



Down's Syndrome Scotland

helping people realise their potential

Tuesday 25th July 2017

Dear Convener,

Call for Views: Clinical Governance

Down's Syndrome Scotland (DSS) welcomes the opportunity to respond to this call for views from the Health & Sport Committee of the Scottish Parliament.

DSS is the only Scottish charity focused solely on the needs of people with Down's syndrome (Ds) and their family carers. We provide information, support and services for people with Ds, their families, carers and those with a professional interest. We also seek to improve public knowledge and understanding of Ds and to champion the rights of people with Ds.

In March 2017 we published a report [*Listen to Me, I Have a Voice*](#) focusing on our members' experiences with healthcare services. Many respondents reported that professionals have been helpful and that they have access to good services. However findings also highlight inconsistent levels of care across Scotland and too many families are still facing negative attitudes and poor communication from healthcare professionals.

Are services safe, effective, and evidence-based?

Members who reported good experiences can contact professionals whom they describe as kind, respectful and with knowledge of Ds. Respondents also praise staff who truly listen to their concerns and take time to explain procedures. The role of multidisciplinary teams in reviewing a patient's needs is also seen as an example of best practice by some carers. A carer was particularly keen to promote the work of the Integrated Health and Social Care Centre based in Kirkintilloch. Health and social care professionals work under one roof thus facilitating the coordination of all services. Importantly there is also a psychiatry service available for people with learning disabilities. As people with Ds grow older this service is crucial to check for conditions like dementia. As she explained in her feedback: 'they work in one large building so the social worker can and did liaise directly with the psychiatry service over suspected onset of Alzheimer's'. In this case, our member also told us that she can rely on a GP who 'always replies to my correspondence and will ring me to discuss issues when I request it'. She describes him as 'outstandingly helpful'.

Down's syndrome causes varying degrees of intellectual and physical disability and associated medical issues (which may include heart disorders, hearing and vision problems, thyroid problem or dementia). The questionnaire we sent out was also an opportunity to assess how much parents/carers know about the health conditions associated with Ds. The majority of parents declared being aware of conditions associated with Ds which is good news. But it is worth noting that many also commented on the fact that their knowledge is often the result of their own research or information provided by organisations like DSS.

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INVESTOR IN PEOPLE

'There are lots of things you as a special needs parent are unaware of. (...) You tend to find out through other parents rather than health professionals e.g. continence items are free after age 3'.

Moreover our research reveals a gap in the provision of recommended health checks for people with Ds¹². Feedback indicates that half of the parents caring for an adult with Ds are unaware of recommended checks. A mother also asked in her response: *'My son is over 50 years - are there any signs I should look out for regarding his health?'* From the age of 40 adults with Ds have an increased risk of developing dementia. The comment above illustrates how healthcare services need to be more proactive to ensure early intervention becomes reality. We believe that it should not be incumbent on parents/carers to search for information on health conditions. DSS is of the view that services need to provide families with relevant information as and when required. Even though many respondents find that services in their area are helpful, the report highlights that not all people with Ds receive the highest standard of care that would help improve their quality of life.

Are patient and service users' perspectives taken into account in the planning and delivery of services?

Unsurprisingly families report that the quality of care for patients with Ds often varies depending on where they live and who is supporting them. The testimony below highlights the inconsistency in accessing good services that people with Ds and their parents/carers have to cope with:

'Most professionals are kind and caring and go out of their way to get to know our son and talk to him on a level he can understand. Most ask his opinion about care choices and he enjoys his visits to the hospital, GP, optician and dentist. The school nurse (mainstream school) is always positive about his capabilities managing to have him dry at night within 3 weeks of using an enuresis alarm and gradually gaining his confidence to have finger pricks and then immunisations done without me being present. We have however visited a paediatric consultant (now retired) who refused to refer my son to ENT for constant nasal infections insisting that his problem was more likely caused by a damp house. It wasn't damp and my son had his tonsils and adenoids done within weeks of GP referral as they were obstructing his breathing! Same consultant tried to persuade me that my son would be very loving but would not achieve anything so don't bother trying mainstream education. We have not had paediatric consultant input since that point about 10 years ago and my son has attended mainstream school. There is no paediatric learning disability team in Moray so we have had to do our own research and contact DSS for advice when stuck'.

The majority of adults with Ds also declare being happy with services. Nevertheless qualitative findings show that their perspective is not always taken into account. In fact our members say that they would like more time to talk to doctors. Longer appointments would help them and their parents/carers feel better supported by healthcare professionals. Some respondents also explained that it would be helpful if professionals could use pictures or sign language to communicate with them.

Furthermore our research illustrates how crucial the support of carers is in terms of facilitating access to services for people with Ds. Findings specifically reveal how significant the role of mothers is. One adult with Ds thus reports: *'everything is fine at this point. I rely*

¹ See *A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability*, Royal College of General Practitioners, 2010, p.5.

² See *The Keys to Life: Improving quality of life for people with learning disabilities*, Scottish Government, 2013, p.29. Available at: <https://keystolife.info/>.

on my mum to make all arrangements'. Mothers arrange necessary appointments, attend consultations with their son/daughter, and deal with test results; they also describe themselves as 'translators' and nurses. Moreover mothers themselves question whether the quality of service received by their son/daughter would be the same if they were not in the room with them. One of them says: 'I (the mother) am always the one who talks to the doctors so have no experience about how she would be treated if she was seen by herself'.

Finally findings from the survey illustrate how parents too often have to fight for tests to be carried out or to get a referral to a specialist. Parents of children and adults with Ds have to fight to access services that should be available to all including education or employment and health is no exception. One mother wrote: 'We seem to have to 'fight' for everything. Education support, healthcare, being included in the community, it's all SO hard!' Another explains 'you get to learn and know how the system works regarding my daughter's health and wellbeing. So I know to go to the top of the tree if anything is not done correctly'. But healthcare should not be a competition between parents/carers and professionals. The wellbeing of children and adult with Ds should not depend on whether their carers have the energy and resources to fight to protect their rights.

Do services treat people with dignity and respect?

It is worth pointing out that too many families still face poor communication and negative attitudes from some professionals. A mother explains: 'Really negative experience was a health visitor "springing" a developmental questionnaire at me when attending for vaccinations, and not adjusting questions or stopping, as I became more upset having to answer "no" to most questions'. Parents are also deeply hurt by the language used by some professionals who refer to their child as 'a Down's baby' for example. Another parent described the attitude of a consultant orthopaedic surgeon who said (referring to her daughter) 'many Down's walk like that' and 'she'll get used to it'. DSS is of the view that all staff should practice 'People First Language'³. Professionals should also stop labelling people with Ds and adapt their methods of assessment to match the cognitive abilities of each patient.

Importantly some parents also chose to share their experiences of ante- and/or post-natal care. Most comments revealed very poor attitudes from professionals - with expectant mothers feeling pushed towards having a termination - and a lack of respect towards patients' decisions. Evidence also emphasise a clear lack of support for expectant/new parents at the point of diagnosis.

'When my screening results came back at 1:30 chance of our baby having Ds, the foetal abnormality midwife straight away offered us an amniocentesis asap at 17 weeks as we were "getting to point in my pregnancy where a needle would need to be used to pierce the baby's heart to end the pregnancy if we waited any longer" these were her exact words, there was no discussion about Ds just the assumption that we would want to end the pregnancy if our baby had Ds'.

'When [my daughter] was born a midwife told me "not to expect too much from [her]". [She] was 1 day old, we were just getting our heads round [her] having Ds and this was so upsetting!'

'After [my son] was born, I was left in a side room. The midwives kept closing the curtains and the door and told the Bounty photographer to "avoid room 6". I was really disheartened

³ See Down's Syndrome Scotland's Preferred Language Guide. Available at: <https://www.dsscotland.org.uk/resources/raise-your-awareness/preferred-language-guide/>.

and felt very alone and confused. I felt their attitude towards a new parent was pretty appalling; however other departments within the hospital where he gets his check-ups have been great with him’.

Findings from our questionnaire identify a serious lack of care towards expectant/new parents. It is important to also consider the consequences of such attitudes which may lead to mistrust towards healthcare professionals in the longer term. It is essential to get the right support and care at all stages. As a result DSS is asking for an urgent review of pregnancy screening practice and of the support provided to parents whose baby is diagnosed with Ds either pre- or post-birth. Patients need to be able to rely on fully trained professionals who possess relevant and up-to-date knowledge of Ds.

Are the correct systems in place to detect unacceptable quality of care and act appropriately when things go wrong?

On this point it is crucial to note and understand that patients are not always willing or able to complain about disrespect or poor services. This may be due to a variety of reasons which may include the lack of information regarding health and social care standards and not knowing how to complain about quality of care. Patients’ concerns may not have been taken seriously in the past and thus they do not trust the system any longer. Service users may also be put off by the length of the process before a complaint is comprehensively dealt with. Last but not least expectant or new parents may not be ready to face such challenge at a time when they may be struggling to cope with a diagnosis of Ds. Another argument could be made that systems might be in place to detect poor quality of care but that they do not necessarily reflect what patients and service users need. More research may be needed on a system that would truly empower people and the NHS to act more promptly.

In conclusion DSS believes that more attention has to be paid to improved staff knowledge and practice. Scotland’s NHS workforce face significant challenges and DSS is not advocating for all healthcare professionals to become experts in Ds. However not acknowledging and addressing the issue of training and negative assumptions about Ds among healthcare professionals will only reinforce ongoing health inequalities. The Scottish Government is working towards improving the quality of life of people with learning disabilities through strategies like *The Keys to Life*⁴ or *A Fairer Scotland for Disabled People*⁵. NHS Health Scotland also recently published its new plan for reducing health inequalities⁶. But children and adults with Ds will only enjoy the highest attainable standards of health when words on paper are actually implemented in practice throughout Scotland.

We trust these comments assist the Committee with its inquiry. Please do not hesitate to contact our office on 0131 442 8849 or by email at rachel@dsscotland.org.uk should you have any questions.

Yours sincerely,

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Policy Officer

⁴ *Keys to Life Implementation Framework 2015-17*, Scottish Government, 2015. Available at: <https://keystolife.info/updates/the-keys-to-life-implementation-framework-and-priorities-2015-17/>.

⁵ *A Fairer Scotland for Disabled People*, Scottish Government, December 2016. Available at: <http://www.gov.scot/Publications/2016/12/3778>.

⁶ Maximising the role of NHSScotland in reducing health inequalities, June 2017. Available at: <http://www.healthscotland.scot/publications/maximising-the-role-of-nhsscotland-in-reducing-health-inequalities>.