does not only apply to this standard but an example given here was ‘the organisation is good and works well’ which was considered to be too vague to be of any use to a person who may want to use the standards to learn what they can reasonably expect from a care service.

Standard 5 “And if the organisation also provides the premises I use”

Comments about the relevance to both Health and Social Care

One group discussed whether or not the standard applied to both health and social care. It was agreed that most of the standards applied to both health and social care, with the exception of ‘my pet can live with me’, as you someone said “can’t take pets in hospital”. It was acknowledged that the standard referred to a care home, but still does not apply to health setting. Another group agreed but added that there could be an alternative of allowing them to visit.

In addition to questioning if this would fit into a health setting some people really do not want to live somewhere where pets are welcome. There is a need to acknowledge that others may have allergies or anxieties. “pet free areas or zones may be required”

One group felt the standard ‘I can take part in things to do, in the building and outside it’ did not really apply to health, but could in some cases. “Can’t really do things inside hospital”, but on the other hand someone said “If you can’t take part in things it could affect your health.” Someone else said “we need to push ourselves to do things sometimes, but it makes us feel better.” Another group thought that this statement did not really fit well within this standard at all.

Comments about putting this standard into practice

There was some confusion over the standard relating to the use of TV, radio, phone and internet. Participants at both events wanted to know why it was only if you get care “all hours of the day” are you entitled to these. “It should apply to everybody if they want it”

Comments relating to this were:

- “we need to pay in hospitals to watch T.V and get internet access”
- “depends if focus is on health or the social aspect”
- “depends on the person - TV and phone can be a life-line for some people to keep them connected ”

There were concerns about the wording of this statement. It should say something along the lines of “ if appropriate for me” There were concerns that someone who has been banned from using the internet in their own home (for protection or legal reasons) may read this and think ‘If I move into a care home I will be allowed the internet back’.

The option to share a room if that is chosen was welcomed by most participants the element of choice is important. At present people are not allowed to share rooms. Some people may prefer company, particularly noted was that respite can be difficult for people if they find it difficult to sleep in a new place. In addition not being allowed to share rooms can prevent people from being able to go on holiday. It is more expensive if they need their own rooms, also as noted above some people may prefer to share if they are somewhere unfamiliar. Most participants said they wouldn't want to share, but it was good to have the choice.

- “I might like someone to stay with me in hospital”
- “I didn't get a choice who I lived with in my house”

Comments and concerns

The inclusion of the statement about the use of CCTV cameras was met with some reservations by all participants. It was considered important that CCTV is only used when there is a very good reason for this. There should be a clear justification for the installation of CCTV. There should be choice and discussion about the use of CCTV not just informing people of it. People need to understand what they are for. Discussions about how to remain private should be had.

This standard talks about the environment but examples are only relating to the cleanliness and maintenance of the building. People thought there is more to environment than just having a clean well maintained building. The atmosphere, decor and ambiance should also be considered.

The Easy Read version needs to include “if I live in a care home” on the statements that apply only to care homes. This is written on the non-easy read but not included in the easy read version of the standards.

Conclusion

Overall, participants at our two events recognised the importance of the standards and agreed with the principles which underpin them. Everyone agreed with the standard headings and there was broad support for statements that relate to these.

Most of the standards and the statements given to illustrate them were considered to be applicable to both health and social care services. There were a few that people thought were less suited to health services than they were to social care services.

The main criticisms from the events concerned the nature of the easy read document. Some participants said the easy read version felt rushed and that there was potential for the statements to be misleading or misconstrued. Comments were made on a number of specific statements that it was felt needed provisos attached but most of the suggested improvements related specifically to the wording of the statements.

This lack of clarity throughout the easy read made it harder for people with learning disabilities to participate fully in the consultation process. A significant amount of time at the events clarifying misunderstandings about the standards caused by misleading information in the easy read.

Ensuring that people with learning disabilities can access and understand the standards in sufficiently clear and simple terms will be crucial for effective implementation of the standards going forward.