



## Responding to this Consultation

### RESPONDENT INFORMATION FORM

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

Are you responding as an individual or an organisation?

- Individual  
 Organisation

Full name or organisation's name

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

- Publish response with name  
 Publish response only (without name)  
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#### Information for organisations:

The option 'Publish response only (without name)' is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.

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  
 No

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## CONSULTATION QUESTIONS

(If you are responding to this consultation electronically, to complete tick boxes, please double click on one of the boxes above and select the default value as 'checked').

### 1. Introduction

The introduction provides information on what the guidance is about, how the guidance should be used, the status of the guidance and principles that should be applied in supporting the healthcare needs of children and young people in schools.

- Is the information provided in the introduction clearly set out? Please tick the box that applies.

**Yes**    **No**    **Don't know**

- If you selected no, please provide details of additional information which should be included or removed and a brief reason for it.

- Are there any areas missing, requiring strengthening, or which are not required? Please tick the box that applies.

**Yes**    **No**    **Don't know**

- If you selected yes, please provide alternative suggestions or indicate the areas which should be removed.

### 2. Chapter 1 – The legislative and policy context

This chapter of the guidance sets out the legal and policy framework which directly affects the provision of healthcare support in schools.

- Does this chapter provide sufficient reference to the relevant policy and legislative provisions? Please tick the box that applies.

**Yes**    **No**    **Don't know**

- If you selected no, please provide details of additional information which should be included or removed and a brief reason for it.

- Does the information provided under each heading in this section adequately explain how the legislation or policy applies in relation to provision of healthcare or administration of medicines in schools? Please tick the box that applies.

**Yes**    **No**    **Don't know**

- If you selected no, please provide suggestions or additions that should be made and a brief reason for it.

### 3. Chapter 2 – Rights and responsibilities

This chapter outlines the framework of responsibility and accountability that NHS boards, education authorities and schools have when putting in place arrangements for supporting the healthcare needs of children and young people at school.

It reflects the importance of collaborative working to provide support and enable children and young people with healthcare needs to participate fully in their learning and in the life of the school.

- Are there any areas missing, requiring strengthening, or which are not required and could be removed? Please tick the box that applies.

**Yes**    **No**    **Don't know**

- If you selected yes, please suggest ways in which this section might be improved.

Children in Scotland is the national network for the children's sector in Scotland. It has over 600 member organisations in the public, voluntary and independent sectors. We promote children's rights and wellbeing and support policy and service developments that are underpinned by the best available evidence. Enquire is the Scottish advice service for additional support for learning and provides information on ASL needs to parents and carers, professionals and children and young people themselves. It produces a range of publications, online information and a helpline. Last year the Enquire helpline dealt with 1491 enquiries<sup>1</sup>, of which 132 involved a physical health condition; other health related needs such as administration of medication, intimate care or health support are mentioned in the majority of calls<sup>2</sup>. Examples of calls received in which a healthcare need covered by this guidance was featured included:

- a child with autism who needed support with toileting and was starting primary school
- a young person who needed to be reminded to eat in order to be able to take their medication

<sup>1</sup> 28 March 2016 – 28 March 2017 (SOURCE)

<sup>2</sup> Autism Spectrum Disorder 683 enquires, social/ emotional/ behavioural factors 297 enquires, Mental Health Condition 115 enquires, reduced mobility 62 enquires from 28 March 2016 – 28 March 2017. (SOURCE)

- a young person whose restricted medicines were locked in the school office
- a parent who was considering of removing their child from school as they felt that the staff had not been sufficiently trained in moving and handling of their child
- a young person not attending school while a decision was made on how their medical needs will be met
- a parent being called into school to meet intimate care needs when young person with additional support needs had accidents.

Enquire often hears from families who are seeking advice about, and clarification on, the allocation of responsibilities among home, school, education authority and NHS board. Lack of clarity in these roles can lead to breakdowns in communication between practitioners and families. Children in Scotland therefore welcomes Chapter 2 of this guidance as it clearly sets out roles and responsibilities in meeting the healthcare needs. We believe, however, that there are aspects of the section that require strengthening.

Firstly, as the Children and Young People’s Commissioner indicates in his letter, the guidance does not make clear the full extent of the duties placed on schools and local authorities under the 2010 Equality Act. Rather than reference to this legislation mainly being set out in Chapter 5, the duties should be integrated throughout the guidance. Children in Scotland therefore advises that the guidance should make more explicit reference to the specific roles and responsibilities the Equality Act places on NHS boards, Education Authorities and schools. **We suggest that providing case studies giving examples of what would constitute ‘reasonable adjustment’, in line with the ‘Equality Act 2010: Technical guidance for schools in Scotland’<sup>3</sup>, would be helpful.** This issue was exemplified in the 2013 disability discrimination case that went to the Additional Support Needs Tribunal which ruled that a young person was discriminated against due to a reasonable adjustment not being made for the administration of his diabetes medication.

**Secondly, we recommend that this section sets out in more detail the role parents/ carers are expected to have in meeting their child’s healthcare needs in school.** The Enquire helpline hears from parents who are going into school to meet the healthcare needs, administer medicine or intimate care needs of their children on a regular basis. This affects their ability to enter, or remain in, the labour market. It also has negative impact on the child’s capacity to develop greater independence. Guidance on this issue that is clear and easy to read would be of great practical value.

**Thirdly, we call for the rights, responsibilities and expectations of school support staff to be set out explicitly.** The recent UNISON survey of Scotland’s school support staff identified the serious pressures support staff are under. Many staff feel the training they have received and risk assessments undertaken are not adequate for the tasks they are expected to carry out.<sup>4</sup> Enquire has heard from parents who say they have been told that no member of staff will volunteer to meet their child’s healthcare needs. We acknowledge that the guidance goes some way in

<sup>3</sup> <https://www.equalityhumanrights.com/en/publication-download/technical-guidance-schools-scotland>

<sup>4</sup> Hard Lessons; A survey of Scotland’s school support staff: January 2017. UNISON Scotland.

setting out that staffing issues need to be jointly agreed between the local authority and the NHS board. We recommend, however, that the guidance make clear that there is a responsibility for healthcare needs to be met in most cases by the school and not the parent, and what rights staff have to refuse to perform certain duties, or to require that specific training is provided before agreeing to carry out such tasks. This guidance is likely to be one of the first points of reference for head teachers and staff when they experience new issues with supporting a pupil. This section should therefore be clearer and should offer practical guidance on an issue that appears to be arising more frequently in schools.

Children's views should be heard in all matters that affect them. This is in line with the United Nations Convention on the Rights of the Child (UNCRC). Article 12 of the UNCRC states that "*When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account*"<sup>5</sup> As a result, we welcome the guidance's emphasis that educational authorities have a duty to seek the views of children regarding the decisions that affect them, including those specifically related to their healthcare needs. However, we recommend that the guidance should make specific reference to ensuring that mechanisms for CYP to share their views and input into decisions surrounding their healthcare needs are accessible and adjusted to meet their requirements.

At Children in Scotland our work is underpinned by the UNCRC and by principles and guidelines around meaningful participation and engagement of children and young people (CYP). In order to engage meaningfully and effectively with diverse groups of CYP, methods of engagement need to be designed and tailored to meet the specific needs of the group. The Commission for Children and Young People in Scotland (CYCPS)'s 7 Golden Rules for Participation supports this approach.<sup>6</sup>

To include children with additional support needs, particularly those with profound communication difficulties, enough time, flexibility and adaptability should be allowed.

#### **4. Chapter 3 – NHS board and education authority agreements and policies**

This chapter sets out that NHS boards must ensure that they have strategic joint agreements in place with the relevant education authority which determines the respective responsibilities of each in relation to supporting the healthcare needs of children and young people in schools in their areas (outlining local protocols and procedures, including training). These strategic joint agreements will reflect or form part of the local arrangements in place for children's services planning and should reflect the principles of Getting it Right for Every Child.

- Are there any areas missing, requiring strengthening, or which are not required and could be removed? Please tick the box that applies.

<sup>5</sup> [https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC\\_summary-1.pdf?\\_ga=1.131600207.1188641315.1447677493](https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_summary-1.pdf?_ga=1.131600207.1188641315.1447677493)

<sup>6</sup> <https://www.cypcs.org.uk/education/golden-rules>

Yes    No    Don't know

- If you selected yes, please suggest ways in which this section might be improved.

Children in Scotland finds it encouraging that the guidance makes reference to consulting with children, young people and their parents in the development of local strategic joint agreements. **However we would recommend that the guidance makes it explicitly clear that CYP should be consulted, as it is their right to have a say in decisions which have an impact on them.** We would also reiterate that any consultation processes need to be adapted and accessible to allow CYP the opportunity to share their views, particularly those who don't often engage in consultation processes.

The guidance should also advise that the policy framework agreed between the NHS board and education authority should be underpinned by a commitment to children's rights and their practical implementation. The guidance should also place a stronger emphasis on seeking the views of children and young people in relation to the design and planning of healthcare services. Children and young people are the experts in their own experience and should help shape the healthcare services they interact with. At Children in Scotland we believe that children, young people and their families should be involved in local decision making process and to enable them to be co-producers of the services they need and use.<sup>7</sup>

We have undertaken a number of consultation activities with children and young people to help shape the direction of healthcare services. In June 2016, we engaged with a group of CYP to find out their views on the school nurse role. The views they expressed helped feed into the Scottish Government review of the school nursing service across Scotland.<sup>8</sup> The CYP that we spoke to highlighted that they would like information and support to cope with some of the following issues: personal hygiene and keeping clean, disabilities, autism and ADHD, anxiety and worry and sexual health.

Young people were more likely to speak to someone about their health and how they were feeling if they had contact with that person on more than one occasion before speaking about a problem. It was also very important for that person to be non-judgemental and good at listening. Having a private and safe space was very important when talking to the school nurse about physical or emotional needs. Some children were concerned about lack of privacy if they accessed the service at home. However, others felt that accessing the service at home would help families to understand "what's going on". Young people indicated that they would like to choose where they receive support from the service and there is potential for using a combination of different settings.

<sup>7</sup> Local Council Elections 2017- What Do You Plan To Do? (Children in Scotland Briefing)

<sup>8</sup> School Nursing Review: Consultation with Children and Young People July 2016 (Children in Scotland)

In October 2016, we worked with children under the age of 12 to feed in the views of younger children to the development of the 10-year mental health strategy.<sup>9</sup> The children identified friendship and positive relationships as important factors in supporting mental health and wellbeing. The main source of support for the mental health and wellbeing within school was identified as teachers. Similar to the school nurse consultation, children were more likely to speak to someone, about how they were feeling, if they felt they could trust that person and they would listen to them. **As a result of these consultation exercises we would advise that the guidance should make explicit reference to issues of privacy, confidentiality and quality of relationships with the professionals within the school setting.**

In addition to the needs of pupils who have ongoing healthcare requirements, we believe that the guidance should also cover time-limited healthcare issues and the healthcare needs of the whole school community.

## 5. Chapter 4 - School level arrangements

This chapter sets out that schools should consider the NHS Board and EA joint policy framework on supporting the healthcare needs of children and young people and adopt or reflect this in any of the local policies and practices that are put in place by any individual school or cluster of schools. This will ensure that the arrangements in place at school are consistent with other schools in the area, and appropriate to the local context of the school and the school community.

- Are there any areas missing, requiring strengthening, or which are not required and could be removed? Please tick the box that applies.

Yes    No    Don't know

- If you selected yes, please suggest ways in which this section might be improved.

In line with article 12 of the UNCRC, we are pleased that the guidance states that CYP should be consulted in the drawing up and signing off the agreed individual healthcare plan. However, the guidance should note that engagement with CYP with communication difficulties will require extra time and support. We also welcome this guidance on specific school arrangements, training issues and the identification of needs. Although we acknowledge that this is mentioned in Chapter 1, we recommend that this section should set be clearer in setting out the relationship between individual healthcare plans and Child's Plans.

As set out earlier in our response, Children in Scotland acknowledges clear evidence that intimate care in school is an issue of concern to support staff and families of

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<sup>9</sup> Mental Health in Scotland a 10 year vision - Report on Consultation with Children aged 12 and under October 2016 (Children in Scotland)



children with additional support needs.<sup>10</sup> Children in Scotland therefore recommends that new national guidance setting out how toileting and menstruation needs should be met in school be introduced<sup>11</sup>. The Enquire helpline hears of parents unable to work or taking time off work to go into school and meet their child's medical or intimate care needs because the school cannot meet these needs and of young people unable to attend school, or participate as they would want to, due to their needs. This has a significant impact on their inclusion and rights. As adults they are likely to receive personal support to lead independent lives; we believe that children and young people should be accorded the same level of respect and dignity. The fact that practical guidance and information on current sources of are being developed should be referenced directly in this section of the guidance. This will be of great benefit in ensuring that schools, staff, parents and young people can be enabled to get this type of support right.

## **6. Chapter 5 – Circumstances where a school may need to make special arrangements for supporting children and young people with healthcare needs**

The policy framework as agreed by NHS boards and EAs on supporting the healthcare needs of children and young people in schools should be adopted or reflected in any of the local policies and practices that are put in place by any individual school or cluster of schools. This will ensure that the arrangements in place at school are consistent with other schools in the area, but are also appropriate to the local context of the school and the school community.

- Are there any areas missing, requiring strengthening, or which are not required and could be removed? Please tick the box that applies.

**Yes**    **No**    **Don't know**

- If you selected yes, please suggest ways in which this section might be improved.

We believe that the duty to make reasonable adjustment should be embedded throughout this guidance. However, we welcome the information provided in this chapter to support CYP to participate in school trips, sporting activities, work placements and transport.

The *#IncludED in the Main?!* report found that 23% of young people who have learning disabilities and/or autism spectrum are excluded from school trips.<sup>12</sup> The report recommends that school inspectors should ask explicit questions on full participation in school trips and report on the barriers to that.

We are encouraged that the guidance makes reference to school staff learning from

<sup>10</sup> Flushed with Success: Setting the Standards for Scotland's school toilets; Briefing: Healthcare Needs in Schools, Children and Young People's Commissioner Scotland; Hard Lessons; A survey of Scotland's school support staff: January 2017. UNISON Scotland.

<sup>11</sup> As the 'helping hand's' guidance on intimate care is over 17 years old and no longer referenced as a resource in this guidance,

<sup>12</sup> *#IncludED in the Main?!- 22 steps on the journey to inclusion for every pupil who has a learning disability* (Enable Scotland)

CYP, parents and other schools, to ensure that everyone is able to benefit from, and fully participate in, different school activities and trips.

## **7. Annexes A & B – Guidance on the use of emergency salbutamol inhalers and other condition specific information**

Annex A provides guidance to education authorities and schools in Scotland on the use of emergency Salbutamol Inhalers to accompany the guidance to NHS boards, education authorities and schools on 'Supporting the healthcare needs of children and young people at school'. Annex B contains other condition specific information.

- Are there any areas missing, requiring strengthening, or which are not required and could be removed? Please tick the box that applies.

Yes    No    Don't know

- If you selected yes, please suggest ways in which this section might be improved.

## **8. Annexes C and D – Other relevant legislation, useful guidance and useful organisations**

Annexes C and D provide additional information/ resources to support the guidance.

- Do these Annexes provide appropriate supplementary detail? Please tick the box that applies.

Yes    No    Don't know

- If you selected no, please provide details of additional information which should be included or removed and a brief reason for it.

We would advise that some of the example forms and plans in the previous administration of medicine guidance were helpful to the parents and professionals Enquire advises in illustrating what they might expect from the school.

We would recommend that the following Equality Advisory & Support Service Helpline 0808 800 0082. [www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com) is added to the annex on useful organisations.

## **9. Paracetamol (and the use of other non-prescription medicines in schools)**

Paragraph 109-112 of the guidance sets out:

### **Paracetamol (and the use of other non-prescription medicines in schools)**

109. Children and young people in schools sometimes ask for painkillers (analgesics) or other non-prescribed medication at school such as antihistamines. However, schools should not hold non-prescribed medication. If a child or young person suffers regularly from acute pain or symptoms, such as a headache, period pain or hayfever, parents may provide the school with non-prescribed medication alongside clear and appropriate instructions and consent for the medication to be (often via the completion of a standard form). Alternatively parents (or where appropriate the young person) may ask for the medication to be prescribed by a GP.

110. A member of staff should supervise younger children taking the medication and ensure that the individual's parents are informed on the day the medication is taken.

111. Some children and young people with the maturity and capacity to carry and self-manage their own non-prescribed medication and symptoms (for example, for period pain, occasional headaches, minor viral illnesses, coughs, sore throats or hayfever) should be allowed to do so. In such circumstances it is recommended that only medication that can be purchased by a pharmacy should be carried and that children and young people carry as little medication as possible in the original pack or bottle. It is recommended that children and young people should carry as little medication as possible in the original pack or bottle - normally only enough for a single school day (although this may not be possible for liquids or sprays). Blister packs, for example, can be cut to ensure only a single day's medication is carried.

112. It should be noted that children under 16 should not be given or take aspirin, unless prescribed by a doctor<sup>13</sup>. Further, codeine should not be provided to children under 12 as it is associated with a risk of respiratory side effects, and is not recommended for adolescents (12 to 18) who have problems with breathing<sup>14</sup>.

- This is a particularly difficult balance to strike, is the guidance on this particular issue appropriate? Please tick the box that applies.

Yes    No    Don't know

- If you selected no, please provide details of additional information which should be included or removed and a brief reason for it.

## **10. Guidance Structure**

Does the structure help the reader to follow/use the guidance effectively? Please tick the box that applies.

<sup>13</sup> <http://www.nhsinform.co.uk/health-library/articles/a/anti-platelets-aspirin-low-dose/introduction/>

<sup>14</sup> <https://www.gov.uk/drug-safety-update/codeine-for-cough-and-cold-restricted-use-in-children>

Yes  No  Don't know

- If you selected no, please explain your answer.

As mentioned earlier we would recommend the Equality Act and the duty to take account and involve young people in the decisions that affect them is embedded throughout the guidance rather than only mentioned in specific sections.

- Is there anything in the body of the document that you would like moved to an annex or anything in an annex moved to the body of the document? Please tick the box that applies.

Yes  No  Don't know

- If you selected yes, please provide details of the changes you would wish to see.

## 11. General

Is the guidance helpful? Please tick the box that applies.

Yes  No  Don't know

- If you selected no, please explain your answer.

- Are there any other comments you would wish to make about the draft guidance in supporting the health care needs of children and young people in schools?

With advances in medicine and care and the presumption of mainstreaming the demography of the school population is changing population. More pupils are likely to require support with their healthcare needs<sup>15</sup>. This includes young people learning to manage long term conditions or physical needs with which they will need assistance, but which will not affect their ability to fulfil their potential at school and move into a positive post-16 destination. We welcome the guidance setting out that their independence and dignity should be respected.

However, as we have highlighted in this response, the Enquire helpline hears of parents unable to work as they need to go into school to meet their child's healthcare needs and young people who are unable to attend or participate fully in school because the school cannot meet their needs. These issues, at their most extreme, can amount to duties not being fulfilled under the Education (Additional Support for Learning) (Scotland) Act 2004 as amended and the Equality Act 2010. As adults these young people may receive personal assistants and self directed support to lead independent lives and we believe they should expect the same level of respect and dignity throughout their school life in Scotland.

<sup>15</sup> Briefing: Healthcare Needs in Schools: Children and Young People's Commissioner for Scotland

We welcome the guidance's highlighting of children and young people being encouraged to develop independence and self-management of conditions. However we would like to highlight that the guidance does not make strong enough the voice of children and young people in the decision making and planning of their healthcare support. In addition, we wish to highlight that both adequate time and resources are essential to ensuring that the voices of CYP with additional support needs are meaningfully included within decision-making processes about their individual needs and the healthcare services they interact with.

We also draw your attention to recommendation 19 of the *#IncludED in the Main?!* which states that the Scottish Government and local authorities should continue to invest in role of Additional Support for Learning Teachers and should take direct action to recruit and retain skilled staff in these positions.<sup>12</sup> In order to support CYP with healthcare needs to fully participate in their learning we would recommend that the guidance should support local authorities to develop strategies for the ongoing training, support and retention of ASL teachers.

**Thank-you for responding to this consultation.**

**Please return a completed copy of respondent information form by email to [HNIS@gov.scot](mailto:HNIS@gov.scot) or by post to HNIS, Support and Wellbeing Unit, Area 2C South, Victoria Quay, Edinburgh, EH6 6QQ.**