

Response ID ANON-N5Q2-P7UV-R

Submitted to **Scotland's Ten Year Strategy for the Learning Provision for Children and Young People with Complex Additional Support Needs 2017-2026**

Submitted on **2017-08-28 10:33:42**

Questions

Structure

Section 1. Our Vision, Aim and Objectives

1 Is this structure correct? Does the content of the document flow in a logical order?

No

Please explain your response.:

In our view the structure would be better if the 'Why we need strategic commissioning' and 'what are complex additional support needs?' sections currently on pages 5 and 6 were moved to page 4 after 'our vision'. At present the link between 'our vision' and 'aim' appears to be missing and adding another section in between them would help to make the document more logical.

2 Does the structure help the reader to follow the strategy effectively?

Yes

Please explain your response.:

Relevant information is definitely included. However at times it is difficult to understand the link between two sections. The section on the Doran review is obviously helpful to follow the strategy however its relevance is only understood once one has read the whole document. As a result it would be useful to have a couple of sentences explaining why the strategy is linked to the review at the very beginning of this section.

3 Do you think the aims of this Strategy and the four objectives are the right ones to achieve the Scottish Government's purpose of improving outcomes for children and young people with complex additional support needs through strategic commissioning of services?

Yes

Please explain your response and provide any relevant evidence.:

Section 2. Why we need Strategic Commissioning for Learners with Complex Additional Support Needs?

4 Within the context of The Doran Review recommendations – do you agree with the explanation of why we need Strategic Commissioning for national provision/services for learners with complex additional support needs?

Yes

Please explain your response.:

5 The 'Scope of Services to be commissioned' on page 8 relate to education, care and health, research and training and is informed by the Doran Review recommendations and the National Needs Analysis, which was completed in 2015. Can you please comment on any services within those headings which you would particularly wish to see featured here? Please tell us if you think it should exclude any aspects or include any others?

Education::

Care::

Health::

Research::

Training::

Section 3. 10 Year Strategy

6 What are your views on the National Commissioning Groups proposal that the first phase of strategic commissioning will focus on pathfinder (testing) activity on training, development and research? Are there any particular areas of training which should be focussed on?

Comments::

We would urge the National Commissioning Groups to first gather evidence already available on training, development and research and assess whether pathfinder activities are still needed or whether one can rely on existing evidence to prove the reliability of some schemes and thus move quicker to an

implementation phase. The issues that the strategy aims to deal with are not new and many projects may have taken place over the years identifying the best ways to solve problems. Instead of spending more time and resources on more pilot projects the group may be able to find relevant information that could help implement the strategy already.

One area important for training/research could be the learning profile of children with Down's syndrome (Ds). As one mother reports: 'There is not enough research around the way our children learn and this leads to some teachers finding it difficult to simply assess needs and plan lessons to accommodate'.

We know that each charity responding to this consultation is likely to ask for a focus on a specific condition and we understand that is not feasible. Nonetheless we firmly believe that one member per team should know about a specific condition like Ds or know whom to contact within the local authority's services or other agency to get the right support and information. This would also work towards partnership working and inter-agency collaboration.

7 For the purposes of this document the National Improvement Framework drivers have been adapted and therefore reflect particular concerns related to children with complex additional support needs? Do you have any suggestions for additions or alternative wording which should be included? Please set it out against the relevant heading below.

Service Leadership::

Education Services::

It is not clear whether input from parents and charities representing children with complex ASN would be sought when developing leadership programmes.

Practitioner Professionalism::

The evidence gathered by Down's Syndrome Scotland's (DSS) family supports service show that teachers complain of not having enough time to have discussion with learning assistants regarding the curriculum, forward planning and strategies to support a child's development. We also know that learning assistants complain of not having enough time to make resources etc.

Furthermore, parents explain that '[their] daughter's ongoing inclusion in mainstream education is dependant on the good grace of individuals and [their] willingness to go into battle to ensure her rights. The legal right to inclusion in mainstream is good, but it must be matched by a commitment to educate staff as to why SEN inclusion is essential in the 21st Century and how they are expected to meet the standards'.

DSS believe that training should be compulsory for anyone supporting children with complex ASN from teachers to support staff in school including janitors etc.

Parental Engagement::

On this issue parents are keen to emphasise how important it is to get it right. One mother explains 'engagement between parents and educational establishments is essential in the successful education of all children. Especially those who need additional support. Research demonstrates that parental engagement is one of the key contributing factors to educational success. Educational establishments need to go beyond inviting parents into school at times convenient for schools to convey information one way from school to home. Schools should ask parents what they think will help them to educate their child and have a conversation without preconceived ideas about outcomes and agendas'.

Another mother whose daughter attended a mainstream school before moving to a special school notes that 'parental engagement was very easy and school was transparent in primary mainstream but not easy to achieve in special school. I've been asking questions and trying to engage about my daughter's education and trying to get them to think about focusing on my daughter's strengths and develop them. This hasn't been looked upon favourably and has left me ostracised, The school have an outlook that they know everything / everything is fine. I continue to try and engage positively but it's very difficult as I am not seen as an equal partner. I have fully supported and supplemented my daughter's learning since birth and I do not intend to step back when her learning is stagnating and she has no clear direction'.

The evidence above demonstrates that more work has to be done to improve partnership between parents and schools. Parents have to be involved in their child's education and need to feel that they are being listened to. They also want their views to be acknowledged and taken into consideration. A key element to evidence 'strong partnership working' in due course will be to focus on parents' views of engagement and perhaps some work could be done comparing the main issues raised by parents and schools at present and then in a few years' time before a final report in 2026.

Regarding transitions, as outlined in our answer to question 6 much work may have already been done on specific topics and this is certainly true of transitions. Principles of Good Transitions 3 supported by the Scottish Government is of great significance and should be a focus of the strategy moving forward.

Moreover successful engagement on transitions also relies on establishing trust between parents and professionals.

Below is a relevant case study:

Family whose daughter is 17 and in mainstream high school:

'It's good to know that there are timelines in place to allow for enhanced transitions, and that generally works well. Nursery to school transition was very good, although there was no role for someone to co-ordinate action points following any multi-disciplinary review meeting, we had to ask someone to do this, as we could see lots of actions with no co-ordination. This situation could be rectified to ensure a well-co-ordinated transition.

Our primary to high school transition was not so good - While there is a council role for including children with Downs syndrome in primary schools, the resource doesn't extend to High School inclusion. There has been no accommodation made for a continued need for SALT in high school. SALT provision has been a battlefield for us since our daughter started in school. This has been frustrating as we understand that our children's needs should be accommodated in mainstream high school. We also understand that our daughter's speech will continue to develop into adulthood. SALT is an investment which pays off. There was reticence on the part of the high school link member of staff, which was fed back to other staff and created poor expectations of our daughter. No-one had responsibility to ensure that the transition adhered to equality standards. This could be why many children are not being included in mainstream high schools. We found council support staff (including the school Psychologist) and Downs's Syndrome Scotland to be supportive of inclusion. Others within the multidisciplinary group of people didn't seem to take this inclusion seriously. Some people didn't seem to know that they had an obligation to make every accommodation for our daughter in mainstream high school and/or didn't want to accommodate her. It was an intimidating atmosphere at transition meetings in which people found it difficult to speak out, in our opinion. We certainly felt intimidated'.

Assessment of Children's Progress::

We asked a few parents to give us their views on the role of coordinate support plans (CSPs). Below is the feedback we receive from a few families:

Family whose daughter is 13 and moved to a special school in P5:

'The current support plan is not being adhered to. School had agreed to provide two mainstream classes each week – [my daughter] is only going to one. This is due to poor organisation and communication between schools. Instead of looking at how communication could be improved they just aren't bothering. They don't seem to see all of the benefits for [my daughter]. It seems a bit of paper exercise. The school seems to act as though it's their job to chase up other agencies as opposed to carrying out their legal responsibilities'. The mother also adds that 'her daughter's specific needs are not met: no SLT (she goes privately), no physio (feet collapsing / flat / extreme flexibility - also goes privately to allow us to progress as no access) and no OT (fine and gross motor skill development issues)'.

Parents whose daughter is 17 and in mainstream school:

'We feel that the CSP is not given its proper place in discussions and decisions made by staff, in fact, we're unsure what its proper place is and what benefits it should have for our daughter'.

Another parent is also of the view that 'CSPs are largely irrelevant except in an extremely small number of cases. They are superseded by the practice of GIRFEC. Less time should be spent on CSPs and more on additional support in the wider sense. The Single Child's Plan is the powerful tool for most children'.

Moreover the strategy may also be an opportunity for the national Strategic Commissioning Group to review/discuss issues around data collection. In particular DSS would welcome better data on pupils leaving school and the so-called 'positive destination' statistics. We also believe that the 'leaving school' transition should be better monitored to properly assess the help received by young people at this critical time and ensure that their progress and wishes are truly supported.

Again parents report on the lack of support received in school:

'We don't feel that our daughter has received the right support for her, she is expected to take a post-school path designated for young people with Down's syndrome, which is woefully inadequate in helping her to achieve her full potential and not in line with GIRFEC and equality standards'. They add 'we haven't received any information from career advisors. There seems to be a lack of strategies within Skills Development Scotland to enable young people with Down's syndrome to aspire to a college course suited to their individual needs, leading to future employment opportunities. We understand that, for many years our children were brought up in institutions, in many cases these weren't positive destinations, one size fitted all. Therefore, we can see why it's difficult for support staff to imagine the future for our children beyond institutions. This issue must be acknowledged and Skills Development Scotland need to understand the history to change the future. There needs to be aspiration for more truly positive destinations for young people with Down's syndrome. We need to stop making our young people benefit dependant, we need to imagine a more positive future where the special skills of the learning disabled can be part of mainstream society. We think that more needs to be done to educate Skills Development Scotland staff around equality guidance which has been developed to include minority groups such as those with disability, to secure their independence. This would include the United Nations Convention on the Rights of People with Disabilities (UNCRPD) recently adopted by Scotland'.

Furthermore with regard to assessments it is also essential to involve children in the process and therefore develop formats which may rely on the use of pictures, sign language or videos for example. It is key to understand and acknowledge that one size does not fit all. Finally it is also crucial to discuss and explain to parents what is being agreed on and documented into the plan. They should also been told who keeps a copy of the plan and under which format (paper copy, online) and who should be their main contact regarding this should they have any questions.

Service Improvement::

There needs to be better collaboration between schools themselves and between schools and other agencies. Again parents' experiences are quite poor. One mother stresses that her 'daughter is not being educated to her ability levels. In fact, expectations are incredibly low. My daughter has brilliant reading and imagination skills which have not been built upon or embraced. She received no SLT as it appears that her just having a voice and being able to talk is enough. She has poor clarity and struggles with processing'. Another parent notes that they haven't witnessed any fruitful co-ordination. Often, good practise interventions are sourced from special school curriculums and plugged into mainstream settings, which don't always work'.

Performance Information::

8 Do you agree that the Governance arrangements detailed on page 14 are appropriate? If not, what else should be included?

Yes

Please explain your response.:

General

9 In relation to the overall 10 Year Strategy - are there any areas missing, requiring strengthening, or which are not required and could be removed?

Yes

Please explain your response.:

Below are a couple of points that may be worth considering as work progresses on the strategy:

- School environment

Evidence from our family support service illustrates how school buildings can have an impact on the wellbeing of children with complex additional needs. For example, if a school building is listed then it can be difficult to have space for a break out room or somewhere outside of the classroom to be able to concentrate in.

- Personal care

Not all learning assistants can/will deal with a child's personal care. There is often a limit on the time a learning assistant can be with the child. This leaves children not getting the time and space they need to have their personal care and toileting needs met. This is exacerbated when there is not enough hours allocated to the child (i.e. the number of hours the Learning Assistant is allocated to the child doesn't match up to their need i.e. too little hours).

- Staff and resources

One parent is keen to emphasise that 'the Standards in Schools Scotland Act 2000 estimated that SEN roles would fall to between 3,000 and 6,000. As of last year, almost 7,000 pupils are still being educated in special schools. This affirms what we, ourselves, have already witnessed – that there isn't enough resource and staff commitment to including pupils with Down's syndrome in MS schools. We've also observed that children with Down's syndrome are not being included in MSHS due to a lack of confidence by all parties concerned and a tendency to follow the well-worn path of removing our children from the mainstream for everyone's 'benefit', which is of course, not how we should see the situation in light of experience. High School teachers must be taught about learning disability equality during their teacher training; otherwise they will continue to see inclusion for Down's syndrome as, whimsical. There must be more aspiration to include'. This can also lead to issues relating to school activities. As an example parents have become unhappy if their child misses out on school trips. A child would miss a trip if the staff don't think the child can manage it e.g. forest trips. Or due to staffing levels or concerns about toileting.

- Examples of good practice (see below evidence from DSS Family Support Service on Markethill Primary School in Turriff - mainstream primary school)

The school has regular meetings with parents and professionals to look at the pupil's IEP and identify targets. The IEP is very thorough and parents views are taken into account. The school has had ongoing input from the Educational Psychologist. The Educational Psychologist suggested that the school would benefit from training delivered by DSS. The school did not hesitate and training was arranged and delivered on Positive Behaviour Support, Numeracy and Literacy. The training also covers the learning profile of children with Ds to raise awareness of some of the barriers to learning they may face on daily basis. Staff engaged well and were genuinely interested to learn and put this into practice. It was also positive to hear that staff are already using some of the strategies and tools covered in the training.

Children with Ds struggle to communicate verbally and some use Makaton as a form of communication. The pupil's teacher was Makaton trained and a number of other staff in the school received training on this. The teacher involves the whole class and the school is making efforts to have a whole school approach with the use of Makaton. It was identified at the last school meeting in May that the new teacher is not trained in Makaton, she will be attending training at the earliest opportunity and will seek support from the previous teacher as and when required.

Children with Ds can have problems with being included within mainstream schools. Staff initially suggested that the pupil may benefit from going to a separate room for maths and language. The current teacher felt that this was not appropriate and that the pupil should be fully included in the class for all of the lessons. The teacher made sure that the pupil had the right level of support from staff in the classroom and the pupil has been fully included in the class for the whole of P1. She has some support from ASN staff and also from her peers.

10 Are there any general comments you would wish to make about 'Scotland's Strategy for the Learning Provision for Children and Young People with Complex Additional Support Needs 2017-2026'?

Are there any general comments you would wish to make about 'Scotland's Strategy for the Learning Provision for Children and Young People with Complex Additional Support Needs 2017-2026':

It would be helpful to include a section on children and young people rights. Whichever policies are in place on the learning provision for children with complex additional support needs, it should be clear that children's views have to be sought and that their thoughts are also taken into account. DSS is of the view that this must have a much more prominent position within the strategy instead of simply referring to UNCRC very briefly on p.10.

About You

What is your name?

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Down's Syndrome Scotland

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

Publish response with name

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 Scottish Government to contact you again in relation to this consultation exercise?

Yes

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Neither satisfied nor dissatisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Neither satisfied nor dissatisfied

Please enter comments here.: