

LISTEN TO ME, I HAVE A VOICE

Healthcare experiences of children and adults with Down's syndrome and their families in Scotland.



Down's Syndrome Scotland

helping people realise their potential



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About Down's Syndrome Scotland

Down's Syndrome Scotland (DSS) is the only Scottish charity focused solely on the needs of people with Ds and their families. 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.

Down's syndrome (Ds) is a genetic condition caused by the presence of a full or partial third copy of chromosome 21 in the body's cells, it is not a disease. Ds usually occurs because of a chance happening at the time of conception. Approximately one in every 1,000 babies worldwide is born with Ds.

Background

People with learning disabilities are likely to experience significant health inequalities, despite often having more health concerns that require treatment¹. To address this, the Scottish government published the *Keys to Life: Implementation Framework and Priorities 2016-2017*. One of the key priorities of the framework is for people with learning disabilities to “enjoy the highest attainable standard of living, health and family life²”. Since then new policies have also been published, like *A Fairer Scotland for Disabled People*, which aim to improve the quality of lives of people with learning disabilities across Scotland³.

Access to good healthcare services and support from medical professionals constitutes significant factors in guaranteeing a good quality of life for people with Ds. But at present this represents a major concern for families. At a consultation event in November 2015, members told us that the lack of awareness about Ds among healthcare professionals was a serious issue. They also referred to the negative attitudes of professionals towards people with Down's syndrome (Ds) and their families. Further to that event we decided to gather more evidence on this issue to assess the quality of care received by people with Ds and their parents/ carers.

How we did this

Last year we sent out a questionnaire to our membership (1068 members, including 417 adults with Ds) focusing on their experiences with healthcare services. We received 418 forms back; a response rate of 39%. 201 responses were from adults with Ds (48%) and 217 from parents/carers (52%) – of the parents/carers who provided an answer, 84 care for an adult with Ds (39%) and 129 for a child with Ds (61%). It is also worth noting that of the parents/ carers who filled in the questionnaire, the majority of them are female.

¹ See *The Keys to Life: Improving quality of life for people with learning disabilities*, Scottish Government, 2013. Available at: <https://keystolive.info/>.

² *Keys to Life Implementation Framework 2015-17*, Scottish Government, 2015. Available at: <https://keystolive.info/updates/the-keys-to-life-implementation-framework-and-priorities-2015-17/>.

³ See *A Fairer Scotland for Disabled People*, Scottish Government, December 2016. Available at: <http://www.gov.scot/Publications/2016/12/3778>



The questionnaire for adults with Ds asked members whether they feel staff listened to them and treated them well during visits to the doctor or the hospital. They also had the opportunity to give feedback on how services could improve. A final question asked them to assess whether they are healthy or not. As for parents/carers, questions focused on their awareness of health conditions associated with Ds and knowledge of required annual health checks. It also asked for their views on the attitudes of healthcare professionals towards the person they care for and the effectiveness of healthcare services.

Aims

At a time when significant steps are taken at policy level to improve the lives of people with learning disabilities, it is important to ensure that the concerns of children and adults with Ds and their families are considered and addressed by relevant authorities.

This report summarises the main findings of our questionnaire which aims to identify examples of good practice as well as highlighting the main concerns of our membership regarding the effectiveness of healthcare services. This report aims to give a voice to people with Ds across Scotland and to their parents/carers. The findings should be used to improve the delivery of services across the country and raise awareness and understanding of the needs of children and adults with Ds.

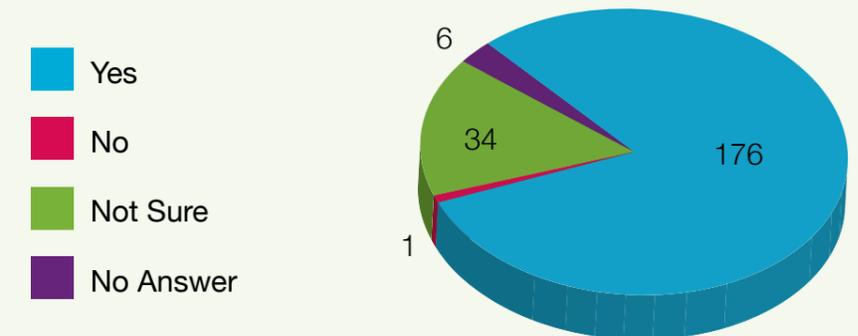
DSS would like to thank all members who took the time to complete the questionnaire and share their thoughts with us.



'I read everything I could about Ds when she was born!'

About 16% of parents/carers who responded are not sure about the health conditions associated with Ds.

Number of parents/carers who are aware of health conditions associated with Ds



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 therefore an opportunity to assess how much parents/carers know about the health conditions associated with Ds. The majority of parents/carers stated that they have some awareness of common health conditions associated with Ds. However 16% of respondents reported that they were unsure about common health conditions and many comments suggest a lack of awareness around the need for regular health checks. One parent explains: 'I thought I knew but recently discovered incidentally about other issues to look out for i.e. prone to severe lung conditions'.

Most importantly qualitative findings reveal that often parents/carers receive little information on health conditions from professionals themselves. One mother says: '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'. Parents who declare being aware of health conditions also explain that their knowledge is often the result of their own research or information provided by organisations like DSS.

'I would like to say that I know about most health conditions but there are parts that myself and other mums find out going to courses with DSS or even off other parents'.



Another area of concern raised by people who responded is the transition to adult services. As outlined in *Principles of Good Transitions 3*, transition is a period when young people 'are required to adjust to different experiences, expectations, processes, places and routines⁴. It is therefore a crucial stage for young people with Ds and their parents who report not being sure about what this entails. One mother explains: 'my daughter is now 16 and adulthood is looming. I need to be looking into what is due to come in the coming years'. During periods of transitions parents also tell us how their child's details can simply 'get lost in the system'. Parents/carers explain that may happen when children move to adult services, when there is a change in personnel like health visitors or when families move to a new local authority. If parents do not then chase up appointments for check-ups, children may not be seen by any professionals for a while.

Parents/carers see themselves as being aware of the health conditions associated with Ds. However comments from those who responded to the questionnaire reveal that they do not necessarily know of all the required checks. One parent asks: 'my son is over 50 years - are there any signs I should look out for regarding his health?' This comment illustrates how healthcare services need to be much more proactive to ensure that all people with Ds receive good quality of care. As adults with Ds grow older, health checks become crucial to identify conditions like dementia which can affect people with Ds from an early age⁵. We believe that it should not be incumbent on parents/carers to search for information on health conditions.

Recommendation 1: The Scottish Government should ensure healthcare professionals inform parents of health conditions associated with Ds and annual health checks as and when required as outlined by Down's Syndrome Medical Interest Group⁶ and the Royal College of General Practitioners⁷.

Recommendation 2: NHS Boards should acknowledge, disseminate and implement the *Principles of Good Transitions 3*⁸.

Recommendation 3: NHS Boards should follow and implement the recommendations outlined in *Dementia and Equality – Meeting the Challenge in Scotland*⁹ regarding the care of adults with Ds.

⁴ See *Principles of Good Transitions 3*, Scottish Transitions Forum, Introduction, p.20, January 2017. Available at: <https://scottishtransitions.org.uk/summary-download/>.

⁵ See 'Managing the care of adults with Down's Syndrome' by Kirstin M Jensen and Peter D Bulova—*Clinical Review*, BMJ, 349, 2014.

⁶ See Personal Child Health Record (PCHR), Down's Syndrome Medical Interest Group, 2011 Edition. Available at: <http://www.dsmig.org.uk/information-resources/personal-child-health-record-pchr/>.

⁷ See *A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability*, Royal College of General Practitioners, 2010: <http://www.rcgp.org.uk/about-us.aspx>.

⁸ See *Principles of Good Transitions 3*, Scottish Transitions Forum, January 2017. Available at: <https://scottishtransitions.org.uk/summary-download/>.

⁹ See *Dementia and Equality – Meeting the Challenge in Scotland: Recommendations of the National Advisory Group on Dementia and Equality*, NHS Health Scotland, 2016. Available at: <http://www.healthscotland.scot/publications/dementia-and-equality-meeting-the-challenge-in-scotland>.

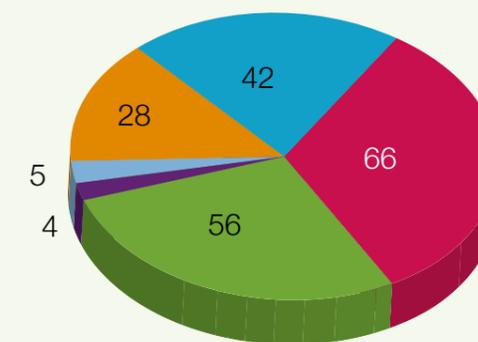


'I eat a pear for my snack. I exercise to get strong muscle'

Of the adults who responded to that question, 1 in 3 thinks their health is 'OK'.

How healthy do you think you are? (Adults with Ds)

- Very healthy
- Healthy
- OK
- Unhealthy
- Very unhealthy
- No Answer



In the questionnaire for adults with Ds we asked members to tell us how healthy they think they are. Almost 1 in 2 adults with Ds did not visit the hospital in the last year but 90% of them say that they saw the doctor in the last 12 months. Of the adults who answered that question, about a third says that their health is ok, while 62% argue that they are healthy or very healthy. Many comments left by respondents refer to the issue of weight. People with Ds have a slow metabolism and put on extra weight more easily, therefore this is a serious concern for many. A few describe how they avoid fizzy drinks and how many times they go swimming or walking every week in order to stay fit. Families also play a key role in ensuring a balanced diet.

'I always stick to my menu plans and like walking for exercise'

Despite this many respondents also tell us that they struggle to maintain a healthy weight. A few explain how they also have to manage other conditions like asthma or heart problems. Some are asking for help with their 'beer drinking' while others are overweight due to bad eating habits or a limited diet. The role of support workers is also questioned in some responses – some parents who helped their son/daughter complete the survey believe that they could be better supported to eat more healthily.



'My son is extremely overweight, he lives in supported housing and staff refuse to listen/carry out my instruction regarding his portions. They give him portions that would feed at least two or three adults'.

It is encouraging to see that our members are aware of the importance of diet and exercise in their daily life. However more support is needed for adults with Ds to maintain a healthy weight and enjoy a healthy lifestyle.

Recommendation 4: NHS Boards should ensure GP surgeries/local clinics are available to help and support adults with Ds with weight management.

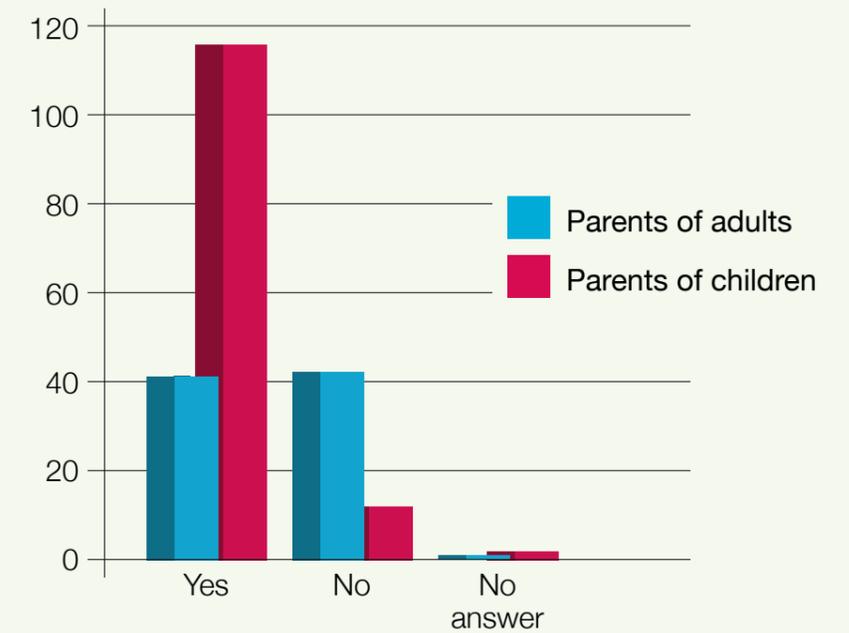


3

'If the recommended frequency of checks is annually, why is my daughter seen less often?'

Of the parents caring for an adult with Ds, 1 in 2 are not aware of annual health checks that should be completed for people with Ds.

Are you aware of annual health checks?



Our survey was an opportunity to gather evidence on the availability of annual health checks for people with Ds. The Royal College of General Practitioners (RCGP) argues that 'people with learning disabilities have poorer health than the general population, yet are less likely to access healthcare. [...] Even once identified the high prevalence of co morbid physical and mental conditions are often inadequately investigated and addressed¹⁰'.

¹⁰ 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.



The RCGP therefore recommends annual health checks for people with learning disabilities:

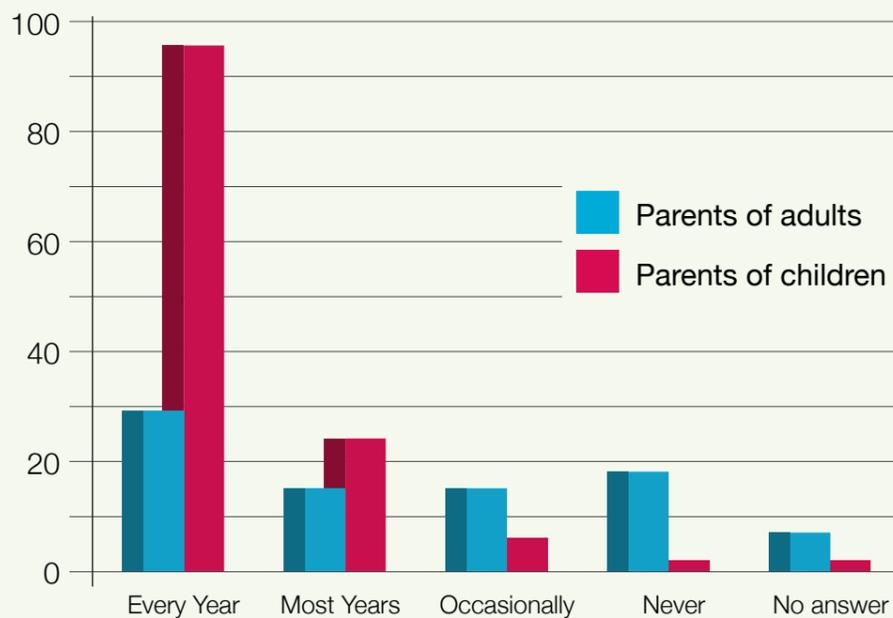
1. To improve health outcomes for people with learning disabilities.
2. To help identify and treat medical conditions early.
3. To screen for health issues particular to people with LD and specific conditions.
4. To improve access to generic health promotion in people with LD.
5. To develop relationships with GPs, practice nurses and primary care staff particularly after the comprehensive paediatric care finishes at the age of 18¹¹.

If recommended health checks are not being carried out this could only affect the quality of life of people with Ds who all too often already suffer from health inequalities¹².

Of the parents caring for an adult with Ds, more than half state that health checks have not been completed every year.

Of the parents caring for a child with Ds, about 1 in 4 says that their child does not get a health check every year.

Frequency of annual health checks:



Our research on this topic is particularly revealing and highlights serious concerns about the quality of care for people with Ds. Half of the parents caring for an adult with Ds declare not being aware of health checks that should be completed annually. Moreover it is important to note that among the respondents whose son/daughter gets annual health checks, qualitative findings illustrate that these checks do not necessarily entail a comprehensive health check as recommended by RCGP.

¹¹ 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.6.

¹² See 'Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study' by M. Buszewicz et al., *Lancet Psychiatry*, 1:522.30, 2014



'My daughter has bloods done every year for thyroid. She gets partial checks which took years to get. Her eyes get checked but I don't know about other things. She is 29 years'

More worrying is the fact that more than 1 in 5 parents/carers of an adult with Ds affirms that those checks have never taken place. People who responded argue that they have never been told of these checks. In some cases they explain that professionals are reluctant to arrange for these checks to be carried out.

'I have asked for this at my GP surgery on more than one occasion over the past couple of years but have been told they are still finalising the details. The last time I was told they couldn't agree on whether they should carry out a fasting blood sugar or not'

'GP surgery never suggested it. I requested thyroid investigations - that is now routinely monitored'

As far as children with Ds are concerned, it is surprising to find out that about a quarter of them are not being seen every year. According to parents/carers' feedback on this issue, as children grow up checks are more likely to be missed because of a change in staff or a move to new local authority which results in the child's details getting lost in the system. Families also face a postcode lottery in terms of access to healthcare services. An argument could be made that this is also likely to lead to poorer transitions to adult services with families not receiving relevant information because services do not have their child's details.

'Some health authorities do [check-ups] every year and some two yearly (we moved when our son was 6 and found different areas do things differently no matter what the rules are)'

Finally 28% of parents/carers explain that they do not receive any reminder from the paediatrician, GP or any other professional about the checks. Again families are therefore under a lot of pressure to gather relevant information, remember checks and chase up appointments. Services need to be much more pro-active to ensure that every child and adult with Ds receives appropriate healthcare and do not get lost in the system. Families need to be informed of necessary annual health checks and be given relevant information on what the checks will entail ahead of the appointment. Appointments could also be booked months in advance since health checks have to be carried out on a yearly basis.

Recommendation 5: The Scottish Government should ensure that every CHILD and ADULT with Ds in Scotland is being seen by relevant professional(s) for health checks.

Recommendation 6: NHS Boards should ensure that appointments for annual health checks are booked in advance and reminders sent to patient and carer closer to the time.

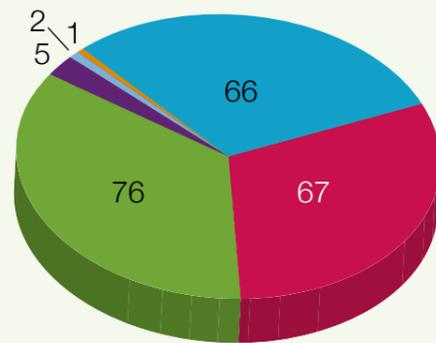


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Factors that facilitate positive experiences

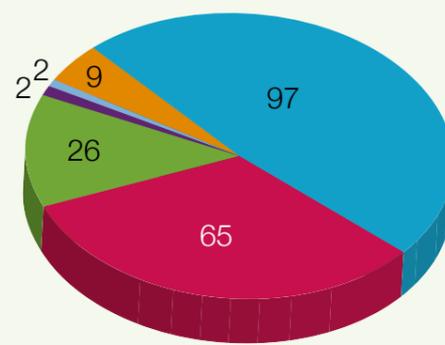
On balance how happy are you with the attitudes of health professionals towards the person with Ds?

- Very happy
- Happy
- Mixed
- Unhappy
- Very unhappy
- No Answer



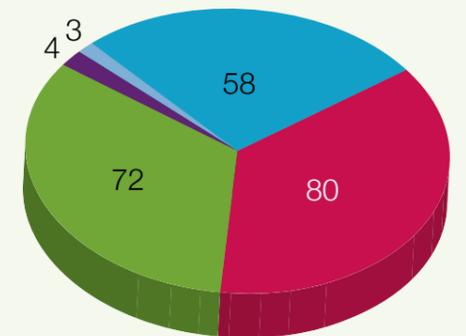
Overall how do you think your experience was? (Adults with Ds)

- Very good
- Good
- OK
- Bad
- Very bad
- No Answer



On balance how helpful have health professionals been in addressing the needs of the person with Ds?

- Very helpful
- Helpful
- Mixed
- Unhelpful
- No Answer



80% of adults with Ds declare that their overall experience with healthcare services was good or very good, while 64% of parents/carers explain that professionals have been very helpful or helpful. This is of course a positive message.

• The doctor 'was very kind, caring, and respectful'

Parents/carers who report good practice explain that health professionals take time to explain procedures, appointments and other tests in a quiet and relaxed atmosphere. Older parents have also noticed progress over the years with one mother explaining that 'every one (**nowadays**) is extremely kind, polite and inclusive of [my daughter] at all (varied) appointments'.

'Visits are made first to make him feel comfortable before anything is done. It took a few visits before the dentist was able to look into my son's mouth. Now he is quite happy to visit the dentist'

'Nurses spent 2 hours at home with him when resistant to plaster removal'

It is interesting to note that several parents commented that the professionals they see are 'ok' but parents still observe how negative or patronising they can be towards their children. Parents also state that professionals can be very nice and helpful but have not much understanding of Ds.

'Our GP practice is very helpful and always strives to see our son as soon as possible. They do not have any real in depth knowledge of Down's syndrome. I often seem to know more than them.'

• Professionals with knowledge of Ds

The majority of adults with Ds feel that professionals listen to them and treat them well. Nevertheless qualitative findings show a more nuanced picture. Indeed out of 162 adults with Ds who declare that their experience was overall very good/good, 38% of them left comments in their responses on how services could be improved to guarantee better support and care. For example one member is asking for 'a wee bit more time on appointment as I usually go myself to talk to doctor'. Their comments specifically focus on giving people more time to speak



and for professionals to make more efforts to actually communicate with patients. Feedback from adults with Ds therefore outlines opportunities for improvement within services even when they appear to fulfil their role at first sight.

As parents/carers' comments demonstrate, it is essential for professionals to explain things clearly, using simple words and to give patients and families enough time to express themselves. For this healthcare professionals need to have a good understanding of Ds.

'All involved allowed me time to speak and also welcomed my helper/ guardian and listened to them too'.

'When I visit the nurse, I am anxious about having blood taken, but the nurse reassures me and calms me before they take blood'.

Respondents also suggest that it would be helpful if professionals could use sign language and/or pictures to explain what they are doing.

- **Importance of multidisciplinary team**

Some of the respondents who declare being happy with services emphasise that their son/daughter benefits from the input of a multidisciplinary team which carries out reviews and includes a wide range of professionals like physiotherapist, dietician, nurse, psychologist, and speech therapist.

Case Study

Integrated Health and Social Care Centre

One of our members shares her experience of the support one of her relatives who has Ds gets in East Dunbartonshire. The quality of care that her relative receives has significantly improved in the past decade and she is particularly keen to promote the work done via 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 e.g. social work, care manager, nurse. 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 for example. As the respondent notes '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'.

Welfare guardian of a 54 year old man

Recommendation 7: NHS Scotland should share examples of good practice across NHS Boards to work towards greater consistency in Scotland.



5

Barriers to positive experiences

As well as examples of good practice, this reports needs to identify issues of concern with regard to the attitudes of personnel and the effectiveness of services. Figures show that 1 in 3 parents has mixed healthcare experiences and this cannot be ignored. It is essential to give a voice to the respondents who shared less positive experiences which illustrate how some services are run and how patients and their families can be treated.

Qualitative findings show that patients and their families seem to have poorer experiences during visits to the hospital. There is also a shared feeling among parents/carers that the quality of care depends on the professional families see and where they live.

Case Study

Variation in care

The experiences from this family illustrate how the quality of care patients with Ds receive often varies depending on who is supporting them. From great support to lack of care the testimony below highlights the inconsistency in accessing good services and reliable professionals 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'.

Mother of a 16 year old boy



• **‘Consultant orthopaedic surgeon [...] said ‘many Down’s’ walk like that and ‘she’ll get used to it’**

The use of poor terminology is an important point raised by our members. Parents/carers are hurt by the use of terms like ‘but he’s a Down’s baby/kid’ or ‘they’ when referring to their child. A mother thus describes her experience with a new doctor: ‘her attitude to addressing my daughter was not by her name but by her condition, e.g. “it’s very well-known Down syndromes will have all different issues, most of THEM usually only get worse as they get older, GET HER to wear these, it will stop that squint for the time being” [...] This hasn’t been the first time my daughter has been called something other than her name and it was Down’s syndrome that she was associated with, it’s infuriating’.

Words are powerful tools. Poor language not only shows disrespect towards people with Ds and their families, it can also have a profound effect on parents who speak about feeling sad, upset and isolated because of these attitudes. The behaviour of some professionals also makes some parents feel like a nuisance when they ask for help.

‘Nurse at Sick Children’s Hospital kept referring to my son as a child with Trisomy 21. A doctor was very cold towards my son and said that I must have the patience of a saint when he was misbehaving. On these two occasions I felt isolated and sad’

This is simply not acceptable. *A Fairer Scotland for Disabled People* states that ‘by using positive and empowering words, we can change the way people see disability’¹³. Now is the time to put words into practice and focus on language as a care standard. As a charity we encourage everyone to practice “people first” language. A person with Down’s syndrome is NOT a Down’s child; they ARE a person with Down’s syndrome. This should be implemented across healthcare services.

Recommendation 8: NHS Scotland should acknowledge and confront the use of language with its workforce and ensure that ALL healthcare professionals practice ‘People First’ language.

• **I hate the phrase ‘it’s common in Ds’**

Among the parents/carers who report mixed experiences with services, it is worrying to note that parents question the quality of health assessments performed for their child. Some also explain how assessments do not always match the cognitive skills of their child.

‘The thoroughness of the annual review is a bit hit or miss, dependant on the paediatrician’

¹³ See *A Fairer Scotland for Disabled People*, Scottish Government, December 2016, p.7. Available at: <http://www.gov.scot/Publications/2016/12/3778>.



‘Mental health and sensory issues are frequently not addressed helpfully. Child has real issues with things near head - so hair washing, haircuts etc. Recommendations have included letting them play with hair clippers. Now at stage where last haircut required four people - three to try and calm child, while one attempts to cut hair’

As explained in the previous section, patients and families want to be able to rely on professionals who know and understand Ds. However too many are confronted with poor practice and they explain how their child can be ‘labelled’ as having Ds. Some families also had to face professionals who suggested that their son/daughter will just have to put up with problems such as limping or ear infections because they have Ds.

‘Professionals are usually very positive but on a few occasions we have had a “good for Down’s” diagnosis and found reluctance to intervene as quickly as for a typically developing child’

‘We do feel that all the time we take our daughter to the GP they say that “it is normal for children with Ds” which is clearly not’.

Recommendation 9: All healthcare professionals should review their methods of assessments to match the cognitive skills of patients and listen and acknowledge parents/carers’ concerns.

Recommendation 10: NHS Boards should consider the setup of multidisciplinary teams to perform holistic assessment of patients.

• **‘There is a difference between listening and being given lip service’**

Listening is crucial in establishing trust between patients, parents/carers and professionals. Adults with Ds are likely to take longer to explain their symptoms and they want to be given the chance to speak for themselves. Most importantly they do not always get the impression that their views matter. Too often they are simply not given the opportunity to take part in a conversation due to short appointments and a lack of understanding from staff. When asked how doctors could do a better job, ‘give me time to answer’ is one of the most important asks from the members who replied to the questionnaire. One adult reports that ‘sometimes the doctor shouts as though I am deaf. My mum had to say there is nothing wrong with my hearing. I just need things explained simply, in a normal voice.’

Furthermore qualitative responses from parents/carers highlight the difficulty families can encounter in receiving help because their concerns are being dismissed. Some parents explain that they simply ‘dread going’ to the hospital. Others describe their ‘difficulty in convincing staff that something is wrong



because the patient does not present in usual way and the patient cannot communicate.'

'I took my son regularly to 'normal' dentist since he was a baby. (...) About 7/8 years ago I was told I had to put him into permanent care or lose day care and respite. He went from 2 annual visit to dentist and 3 visits to hygienist to NONE. (...) I had a meeting about dental care. I was assured he would get preventative dentistry. He had none for years then I refused to get off the phone until he was seen. This was YEARS! He had 5 teeth extracted in Sept 2013'.

Poor practice can also have potential devastating consequences for the patient, his/her family and also be costly for the NHS. As one mother points out: 'serious lack of good practice during hospitalisation for pneumonia with zero support for us as parents. Traumatic experience led to a year of psychology input to deal with anxieties caused by stay. Would have been more cost effective for the NHS if staff at hospital had respected him and cared about his wellbeing at the time'.

- **'Just because it's quicker to do a blood test one way, it doesn't mean a young child should be traumatised for the sake of saving time'**

As indicated previously in the report, patients experience good quality of care when professionals take time to communicate with them by addressing any concerns and explaining procedures in a simple way. For the families who experienced poor support, the lack of knowledge of professionals on how to communicate with people with Ds is a source of concern. It is important to understand that lack of communication can result in causing distress for patients and parents/carers.

'Lack of knowledge of how to approach/communicate with learning disabled children caused distress on several occasions e.g. taking blood, being examined, taking x-rays, giving medicine. In general most people are not deliberately cruel or impatient; they lack the time/knowledge to allow the children to come to terms with stressful situations thereby making the experience even more unpleasant'.

Parents explain how at times professionals do not speak to their child directly or are patronising. One mother comments that 'sometimes as [her daughter] cannot speak or walk she feels she is treated like a baby...she is 4. They can't communicate with her as many cannot use sign language'. Another family also told us of their efforts to reduce their son's very strong phobia about doctors and hospital due to earlier life experiences by visiting their local surgery/hospital. However it is disheartening to read that no doctors or medical staff had spoken to him during those visits.

Some answers also reveal how useful tools of communication like hospital passports are being discarded. As one mother tells us: 'a hospital passport had been filled in but the doctor had not looked past the first page to see it so did not know that my daughter had had open heart surgery twice until sounding her chest and seeing the scar!!'. She continues: 'one night while in hospital she had no tea because 'she didn't fill the form in'. I pointed out that she couldn't read and would need it read to her to make a choice. They did get her some toast but again...lack of communication because this was in the hospital passport!'



Communication is key to ensure high quality of care and support. Professionals need to be able to arrange for longer appointment for people with Ds. They also need better awareness of conditions like Ds and training on various ways to communicate with children and adults with Ds. It would also be helpful if specialist learning disability nurses were available at all time in all hospitals¹⁴. Healthcare services must adhere to UNCRPD principles by requiring 'health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care¹⁵'.

Case Study

Lack of care and support

The evidence below demonstrates the importance of listening to parents and emphasises the critical need for professionals to receive appropriate training.

'Initially when my son was discharged from Queen Elizabeth Hospital, approximately a month old we were not advised as to what health issues he might face. He had reflux; he was prescribed medication for this - other than that we were told to proceed as normal. When he started to have problems with feeding the Health Visitor and GP were in my opinion out of their depth. At no point did they suggest he might be aspirating (which is what we have now been advised was likely). Following a chest infection, likely aspiration incidents and severe reflux, my son was put on oxygen (4 months old), and has remained on it since. We spent about 3 weeks with him vomiting to a serious extent, and most likely aspirating milk. At 7 months he was given a nasogastric tube which appeared to assist greatly, and age 1 he had a fundoplication and gastrostomy. We have since been told that he had a safe swallow (he had all the diagnostic tests which confirmed this). As such it is possible that he had silent aspiration.

Following his successful surgery, my son was injured as he was recovering in the ward – his arm became swollen and inflamed due to lack of care and poor practice from nurses and doctors regarding the monitoring and dressing of cannula. My concerns about my son's wellbeing were ignored at the time. We submitted a complaint to NHS due to negligence regarding his care, also regarding him being referred to as 'the Down's boy' whilst within the intensive care unit. A year later we got an apology in respect of the lack of care and there was a change in the practice within the hospital on cannulas. With regard to him being referred to as 'the Down's boy' we were advised that there was insufficient information to evidence this.

As parents and in hindsight it is fair to say we were pretty clueless during the first year and very much guided by medical professionals. Until we were referred to the respiratory consultant in December 2013 I don't believe any of the medical professionals really gave us any advice of use.'

Mother of a three year old boy

¹⁴ See also 'Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'Getting it right' for people with learning disabilities receiving general hospitals care' by J. MacArthur et al., *Journal of Advanced Nursing*, January 2015.

¹⁵ Article 25, *UN Convention on the Rights of People with Disabilities*.



Recommendation 11: NHS Scotland should review workforce training and certify that relevant professionals have up-to-date knowledge of Ds so that all patients and their families are treated with dignity and respect.

• **Appointments and waiting times**

Another relevant point to raise, is that it can be difficult for our members to access healthcare services in the first place. Carers are struggling to book appointments while patients have to wait for lengthy time before being referred to specialists – one patient had to wait over 6 months for dental surgery. These issues affect all services and not only patients with Ds. However since it is common knowledge that people with Ds are more prone to some health conditions than others, booking appointments should not be the first hurdle our members have to overcome. Parents also argue that there is a need for better follow-up.

Our members also struggle with long waiting times. Often patients have to wait for too long and adults with Ds tell us that they get bored or more nervous because of this. In one case, parents actually complained to the hospital due to the lateness of appointments (at times 45mins to 1 hour beyond the time) and the lack of staff explanations/support when instructing [their son] to do something. One adult also suggests that a member of staff should 'come get you when it's your turn' because sometimes he does not hear what room the appointment is in. Time is the essence and healthcare professionals should be empowered to spend more time with children and adults with Ds.

Recommendation 12: NHS Boards should ensure services offer longer appointments and shorter waiting time for people with Ds and their families; and encourage GP surgeries to consider whether some tests could be performed by visiting patients with Ds at home to avoid the stress of going to surgery.



Health Visitors

As outlined in the *Universal Health Visiting Pathway in Scotland*, 'the early years have a profound impact on an individual's future experience of health and wellbeing. Health professionals, particularly Health Visitors, have a vital role to play in supporting children and families in the first few years of a child's life'¹⁶. Health Visitors are the main points of contact for families who have welcomed a baby with Ds and for parents who may still be struggling with the diagnosis. They have to build a relationship based on trust and understanding with the families they visit and their attitudes should be irreproachable.

There is at present a critical lack of Health Visitors and their workloads are significant. However these are no excuses for the poor behaviour some professionals display. In their responses to the questionnaire, parents/carers illustrate how services can go wrong leaving them feeling disempowered, hurt and frustrated. Our aim is to give a voice to these families so that services like health visiting teams can learn from those experiences which too often go unreported.

'Only yesterday, our health visitor referred to our son as a "Down's baby". My husband raised this with her. It hurts so much that health professionals label people'

'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'

'My health visitor was very negative - her first comment was this is my first down's baby! It then got worse she refused to send us on Makaton courses as it was "too expensive" and told me to buy a book. [...] She then ignored [my son's] constant sickness after feeding saying it's just his Ds. [...] I have since complained and due to a reshuffle of staff have a new Health Visitor but she still refers to Down's baby!! There is a complete ignorance in this area of health care!!'

Some parents are even considering moving to another local authority to access better services. Comments also reveal how Health Visitors leave or retire and are not being replaced leaving some families without any help.

The Scottish government's aim to recruit 500 new health visitors between 2014 and 2018, the implementation of the *Health Visitor Universal Pathway* and of recommendation 22 of *Fairer Scotland Action Plan*¹⁷ may help to improve services. But increasing the number of Health Visitors will be of little comfort to families if not more attention is given to the education and training of the workforce.

Recommendation 13: The Scottish Government and NHS Education for Scotland should review the formation of Health Visitors (student training and CPD) as a matter of urgency and guarantee that at least one Health Visitor per team has up-to-date knowledge of Ds.

¹⁶ See *Universal Health Visiting Pathway in Scotland*, Scottish Government, December 2015. Available at: <http://www.gov.scot/Publications/2015/10/9697/downloads#res-1>.

¹⁷ See *Fairer Scotland Action Plan*, Scottish Government, October 2016. Available at: <http://www.gov.scot/Publications/2016/10/9964>.



'If my mum wasn't able to be there at any time I would be sad'

We know that carers across Scotland play a vital role in supporting children and adults with Ds every day. Our research illustrates how crucial their support is in terms of supporting people with Ds to access healthcare services. The experience of members who responded to our survey also specifically reveals how significant the role of mothers is. One adult with Ds thus reports: 'everything is fine at this point. I rely 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. Of course people also receive support from other members of their family or support workers but the overwhelming evidence from our questionnaire is that mothers are the most likely to be involved in their child's healthcare.

Some adults with Ds were supported to fill in the questionnaire and their answers emphasise the role of advocate played by parent/carers. One of them explains: 'radiographer told mum she did not need to come with me. Mum said she would come in.'

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.

'I have normally been treated well but 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'

'My mum always takes me to the doctor so if she wasn't there I am not sure I would get on so well.'

Recommendation 14: NHS Boards should ensure parents feel welcome during visits to hospital and make provisions for them to attend checks and/or to stay overnight if required.



• 'Why do I have to be a fighter mummy for tests that should be available for our children?'

Parents of children and adults with Ds often have to fight to access a wide range of services that should be available to all including education or employment and health is no exception. Findings from the survey illustrate how they have to fight for tests to be carried out or to get a referral to a specialist.

'I also have to fight for a sleep study, which should be done yearly. Her paediatrician agreed. I saw respiratory consultant, he told me that because my daughter doesn't snore it is not needed. Sleep apnoea doesn't mean that the person snores, my daughter wriggles and has a really poor sleep I can't monitor her at night and her saturation can drop below 92 few times and I don't know.'

'We had problems with our paediatrician regarding tests for under active thyroid when she assumed [our daughter] didn't have that and I had to push and push for test and proved her wrong'.

'We seem to have to 'fight' for everything. Education support, healthcare being included in the community, it's all SO hard!'

At other times it is getting through the door that poses a problem; evidence illustrates the powerful position of GPs as gate keepers which can prove distressing for some people with Ds and their parents/carers.

'I asked GP to refer my son to audiology as he had an ear problem and GP refused. He said there was nothing the hospital could do and my son would have to live with it. I got a referral another way and my son had an operation which greatly relieved the pressure in his ear. It was only my persistence and 'getting in the back door' that made things happening. I refuse to see this GP now'.

'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'

Healthcare is not a game and access to good services should not be a competition between parents/carers and medical professionals. The wellbeing of children and adult with Ds in Scotland should not depend on whether parents/carers have the energy and resources to fight to protect their child's rights.

Recommendation 15: The Scottish Government should guarantee easy access to services for children and adults with Ds and protect a child's right to good quality health care¹⁸ and the right of people with disabilities to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability¹⁹.

¹⁸ Article 24, UN Convention on the Rights of the Child.

¹⁹ Article 25, UN Convention of the Rights of People with Disabilities.



Recommendation 16: The Scottish Government should ensure patients and families are familiar with care standards including the new National and Social Care Standards due in spring 2018; and that NHS Scotland support parents who wish to complain about services through a quick process.



Ante/Post-Natal Care

Our questionnaire did not ask for specific details about parents' experiences during pregnancy and/or shortly after birth. However a significant number of their comments refer to ante/post-natal care. More than 1 in 4 parents caring for a child with Ds chose to raise the issue.

Only three respondents who commented on this topic reported a positive experience. Their experiences emphasise once more the importance of communication and respect towards patients. One family describes how staff were respectful of their decision: 'we had a high "risk (!)" result after nuchal screening. We had already decided we wouldn't go for any invasive testing, and obstetric/ midwifery staff happy to go along with our decision. They offered to arrange a cardiac foetal scan which we appreciated, as being prepared for any significant problem was important to us'.

Case Study

Good practice following post-natal diagnosis

One mother describes how the care she received following the birth of their daughter was 'as positive an experience as possible'. In the recovery room, parents were given the baby pack delivered to all maternity units in Scotland by DSS with information about Ds and the organisation. Neonatal staff in Aberdeen Royal Infirmary were helpful and 'kept [her] informed at all times of [her] daughter's progress'. An appointment was also arranged quickly for them to see a specialist as their daughter was born with a congenital heart condition; they were given clear explanations by the consultant. Finally when their daughter was two days old, the associate paediatrician also gave them all the relevant information they needed and requested at the time.

Mother of a three year old girl.

However most of the comments describe very poor attitudes from professionals (including Midwives, Health Visitors, Nurses and consultants). From feeling pushed towards having a termination following a pre-natal diagnosis to being left alone after birth, parents share their experiences of what can only be described as appalling behaviours towards expectant/new parents. This is an issue that our members often raise and urgent action is needed to ensure that all expectant and new parents can rely on outstanding support and care within maternity services.



• 'Immediate question was did I wish to terminate'

'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 I was pregnant with my son I was told that I had a 3% chance of having a child with ds. They gave me a leaflet with the phrase "You may wish to terminate" on it. This was the phrase that came back to me when I had my son without anything positive to balance that up about children with Ds being able to live fulfilled lives'.

'Obstetrician who gave me prenatal diagnosis was only interested in knowing when I would be in for termination - very little idea what to do when I said I wasn't going to terminate the pregnancy'.

DSS continues to call for easily understood and up-to-date information to be provided in a balanced way by well trained professionals to parents. This should include:

- The accuracy of screening/test results and associated risks of further screening/tests for expectant parents;
- The life of a person with Ds in today's society;
- The impact on families (challenges and joys);
- The support available from Down's Syndrome Scotland and in the community;
- The offer of informed, broad and non-directive counselling from a suitable specialist.

• Lack of respect for patients' decisions

'When I was pregnant I refused screening as termination was not a route I would have considered. The ante natal nurses tried to make me feel shunned because I told them that I was not willing to risk miscarriage of my developing baby whether it had abnormalities or not. [...] The nurses were curt and clinical to me and I felt very upset that my choice was not respected or supported. I was 38 when my daughter was born in 1999 with Trisomy 21. She is 17 now and the apple of my eye'.

'I was unhappy with my midwife and other health professionals as they tried to bully me into amniotic testing for my second pregnancy - I was aware of the risks and made my own choices'.

'Midwives should not be allowed to go on and on about termination once a family have decided to continue with their pregnancy'.



• No information or support at point of diagnosis

'The delivery of our prenatal diagnosis was less than ideal: over the phone on a Friday afternoon. The specialist midwife delivering the news knew a Ds diagnosis wasn't a worry but still she said I'll let you prepare yourself it's not good news. I then assumed it was something else. When she said it was Ds I said that was fine. End of conversation. No offer of an appointment to discuss, information, where next. I had to phone her back to ask this. We were given an appointment for the following week and handed a pack of information and not a lot else. I will say that at no point was termination suggested or pressured. After birth health visitor service didn't seem to have much of a clue about a baby with Ds sending me into blind panic one day when they suggested she wasn't even on the graph (not using Ds one)'.

'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!'.

'Being told our son may have Ds in a bereavement room. Being asked after his birth if we want to take him home or leave him there!'.

'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 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 on this topic identify a serious lack of care and support towards expectant/new parents. Issues around the screening process and care and support available to parents following a diagnosis of Ds pre- or post-birth should be considered as a matter of urgency by the Scottish Government and NHS Scotland. Patients need professionals who are fully trained and possess relevant and up-to-date knowledge of Ds. The Scottish Government recently published *The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland*²⁰. Recommendations from the review are welcome however the plan falls short of addressing the needs of expectant/new parents during the screening process and/or at the point of diagnosis post- birth.

Recommendation 17: The Scottish Government should review pregnancy screening practice and the support offered to expectant parents pre-birth, as well as the support offered to new parents whose baby is diagnosed with Ds post-birth; this should include the training of relevant healthcare professionals.

²⁰ See *The Best Start: A Five-Year Forward Plan for Maternity and Neonatal Care in Scotland*, Scottish Government, January 2017. Available at: <http://www.gov.scot/Publications/2017/01/7728>.



Recommendation 18: All maternity units should distribute to expectant and new parents the baby packs produced and delivered to all units in Scotland by DSS.



Conclusion

The findings in this report provide an insight into the experiences of our members with healthcare services. Many respondents experience good quality of care and support which is to be welcomed. Based on the findings, we can identify several factors which facilitate positive experiences for children and adults with Ds and their families. Professionals who are caring and respectful with good communication skills make patients and parents/carers feel welcome. Good care and support also rely on professionals who understand what it means to have Ds and who are willing to adapt their methods to assess patients effectively. We also believe that multidisciplinary teams allow for better care and assessment of the needs of people with Ds.

However this report also highlights concerns around annual health checks for people with Ds. These checks must become standard practice and GP surgeries across Scotland need to arrange for them to take place now. Information should also be made more widely available to families regarding health conditions associated with Ds without parents having to fight for their rights. Findings also show that children and adults with Ds and their parents/carers still face poor attitudes from professionals. Issues around terminology and labelling of people must be addressed to guarantee that every child and adult with Ds in Scotland is treated with dignity and respect.

With regard to ante/post-natal care, findings from our questionnaire illustrate appalling behaviours from professionals who are supposed to support expectant/new parents. DSS therefore asks for the review of pregnancy screening practice as a matter of urgency, as well as a review of the support given to parents whose baby is diagnosed with Ds at birth.

Most importantly serious consideration needs to be given to the training of healthcare professionals from all services to ensure that every family no matter where they live can rely on professionals who understand the needs of people with Ds and how best to address them. Scotland's NHS workforce face significant challenges²¹ 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.

Over the past couple of years the Scottish Government has worked towards improving the quality of life of people with Ds through the publications of important strategies like *The Keys to Life* or *A Fairer Scotland for Disabled People*. Nonetheless these will likely fail if not more consideration is given to the implementation of these policies through improved staff knowledge and practice. Recommendations outlined in this report would help improve services for people with Ds and their families. 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.

²⁰ See *Scotland's NHS Workforce: The Current Picture*, Audit Scotland, February 2017. Available at: <http://www.audit-scotland.gov.uk/report/scotlands-nhs-workforce>.



Recommendations

- Recommendation 1:** The Scottish Government should ensure healthcare professionals inform parents/carers of health conditions associated with Ds and annual health checks required as outlined by Down's Syndrome Medical Interest Group and the Royal College of General Practitioners.
- Recommendation 2:** NHS Boards should acknowledge, disseminate and implement the *Principles of Good Transitions 3*.
- Recommendation 3:** NHS Boards should follow and implement the recommendations outlined in *Dementia and Equality – Meeting the Challenge in Scotland*²² regarding the care of adults with Ds.
- Recommendation 4:** NHS Boards should ensure GP surgeries/local clinics are available to help and support adults with Ds with weight management.
- Recommendation 5:** The Scottish Government should ensure that every CHILD and ADULT with Ds in Scotland is being seen by relevant professional(s) for health checks.
- Recommendation 6:** NHS Boards should ensure that appointments for annual health checks are booked in advance and reminders sent to patient and carer closer to the time.
- Recommendation 7:** NHS Scotland should share examples of good practice across NHS Boards to work towards greater consistency in Scotland.
- Recommendation 8:** NHS Scotland should acknowledge and confront the use of language with its workforce and ensure that ALL healthcare professionals practice 'People First' language.
- Recommendation 9:** All healthcare professionals should review their methods of assessments to match the cognitive skills of patients and listen and acknowledge parents/carers' concerns.
- Recommendation 10:** NHS Boards should consider the setup of multidisciplinary teams to perform holistic assessment of patients.
- Recommendation 11:** NHS Scotland should review workforce training and certify that relevant professionals have up-to-date knowledge of Ds so that all patients and their families are treated with dignity and respect.

²² See *Dementia and Equality – Meeting the Challenge in Scotland: Recommendations of the National Advisory Group on Dementia and Equality*, NHS Health Scotland, 2016. Available at: <http://www.healthscotland.scot/publications/dementia-and-equality-meeting-the-challenge-in-scotland>.



- Recommendation 12:** NHS Boards should ensure services offer longer appointments and shorter waiting time for people with Ds and their families, and encourage GP surgeries to consider whether some tests could be performed by visiting patients with Ds at home to avoid the stress of going to surgery.
- Recommendation 13:** The Scottish Government and NHS Education for Scotland should review the formation of health visitors (student training and CPD) as a matter of urgency and guarantee that at least one health visitor per team has up-to-date knowledge of Ds.
- Recommendation 14:** NHS Boards should ensure parents feel welcome during visits to hospital and make provisions for them to attend checks and/or to stay overnight if required.
- Recommendation 15:** The Scottish Government should guarantee easy access to services for children and adults with Ds and protect a child's right to good quality health care²³ and the right of people with disabilities to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.
- Recommendation 16:** The Scottish Government should ensure patients and families are familiar with care standards including the new *National and Social Care Standards* due in spring 2018; and that NHS Scotland support parents who wish to complain about services through a quick process.
- Recommendation 17:** The Scottish Government should review pregnancy screening practice and the support offered to expectant parents pre-birth, as well as the support offered to new parents whose baby is diagnosed with Ds post-birth; this should include the training of relevant healthcare professionals.
- Recommendation 18:** All maternity units should distribute to expectant and new parents the baby packs produced and delivered to all units in Scotland by DSS.

²³ Article 24, *UN Convention on the Rights of the Child*.



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