

## National Health and Social Care Standards Consultation

### Down's Syndrome Scotland

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*Down's Syndrome Scotland welcomes the opportunity to respond to this consultation. As a charity, we work to improve the quality of life of people with Down's syndrome (Ds) and their families across Scotland.*

#### **Q1: To what extent do you think the Standards will be relevant and can be applied across all health, care and social work settings?**

The standards are relevant. However at present and given the evidence DSS has gathered from members it is fair to say that the standards do not necessarily reflect the care received by all people with Ds in Scotland. As one of our members points out the standards hardly reflect the services that her daughter has accessed over the last 16 years. She adds: 'Unless there is a commitment to bring services up to, or even close, to this standard, then it would be dishonest of the Government to issue them'.

#### **Q2: To what extent do these Standards reflect the experience of people with care and support?**

As always the care people experience often depends on where they live and whom they see. Many of our members have had good experiences in care but a lot of families have also experienced poor service, especially during stays in hospitals. As per our answer above, some parents would also argue that the standards do not represent what they have encountered until now in terms of access to quality care and support.

#### **Q3: (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?**

*1.1: I am accepted and valued whatever my needs, disability, gender, age, faith, spirituality, mental health status, background or sexual orientation.*

One of our members believes that 'this statement should be more inclusive, the current statement has included groups [e.g. disability, gender, age], it should clearly include everyone, and say "Everyone should be accepted and valued, no exceptions"'.

*1.3: I am supported and cared for using a positive and understanding approach, even if my behaviour is challenging to others.*

Further to a public petition [PE01548 on National Restraint and Seclusion by Beth Morrison], the Scottish Government agreed to consider new guidance on the use of Restraint and Seclusion in schools against children with disabilities last year. However progress is slow. In light of the new standards, DSS would argue that further consideration should be given to Ms Morrison's petition by the government with a view to protect the rights of children with disabilities. Such move would

demonstrate the relevance of health and social care standards in all settings and their role in ensuring that every child in Scotland is indeed treated with dignity and respect.

*1.8: 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.*

Our evidence suggests that if many families do receive great support, too often children or adults with Ds are still confronted with a lack of understanding of their condition and at times a lack of respect from staff. Our members tell us that 'some staff have been wonderful but most have preconceived notions and very little time'. People ask 'give me time to answer' and would like staff 'to be more understanding and patient as it takes time for [children or adults with Ds] to explain what is wrong'. Others explain that 'doctors and nurses can be rude sometimes' or that 'usually the doctors are very nice but once one doctor said hello to me asked me to get on the couch then carried out a procedure with no explanation of what he was doing - I had had it done before but I was a bit upset he did not talk to me'. Some parents clearly say 'we dread going' at the thought of returning to the hospital for an appointment. These are just a handful of examples gathered from our membership in terms of their experience with healthcare services and it illustrates that a lot more work needs to be done to reach the quality of standards this consultation is considering. Words on paper will not suffice.

*1.9: I am supported to discuss changes in my life, including death or dying, this is handled sensitively and my wishes and choices are respected.*

According to a parent, this should have a statement added, such as 'within the context of the law'. Those who are ill/disabled/dying are the most vulnerable in society, it would be prudent to ensure that at such a precarious time that carers are fully aware of the statutory protection afforded to people at this time'.

*1.22: If I, or others, have concerns about my health and wellbeing, these are acted on and appropriate assessments and referrals are made.*

Some of our members would question the response they received from services after raising their concerns (hospitals and care homes). We have evidence that some families have had 'difficulty in convincing staff that something is wrong [with their child] because the patient does not present in usual way and cannot communicate'. Another told us that 'it took months for doctors to discover [their son] had gastritis and ulcer as all he ever did was collapse to the floor when he was in pain. There were no other clues to what was wrong, he never once said he had a sore stomach. This was put down to 'attention seeking' until he started to lose weight and started screaming one weekend when he was eventually admitted to hospital after being turned away from A&E the previous night. All because he couldn't tell doctors what was wrong and once the pain had passed (usually when the doctor examined him) he said he was 'fine'.

*1.27: I am helped to access the health care that I need and any other public services.*

A mother told us how her son has been poorly treated while residing in a care home. She took him regularly to dentist/hygienist all his life. In care she was assured this would be seen to, it wasn't despite her calling the care unit every 6 months to. After more than 3 years, care staff made a dental appointment - only after his mother

declined to get off the phone until they promised to actually do so! Her son was experiencing 'oral pain when eating' at the time. No one should have to go to such desperate measures to ensure that their son/daughter/sibling is treated with respect and looked after. The publication of new standards will hopefully ensure greater consistency in terms of service delivery across Scotland but greater work should also be undertaken to ensure families know about the standards and can get help to complain about them when things go wrong.

*1.49: If I attend all day and I am under school age, I can if needed have a sleep on a sleeping mat or bed with my own bed linen.*

One parent argues that 'it is probably not good for many reasons to have vulnerable people sleeping in a public area and sleeping during the day. It leads to vulnerability and bad sleeping patterns. If there are sleep issues they should be addressed and resolved for an individual'.

*1.50: I can choose to grow, cook and eat my own food, if possible.*

One parent rightly says that she doesn't see how this is a standard that can be met regarding being able to provide facilities/resources to grow food for a child in its early years.

**Q4: (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?**

*2.4: I am supported to communicate in a way that is right for me, at my own pace, by people who are sensitive to me and my needs.*

See answer to point 1.8 above. Our members would appreciate if some staff were able to use sign language and/or use pictures to explain to patients who they are/ what they are doing etc. At present communication appears to be lacking in places, it would thus be difficult to achieve standard 2 if not more efforts are being made to actually engage with and listen to patients with learning disabilities, especially in hospitals.

**Q5: (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?**

*3.1 and 3.18: I experience people speaking and listening to me in a way that is courteous and respectful, with my care and support being the main focus of people's attention, and, people have enough time to support and care for me and to speak with me.*

see answers to points 1.8 and 2.4 above.

**Q6: (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?**

*4.2 – 4.3 – 4.16 – 4.17: I receive an apology if things go wrong with my care and support or my human rights are not respected and the organisation takes responsibility for its actions; I use a service where all people are respected and*

*valued; I know how to make a complaint or raise a concern about my care and support; If I have a concern or complaint, I know this will be acted on without negative consequences.*

The issue of complaint is a significant one and one of the problems at present is that patients and their families are often not aware of the existence of such standards. As one mother explains: 'I was unaware that these standards existed over the last half century and no-one in our household was aware of them. Assuming that those providing public services have a similar set of standards to adhere to, is there any need for this second set of standards, such as this, to exist?' More attention should also be given to the way complaints are handled and the length of the process. Families often do not have the resources or energy to fight once again for their rights after things went wrong - it would thus be helpful if that could be taken into account.

**Q7: (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?**

*5.12-13: I experience a service as near as possible to people who are important to me and my home area if I want this and if it is safe, and, the location and type of premises enable me to experience care and support free from isolation and for me to be an active member of the local community if this is appropriate.*

One of our parents believes that 'often services for special needs provision are centralised rather than accommodated locally. Unless there is a commitment and budget to change this, then this is an unattainable standard'.

*5.15: I can independently access all parts of the premises I use and the environment has been designed to promote this.*

One of our members notes that 'often special needs provision do not fulfil the stated criteria. Unless there is a commitment and a budget to change this, this is an unattainable standard'.