



**Scotland's Commissioner
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'No barriers to medication at school'

**The Administration of Medicines and Health Care
Procedures in Schools:
The views of parents and carers**

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Introduction

In January 2013, Scotland's Commissioner for Children and Young People commissioned a small piece of research to:

1. gather the views and experiences of parents and carers of children and young people who require medication at school
2. deepen understanding about those practices which parents and carers feel have an impact on school and family life.

This report presents the findings of the research study.

Legislative and policy context

The *presumption of mainstreaming* exists in Scotland, or educating children with additional support needs - including health care needs - in mainstream schools. It is, however, reflected in the legislation that the needs of some children are best met in specialist provision rather than in mainstream schools¹.

In 2001, the Scottish Executive issued guidance entitled *The Administration of Medicines in Schools*. It noted that NHS Boards have statutory responsibility 'for the medical treatment of pupils in schools and in carrying out this function they can enter into agreements with other parties' and that the Standards in Scotland's Schools etc Act 2000 places a duty on education authorities 'to educate children to their fullest potential'². Since the 2001 guidance was published, the Additional Support for Learning (Scotland) Act (2004) (amended 2009) has placed new obligations on local authorities and NHS boards to make clear arrangements for joint working to improve outcomes for children.

Schools and education authorities have had a duty to provide reasonable adjustments for disabled pupils under the Equality Act (2010). From 1 September 2012 the reasonable adjustments duty for schools and education authorities includes a duty to provide auxiliary aids and services for disabled pupils. The object of the duty is the same: to avoid as far as possible by reasonable means, the disadvantage which a disabled pupil experiences because of their disability. There is no legal duty requiring staff in educational establishments to administer medicines or health care procedures in schools; instead school staff volunteer or are contracted to support a child or young person with health care needs³. The Scottish Executive guidance states that Headteachers must ensure that any members of staff administering medicines or health care procedures 'receive proper support and training where necessary'⁴.

¹ Section 15 of the *Standards in Scotland's Schools etc Act 2000*

² Scottish Executive (2001) *The Administration of Medicines in Schools* p. vi

³ Scottish Executive (2001) *The Administration of Medicines in Schools* p. vii

⁴ Scottish Executive (2001) *The Administration of Medicines in Schools* p.4

The duty to make reasonable adjustments requires a school to take positive steps to ensure that disabled pupils can fully participate in the education provided by the school, and that they can enjoy the other benefits, facilities and services which the school provides for pupils. Many reasonable adjustments are inexpensive and will often involve a change in practice rather than the provision of expensive pieces of equipment or additional staff. A school's duty to make reasonable adjustments is an anticipatory one owed to disabled pupils generally and therefore schools need to think in advance about what disabled pupils might require and what adjustments might need to be made for them⁵.

Lack of adequate support and training for school staff who administer medicines and health care procedures in schools was raised as a concern in a recent study of workers (classroom assistants, nurses, and other health professionals) who provide support in schools. Respondents reported that their confidence and competence was impaired by inadequate training, leaving them uncomfortable administering medicines or health care procedures in schools⁶.

Getting it right for every child (GIRFEC), introduced in Scotland in 2008, is a multi-agency approach to identifying and meeting the needs of all children, by putting the child at the centre of all decision-making, support and intervention. The eight indicators used to assess a child or young person's health and wellbeing are: *safe, healthy, achieving, nurtured, active, respected, responsible and included*⁷. Scotland's Curriculum for Excellence aims to enable all children and young person to become successful learners, confident individuals, responsible citizens and effective contributors. One of the key attributes of confident individuals is *a sense of physical, mental and emotional wellbeing*⁸. Thus, this reinforces the importance of supporting children's health and wellbeing.

Concerns raised by parents and carers of children and young people requiring medicines to be administered in schools, and responses by local authorities to a Freedom of Information (FOI) request from the Commissioner's office⁹, highlighted the need for further evidence and information regarding health care practice in schools.

⁵ <http://www.equalityhumanrights.com/advice-and-guidance/education-providers-schools-guidance/key-concepts/reasonable-adjustments/>

⁶ RCN and UNISON (2012) *Supporting pupils with health needs in schools – RCN and UNISON survey*

⁷ <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

⁸ <http://www.educationscotland.gov.uk/thecurriculum/whatiscurriculumforexcellence/thepurposeofthecurriculum/index.asp>

⁹ Scotland's Commissioner for Children and Young People (2012) *The Administration of Medicines in Schools: Report on FOI responses*.

Research aims

The five main aims of this research study were to ascertain parents' and carers' views about:

- current practice around the administration of medicines in schools
- the extent to which they believed the medical needs of their children were being met
- factors which they felt helped or hindered effective practice
- their views about how practice could be improved
- the extent to which they believed their own and their child's views were taken into account by their child's school.

Scope of the research

This was a small-scale study, due to the time available and to the relatively small group of parents and carers (44) who participated. The research took place between early February and the end of March 2013. Contact was made with parents and carers through several networks and organisations¹⁰ and via the newsletters of Scotland's Commissioner for Children and Young People and WithScotland. Parents and carers were informed that this research study applied to children:

- finishing a course of medication
- with medical or long term conditions such as asthma or diabetes that if not properly managed could limit their access to education
- with conditions which could require emergency treatment e.g. severe conditions (anaphylaxis) or epilepsy
- with intimate care needs, which could include invasive treatment.

Although the Scottish Executive guidance is entitled *The Administration of Medicines in Schools*, the scope has been widened for the current study to also include health care procedures. For the purposes of this research, 'schools' were defined as pre-five local authority centres, primary and secondary schools (including special units in those schools), special schools and independent primary and secondary schools. It did not include private nurseries or play groups. As the research focus was on current arrangements and practices in schools, it did not include children or young people who were home educated, although it is recognised that some parents might elect to home educate their children because of difficulties or concerns around the administration of medicines or health care procedures in school.

Following the publication of the findings of the FOI request in October 2012, this research sought to ascertain the views of parents and carers about current arrangements and practices in schools, and the implications for the wellbeing of their child and on family life. Research with Headteachers on the administration of medicines and health care procedures in schools is currently being undertaken by the Commissioner's office, and will be published in a future report. The focus of this

¹⁰ A full description of the research methodology appears in Appendix 2

research study, therefore, was on the views of parents and carers of children requiring the administration of medicines and health care procedures in schools.

Research methodology

The research consisted of two main stages:

- **Stage 1**
A review of preliminary information gathered by the Commissioner's office was undertaken, including *The Administration of Medicines in Schools: Report on FOI responses* (2012) and data collected from interviews and focus groups with children, parents/carers and health professionals. That information and additional reports and resources accessed during the literature search provided insight into some of the key issues for children and young people with health care needs (including how they are supported at school).^{11,12,13,14} The literature review further informed the survey design.
- **Stage 2**
An online survey was designed, asking parents and carers for their views and experiences relevant to the administration of medicines and health care procedures in schools. Parents were made aware of the survey through support organisations and networks and newsletters produced by the Commissioner's office and WithScotland. No personal data was requested from participants; all responses were anonymous. A thematic analysis of the data was undertaken, and the findings are presented in subsequent sections of this report. The research methodology is described in more detail in Appendix 2.

¹¹ Scottish Government (2010a) *Guidance on Partnership Working Between Allied Health Professions and Education*.

¹² LTCAS (Long-Term Conditions Alliance Scotland) (2010) *Seen and Not Heard? Exploring issues facing children and young people living with long term conditions*.

¹³ Scottish Government (2010b) *Diabetes Action Plan 2010: Quality care for diabetes in Scotland*.

¹⁴ PAMIS & White Top Research Unit, Garrard, B., Lambe, L. and Hogg, J. (2010) *Invasive Procedures - Minimising Risks and Maximising Rights: Improving practice in the delivery of invasive procedures for people with profound and multiple learning disabilities*.

1. Current practice - the administration of medicines and health care procedures in schools

One of the main objectives of this research study was to gain a better understanding of parents' views about health care practice in schools, and how current arrangements affect children's experiences at school and wider family life. The survey asked for information about the health care needs of the child and about relevant practice in schools. This section looks closely at the information provided by parents¹⁵ about these issues.

1.1. Children's health care needs in schools

A range of health care needs were identified, from common conditions requiring occasional support to complex needs requiring regular and skilled support. There is no single accepted definition of 'complex needs'^{16,17}; therefore the use of the word 'complex' in relation to health care needs in this report requires further explanation. Although the NHS's assessment criteria for complex and exceptional needs is used across health services¹⁸, many parents who participated in this study described their children's health care needs as 'complex'. Understandings and definitions of complexity may vary from place to place, between sectors, and even from one family to another. A health care procedure which seems routine to one family might seem risky to another, depending on individual circumstances, skills or confidence levels¹⁷. Given that this report focuses on parents' views, our use of the term 'complex' reflects the ways that families conceptualise and describe it.

Perhaps unsurprisingly, many children were identified as having the most common medical conditions in school-aged children:

- Asthma
- Diabetes
- Epilepsy
- Eczema
- Allergic reactions/Anaphylaxis.

Although it is a common condition, no children were identified as having cystic fibrosis.

There was also evidence of some complex health care needs requiring carefully managed help and support in school.

¹⁵ From this point, 'parents' will be used to mean 'parents and carers', for brevity.

¹⁶ Scottish Government (2012) *The Right Help at the Right Time in the Right Place: Strategic review of learning provision for children and young people with complex additional support needs (The Doran Review)*.

¹⁷ Marchant, R., Lefevre, M., Jones, M. and Luckock, B. (2007) *'Necessary Stuff': The social care needs of children with complex health care needs and their families*.

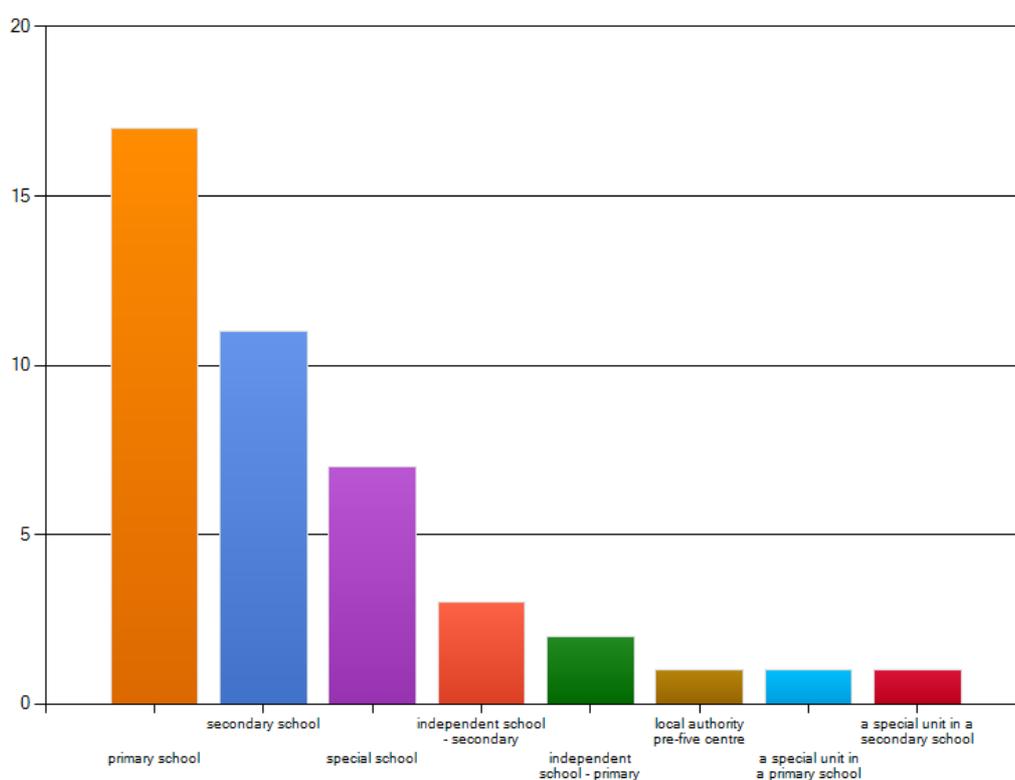
¹⁸ <http://www.cen.scot.nhs.uk/definition>

Further details about the health care needs described can be found in Appendix 1 (Conditions, treatments and interventions described by parents, with definitions). Care has been taken in the presentation of these findings to prevent any participants from being identified by information given about their child’s condition, which were in some cases rare. Due to the range of conditions identified, it was not possible to code them according to the participation criteria described on page 6.

1.2. Type of school attended

Parents were asked which type of school their child currently attended, and 43 provided responses.

Graph 1 – Type of school parents reported their child(ren) attended

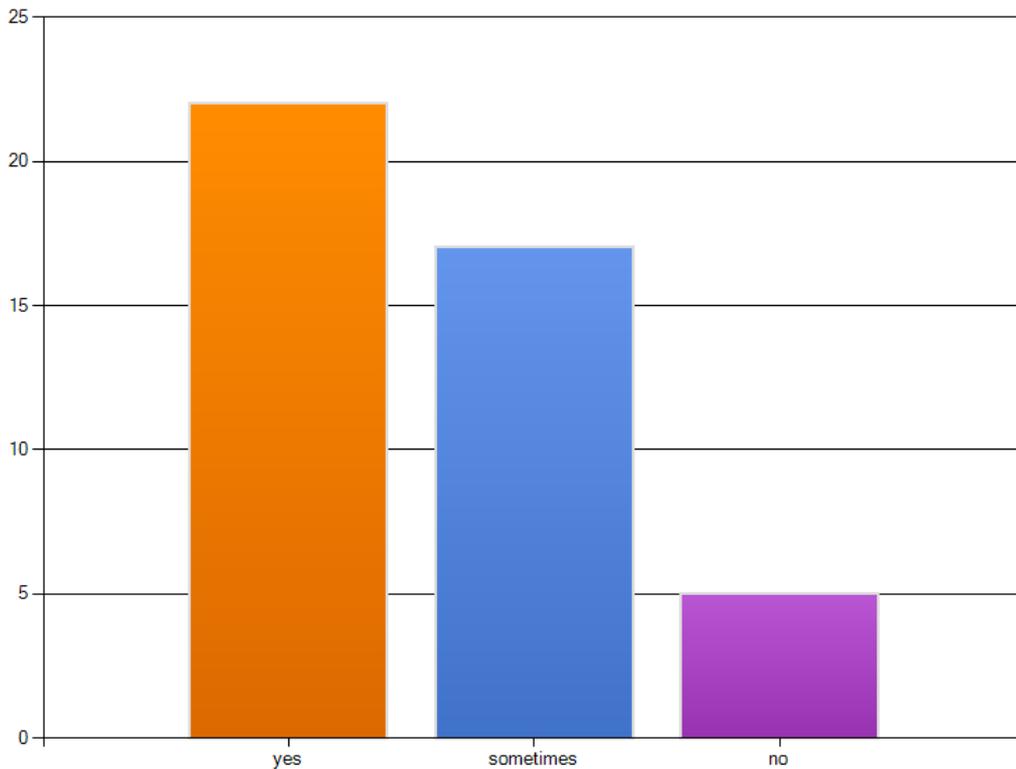


Seventeen parents (39.5%) reported that their children attended primary school and 25.6% (11) reported that their children attended secondary school. Although the graph shows that 16.3% (7) reported that their children attended special school, a closer look at the data suggested that some parents might have understood ‘independent school – primary’ or ‘independent school – secondary’ as a special school, not a *private* independent school. Thus, the number of children attending special school might be slightly higher than is indicated on the graph. Only one parent who completed the survey each stated that their child attended a local authority pre-five centre or a special unit in a primary or secondary school.

1.3. Children requiring medicines to be administered in school

Parents were asked whether their child required medicines to be administered in school, and 43 responded.

Graph 2 – Number of children requiring medicines to be administered in school, as reported by parents



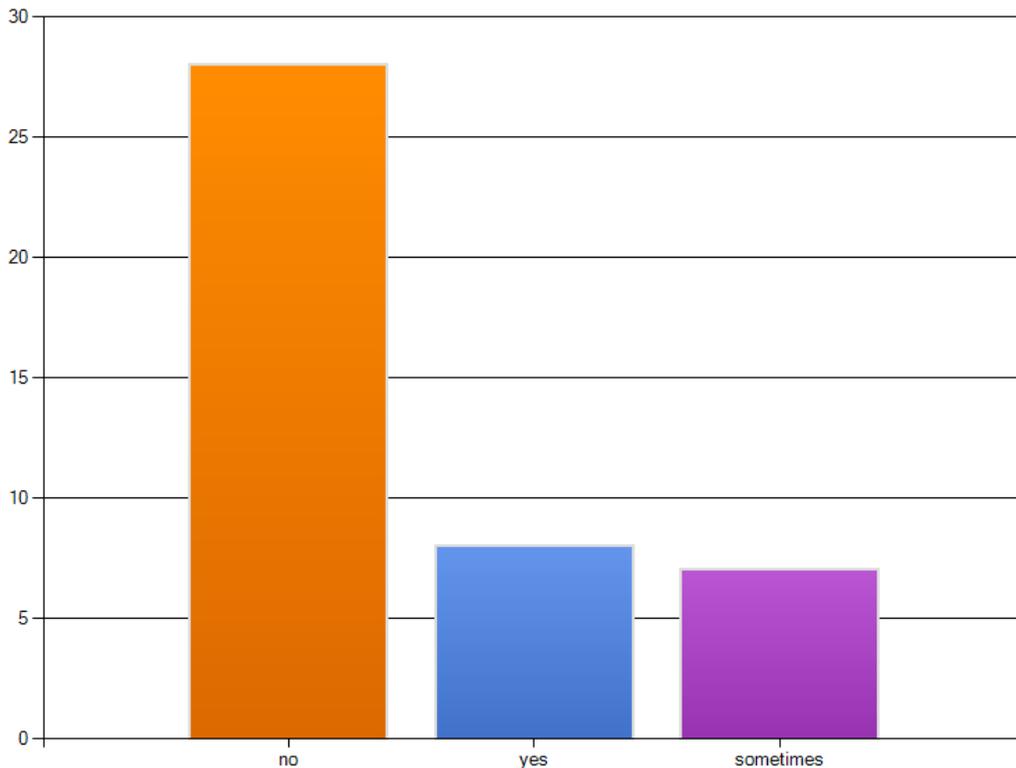
Fifty percent of parents (22) reported that their children *required* medicines to be administered in school. Sixteen parents (38.6%) reported that their children *sometimes required* medicines and 5 (11.4%) reported that their children *did not require* medicines in school. Thirty-five parents provided additional information about the administration of medicines, much of which gave specific details of the types, dosages and timings of medicines required. A number of parents explained that the administration of medicines depended on their child's medical condition at any given time, and was therefore variable. The requirement for emergency medication as and when needed was also described by a number of parents; some explained that their child self-managed, or self-managed with support, whereas other parents stated that their child would always require help and support from an adult.

The evidence shows that children's conditions and treatments are changeable, and therefore the provision of health care often requires to change over time. In terms of planning and organisation, different responses are needed to meet children's health care needs. For example, as children grow older they could take more responsibility in some situations; or different approaches might be needed depending on whether they participate in activities in or outside of school, or on the variable symptoms of the condition.

1.4. Children self-managing their medication in school

Parents were asked whether their child self-managed their medication at school. Self-management was defined as including any or all of these aspects: remembering to take the medication, going to get it, dealing with the dose and taking it. Forty-three parents responded.

Graph 3 - Number of children self-managing their medication in school, as reported by parents



Twenty-eight (65.1%) parents reported that their children *did not* self-manage their medication; 8 (18.6%) parents reported that their children *did* self-manage; and 7 (16.3%) reported that their children *sometimes* self-managed. Twenty-two parents provided further information about self-management. Some of the common issues raised by parents were:

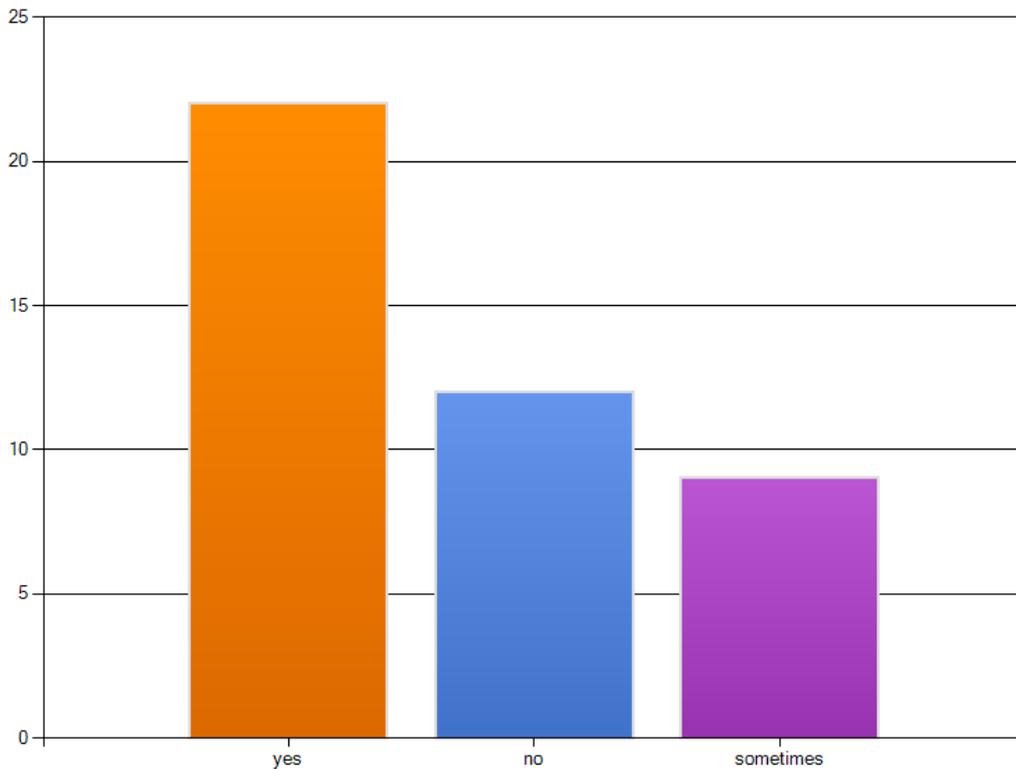
- the ability of their child to self-manage with support or help if needed
- the need for school staff to remind their child to self-manage
- that their child was too young to self-manage but will hopefully become more independent in future
- that self-consciousness was often an issue for their child when self-managing, and having appropriate spaces in which to self-manage was important.

One parent explained that although self-managing happened at home, it was not yet happening at school. There was no clear evidence of any differences in practice between special and mainstream schools.

1.5. Children requiring health care procedures in school

Forty-three parents responded to the question asking whether their child required health care procedures in schools.

Graph 4 - Number of children requiring health care procedures in school, as reported by parents



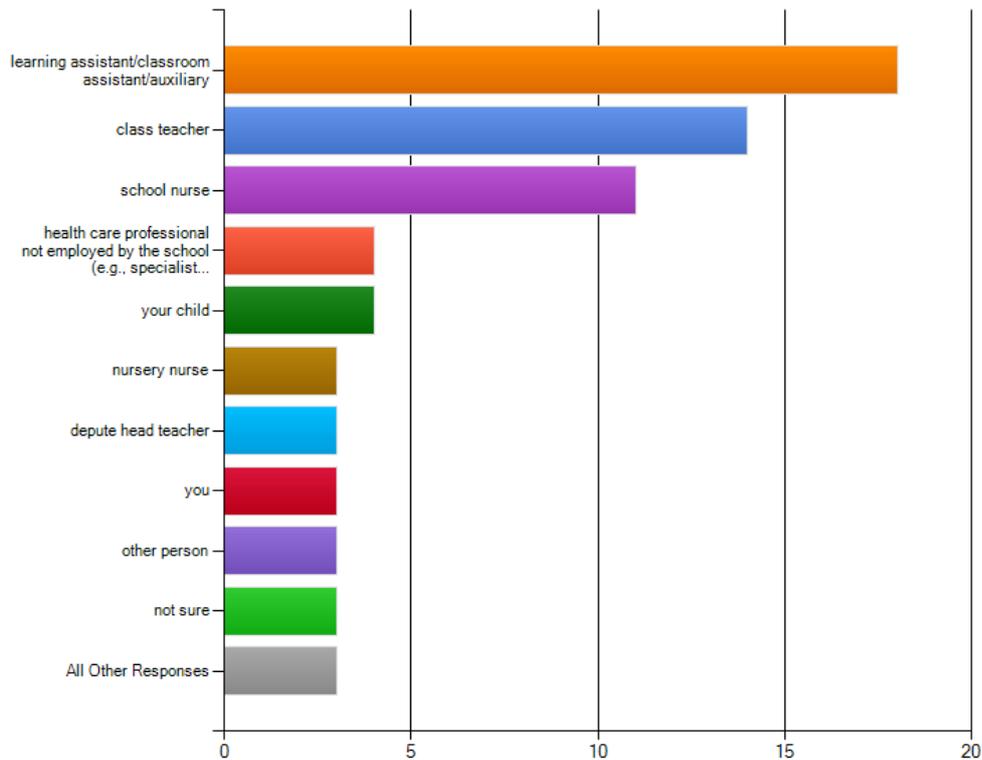
Twenty-two parents (51.2%) reported their children *required* health care procedures to be carried out at school. Twelve (27.9%) *did not* and 9 (20.9%) *sometimes required* health care procedures.

Twenty-seven parents provided additional information about the health care procedures required at school. The evidence provided was very specific in nature, and varied significantly from child to child. Whilst there were some similarities across conditions (such as the need to use an inhaler in case of an asthma attack or help in applying skin creams for eczema), the overall picture was of highly varied, individualised health care procedures to meet children's complex health care needs.

1.6. Who supported children at school

Parents were asked to provide information about *all* of the people who provide help and support at school.

Graph 5 - Who usually provided help and support to children at school



The three members of staff most likely to provide help and support to children with health care needs in schools were learning assistants (who in some areas might be called a classroom assistant or auxiliary, for example), class teachers and school nurses. Nearly half of parents (45%, or 18) reported that a learning assistant provided help and support with the administration of medicines or health care procedures. Fourteen parents (35%) reported that the class teacher provided help and support and eleven parents (27.5%) reported that the school nurse supported their child.

Three parents (7.5%) reported that they provided help and support, whilst 2 parents reported that their partner/spouse provided help.

Three parents reported that sometimes a depute head teacher provided help and support and one parent reported that a head teacher provided help, giving a combined total for senior managers in schools of 10%. In 10% of cases parents reported that a health care professional not employed by the school provided help and support. Four parents reported that their children self-managed health care at school.

Ten parents provided further information about who helped their child in school. Four parents responded that school administrative staff provided help and support. One parent reported that a therapist employed by the school provided support. Two parents stated that they received a phone call if support was required, and the parents themselves provided the care.

Only three parents who responded indicated that *more than three* people provided help to their children at school. In two cases, the children's complex needs required a range of staff to meet their health care needs, whereas the third parent reported that multiple members of staff needed to be available to administer an EpiPen if required. Of the 18 parents who reported that a learning assistant provided help, only 3 indicated that it was *only* the learning assistant who supported their children; in all other cases, a learning assistant and at least one other adult provided help and support.

Continuity of staff providing help and support

Parents were also asked whether the same person administered medicines or health care procedures to their child in school. 50% said yes; 31.8% were not sure; and 18.2% said that the same person did not provide help and support for their child at school. Thirty parents provided further information about this issue. Many reported that they were happy with the current arrangements. One parent reported that having one person provide help and support "*makes it easier when dealing with the changes his condition requires*". Several parents described feeling confident and trusting in school staff's ability to provide help and support.

Sometimes, the involvement of several staff members in providing help and support was seen as good practice for ensuring continuity of education:

"There is a group of 6 people trained and supervised by a nurse. It's a lot of different people but necessarily so - too few and she might occasionally be unable to attend school."

Some parents expressed concerns about current arrangements. One explained:

"It's a variety of people despite the fact I asked for two named staff for intimate care."

Another parent expressed concern about lack of awareness or willingness among staff to provide help:

"It worries me that all the staff may not be aware of who she is and her health needs or refuse to help in an emergency."

The key issues raised by parents about who provides help, such as continuity and consistency of care; provision of adequately trained staff; and staff attitudes or approaches, will be discussed in more detail in sections 4 and 5.

Parental requests to help and support in school

Parents were asked whether they had requested to provide help and support to their child at school: 54.5% answered no and 45.5% replied that they did. Nineteen out of the 44 respondents explained a bit more about this, and it was clear from the data that some parents interpreted this question as ‘*Did you request help and support for your child at school?*’ instead of ‘*Did you request to help and support your child at school?*’ The question was asked to distinguish between parents who were providing help and support in school at their own request for whatever reason(s), and those who had been requested by the school to do so for whatever reason(s).

Four responses provided more information about the issue of parental requests to support their child in school:

“I understand teachers are busy so would be willing to help. This has not been needed as yet”

“Didn’t know I could”

“I had no choice. The Children’s Community Nurse couldn’t always attend at specific times of every day and the staff hadn’t done these things before. Once they had their initial training then I could help the staff to gain confidence with what they had to do”

“To ensure that my child was taking what he needed when he needed with the appropriate privacy and he had access to toilets when he needed”.

These additional comments show that parents in this study have provided, or would be willing to provide, help and support to their child in school for reasons of additional help; providing training to support staff in school; and to establish or embed health care procedures for their child in school.

1.7. When/How many times per day children required help and support at school

The information which parents provided about when or how many times a day their child requires help at school showed no clear pattern(s). Most of the parents who provided additional information explained that help was required as and when needed. This research suggests that as a child’s individual health care needs can change frequently, there are associated implications for schools in providing effective health care support. When children’s needs are not predictable and requiring regular help and support, there are clear challenges for school staff in terms of remaining up-to-date and competent in carrying out procedures rarely performed.

1.8. Where in the school did children get help and support

Almost half (16 out of 36 responses) of the parents identified that the administration of medicines or health care procedures happened in a private or semi-private space in the school, such as a medical room, or designated space within the class room. Depending on the nature of the child's condition, the administration of medicines or health care procedures happened wherever the child required it at the time. Five parents reported that they did not know where help and support happened in school. Three parents explained that if their child were to have an allergic reaction, they would need to locate the EpiPen and/or the staff member responsible for storing and administering it, as quickly as possible.

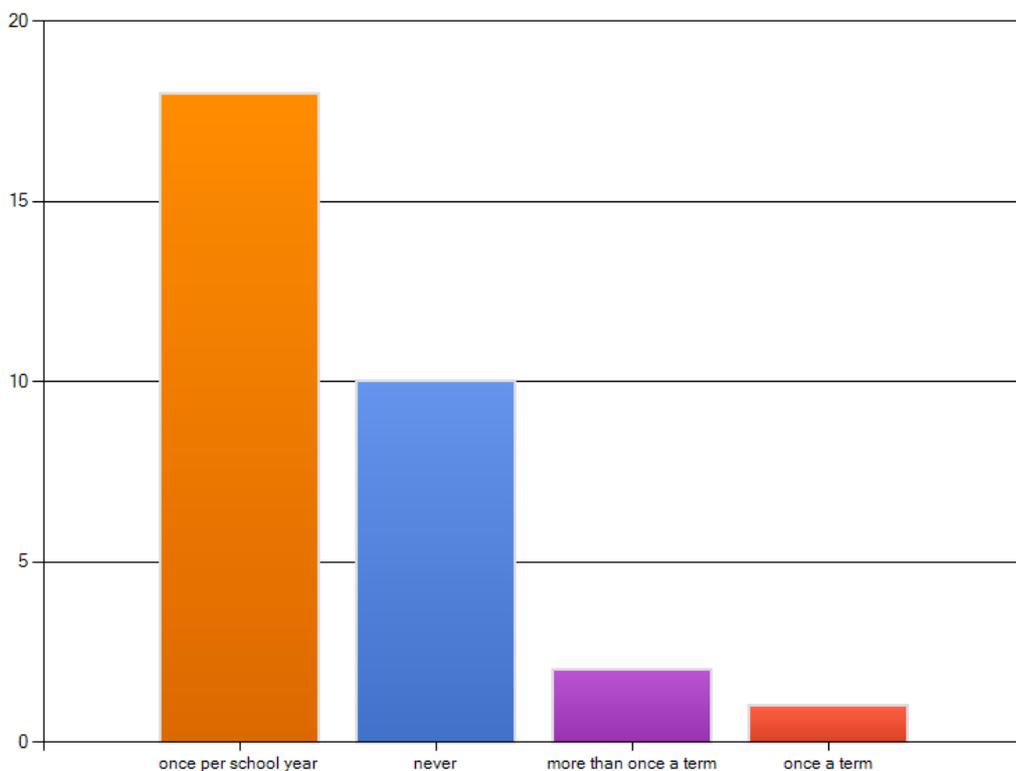
1.9. Plans

Thirty parents (71.4%) reported that their child had a health care plan, or a relevant plan called by another name. Seven parents (16.7%) stated that their child did not have a health care plan and 5 parents (11.9%) said that they did not know.

1.10. Meetings

Parents were asked how often they attended meetings in school, to discuss and review their child's health care needs. Thirty-one responded.

Graph 6 – Number of times per school year meetings were held in school to discuss children's health care needs



Eighteen parents (58.1%) stated that they attended meetings in school once a year, to discuss their child's health care needs. Ten parents (32.3%) reported that they had never attended a meeting to discuss their child's health care needs. Two parents stated that they attended meetings more than once per term and one reported that they attended meetings once per term. Three other parents explained that they had only ever attended one meeting during their child's school life, and another parent indicated that they were told about arrangements, not invited or asked to share their views.

Frequency of meetings did not seem to be an issue for most parents; indeed, there was a high level of satisfaction expressed about current arrangements. Many parents indicated that they felt they could contact the school to discuss issues, including any changes in their child's health care needs, whenever they needed to.

A small number of parents indicated that they were not happy with current arrangements. One parent said:

"This could be improved – I update them, they never proactively ask me for information."

1.11. Attendance

Parents were asked whether their child's attendance had been affected by current arrangements at school for the administration of medicines or health care procedures. Twenty-nine parents (67.4%) answered no, and 14 (32.6%) said yes. Fifteen parents provided some further information about this issue; all but one of these comments described practice which was *not* effective, and will be discussed in more detail in section 5.

1.12. Reasonable adjustments

Twenty-five parents (59.5%) who took part in this study reported that their child has a disability, and provided further information about reasonable adjustments. Many responses revealed that parents were not aware of their rights with regard to legislation about reasonable adjustments and several parents were of the view that they were required to take the lead and be proactive in ensuring that reasonable adjustments were made for their child.

A small number of parents (2) reported that failure by the school or local authority to make reasonable adjustments resulted in the decision to place their child in an independent school. Several parents (5) reported feeling confident that reasonable adjustments were in place because their child attended a special school.

One parent raised an important issue about reasonable adjustments and discretion, explaining that when such adjustments or adaptations are obvious, they can result in the child or young person feeling singled out or different:

“The adjustments offered to us all require my child to be treated differently from her friends, to leave class early or to arrive late (with no guarantee that all teachers will be sympathetic) or to go to the other end of the school building to be supervised giving an injection. It has been impossible to help find ways of making sure medications and equipment are readily available and not locked away with schoolbags during practical classes, because the class teachers are not contactable and the nominated contacts cannot anticipate what will be required. In the end we muddle through without involving them. My child is reluctant to make a fuss and I have no way of contacting the school - emails to the guidance teacher go unanswered and so we work at making sure my child can be independent because this seems safer.”

There are legal requirements for schools to make reasonable adjustments for children and young people with disabilities, and there are also pastoral care issues about acting with respect and discretion. This evidence highlights the importance of placing the child at the centre of all decision-making processes and actions which affect them; children’s views and feelings need to be taken into account to ensure that reasonable adjustments are not something done *to* them but *with* them.

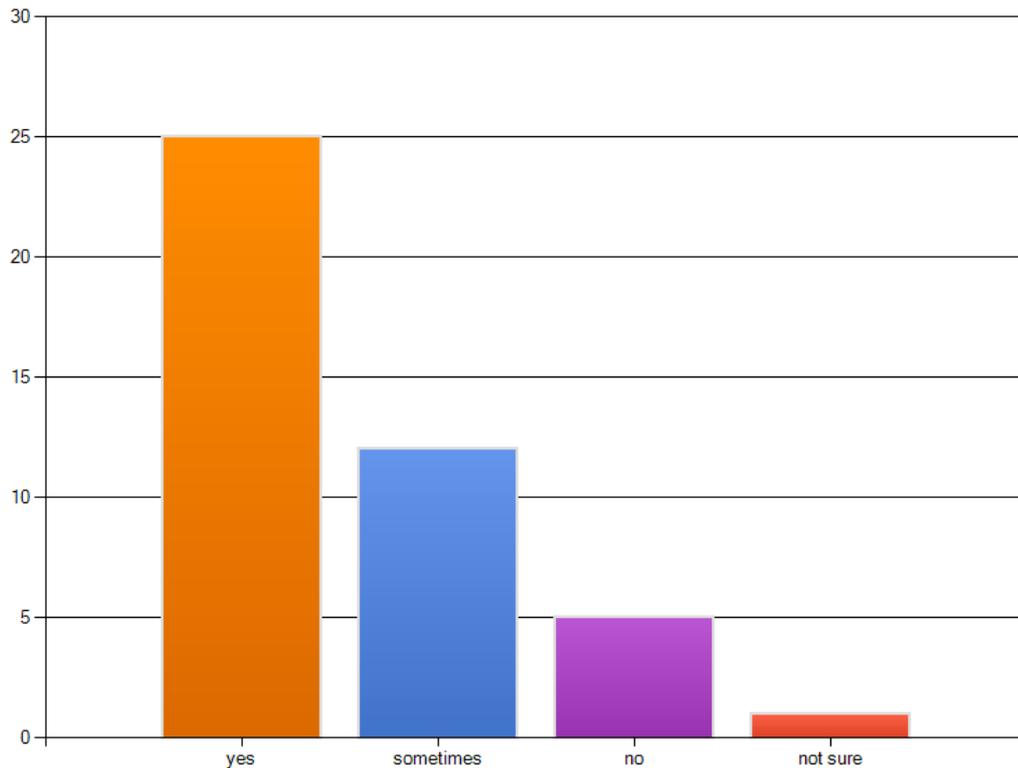
1.13. Summary

Children and young people with health care needs depend on the people around them to provide the right care and support if they are to participate fully in their own education and in the life of the school. Parents in this study identified a range of health care needs, from common conditions requiring occasional support to complex needs requiring regular and skilled support. Learning assistants most often provided help and support, despite the complexity of need and of care required. There was strong evidence that parents felt the need to be proactive in securing health care for their child at school. Confusion around reasonable adjustments for disability suggests the need for support and guidance for parents in understanding their legal rights.

2. The extent to which parents felt their child's health care needs were being met

One of the main aims of this research study was to ascertain the extent to which parents believed the health care needs of their children were being met in school. This section looks at parents' views and opinions about this issue.

Graph 7 – Number of parents who felt their child's health care needs were being met



Almost two thirds (58.1% or 25) of parents who participated in this study reported that their child's health care needs *were being met* at school. Nearly one third (27.9% or 12) felt that their child's needs *were sometimes met* at school, 11.6% (5) felt that their child's needs *were not being met* at school, and one respondent (2.3%) was not sure. Thirty parents provided more information about why they felt this way, which is discussed below.

2.1. The views of parents who felt their child's health care needs were being met at school

Parents who felt that their child's needs *were being met* gave similar reasons for this:

- good, regular communication between themselves and school
- willingness to work in partnership with the parent
- a sympathetic attitude and helpful approach
- good staff training
- consistency in carrying out health care procedures.

Some responses indicated that parents felt their child's needs *were being met* after considerable investment on their part to make this so. One respondent wrote:

"I feel lucky that we were understood by the school management at the time we had our transition meeting. However, I think this is because we had done our own 'homework' on our rights, as no one actually told us to arrange that meeting or talked about a plan with us prior to my request to put things in place for our daughter."

Another parent reported: *"I have spent a lot of time going over her needs."*

Parents whose children attended special schools or special units in mainstream schools *all* indicated that their needs *were being met*. Many of their responses highlighted good staff training, the presence of nursing staff, and a clear understanding of their child's healthcare needs as important factors in achieving this. Thus, there was a significantly high level of satisfaction with health care needs being met in special schools and units in mainstream schools.

2.2. The views of parents who felt their child's health care needs were sometimes being met at school

Parents who felt that their child's healthcare needs *were sometimes met* at school gave specific reasons and examples for this. One respondent stated:

"My child does not like having the cream applied and will avoid if possible. Due to the nature of the eczema, I cannot tell if the cream is being applied."

A similar response indicated the difficulties for children who resist unpleasant health care procedures, and the difficulties for parents in knowing whether procedures have been carried out:

"My daughter sometimes doesn't like getting her creams on so will not mention it to the teacher. I have to do this when her skin is particularly bad. Although the teacher responds to her itchiness, she cannot always see how dry her skin is getting."

Parents also reported difficulties when children preferred to self-manage, in some cases because the child wanted privacy and discretion, or due to previous negative experiences with support. One parent explained:

“My child is able to manage independently and I want to support that, but sometimes there are problems that are more difficult to manage (such as forgetting to take insulin to school, persistent hypoglycaemia or very high blood glucose levels) that would be safer to manage with help or at least a teacher being aware that help might be required. The school have not been able to respond in an unobtrusive way, when we have asked for occasional help they tend to remove my child from class or instigate restrictive supervision measures - those really are not what is required. One staff member in particular has made numerous unhelpful comments to my child.”

Taking an active approach to ensuring that their child’s health care needs were met emerged as an issue once again, in this case by a parent who stated:

“There is a reactive as opposed to proactive approach which heavily relies on me.”

Another parent explained that their child’s health care needs were only met in school when adequate provision, in the form of nursing staff, was provided. The issue of adequate provision of staffing will be discussed in more detail in section 5.

Contrasting views were evident in the accounts of two parents, who reported discrepancies in practice in the primary and secondary sectors. One parent reported that it was “not so clear in high school” how their child’s health care needs were managed. However, another parent reported:

“Since starting secondary school, I have been much more confident that his needs will be met and the right advice given. Primary school was less reliable and often put barriers in the way of him being able to get his medication when required.”

2.3. The views of parents who felt their child’s health care needs were not being met at school

Five parents reported that they felt that their children’s healthcare needs were *not being met* at school, and gave frank accounts of why they felt this way. A detailed discussion of these views follows in section 5, however some of the key issues emerging were:

- unsympathetic, uncaring attitudes and approaches
- lack of discretion and respect in providing support
- lack of staff training or qualified staff (including nursing staff)
- failure to administer medicines or health care procedures when required
- lack of understanding of the child’s condition, including the seriousness of the condition.

2.4. Summary

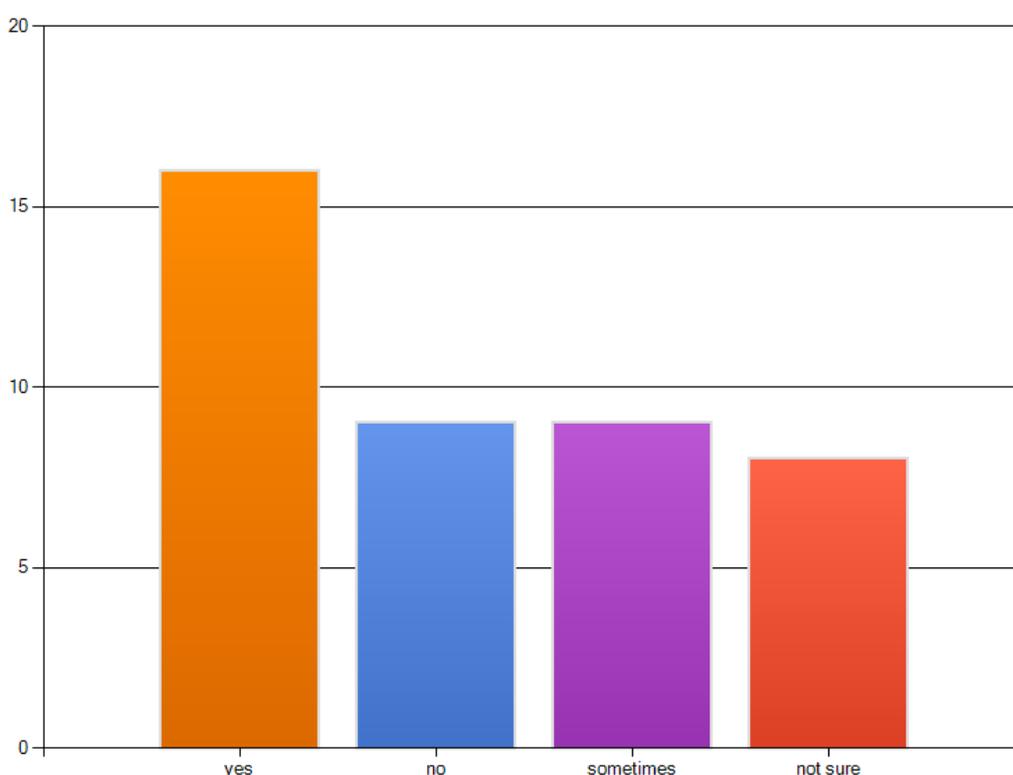
Almost two thirds of parents who participated in this study reported that their child's health care needs *were being met* at school. Only a small number of participants felt that their children's needs were *not being met* at school, and nearly one third felt that their child's needs were *sometimes* met at school. Some parents highlighted the importance of being proactive in ensuring that the school met their child's health care needs, and there was some evidence of frustration that this requirement existed.

3. The extent to which parents believed their own and their child's views were taken into account by the school

Working in partnership with parents, including sharing information, is important to ensure the best possible care for of children with health care needs¹⁹. Children and young people have the right to express their views freely in matters affecting them²⁰. One of the main aims of this research study was to ascertain to what extent parents felt that their own and their child's views were taken into account by the school.

3.1. Parents' views about whether the school took their child's views into account

Graph 8 – Parents' views about whether the school took their child's views into account



From 42 responses, 16 parents (32.6%) felt that their children's views were taken into account by the school. Parents in this group described feeling happy, pleased that their child was being supported by the school generally and in terms of promoting independence in managing their health care needs, and confident that needs were being met because the child was involved in their own health care at school.

¹⁹ Scottish Executive (2001) *The Administration of Medicines in Schools* p.1

²⁰ United Nations (1989) *United Nations Convention on the Rights of the Child*, Article 12

Nine parents (21.4%) stated that they felt their child's needs were *sometimes* taken into account, and gave a range of reasons for this. The same number of parents (9) felt that the school *did not* take their child's needs into account and a few stated that it was important to seek the views of the child in their own care. One parent explained that their child was not asked for their views and another parent expressed the view that the school's actions tended to be procedure-bound rather than needs-led. However, looking closely at the reasons parents gave for claiming that their child's views were not taken into account, some parents answered no to this question because their child did not have the capacity for verbal communication, or was described as too young to be asked their views. Their answers might be interpreted as meaning that their child was *not able* to give their views.

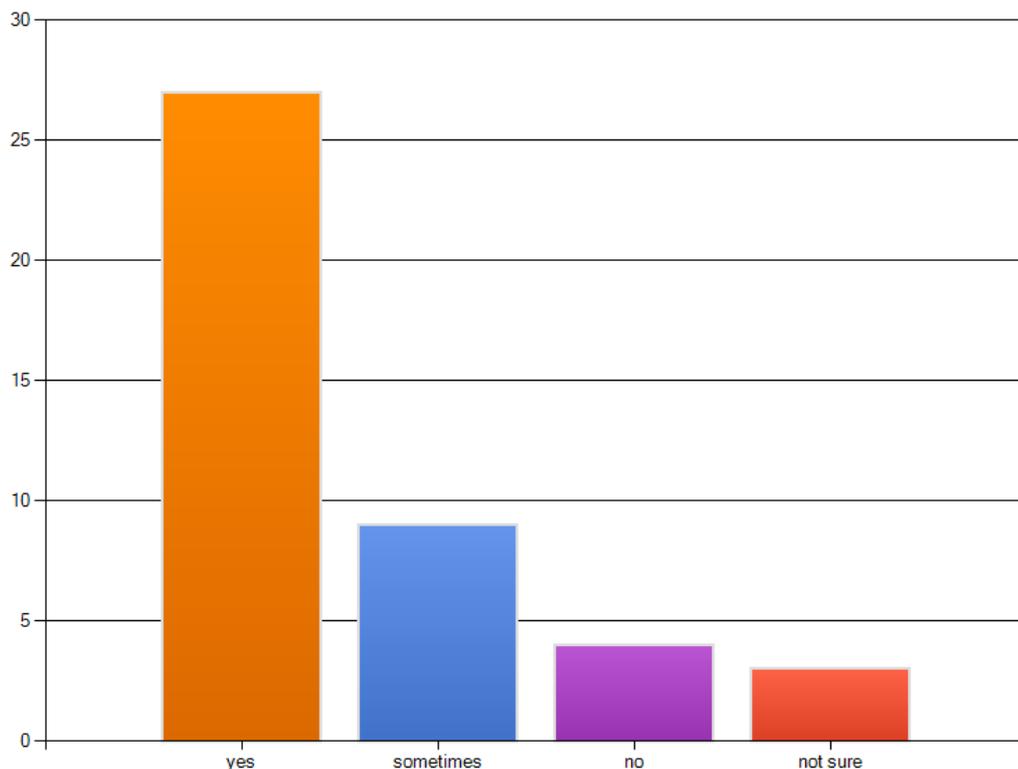
There was one striking comment from a parent who stated:

"Feel it's a constant struggle as if his illness is a nuisance for them to deal with."

A few parents who answered that they *sometimes* felt their child's views were taken into account made recommendations for improved practice, which will be discussed in more detail in sections 5, 6 and 7.

3.2. Parents' views about whether the school took their views into account

Graph 9 – Parents' views about whether the school took their views into account



From 42 responses, 27 parents (64.3%) felt that the school took their views into account. Those parents reported feeling happy about existing arrangements and communication, and satisfied that if they did need to contact the school with any issues, these were listened to and dealt with.

Of the 21.4% of parents (9) who felt that the school *sometimes* took their views into account; the 9.5% of parents (4) who felt that school *did not* take their views into account; and the 7.1% (3) who were *not sure*, there were some common reasons for feeling this way. Parents described concerns that the school might not be fully aware of the seriousness of their child's health care needs, and some also reported not feeling listened to.

One parent, whose views were not sought by the school, explained that the school's lack of interest might be seen as lack of interference:

"The school have not asked for my views nor provided any space for me to put my views forward. As above, they have at least not interfered so long as we manage ourselves."

Other parents described feeling "*cheated*", "*frustrated*", and "*feel a little dismissed at times or spoken over*". One said bluntly: "*I do not feel I have a voice*". Another parent expressed the view that "*school should work in partnership with parents*".

3.3 Summary

Although 64.3% of parents reported that they felt the school took *their views* into account, only 38.1% felt that the school took *their child's views* into account, a considerable discrepancy. This suggests that although children have the right to express their views freely in matters affecting them, their voices were not being heard as consistently as parents' voices.

4. Factors which helped effective practice

In section 2, it was reported that 58.1% of parents felt that their child's health care needs *were being met* at school. They identified several factors which helped effective healthcare practice in their child's school, which will be considered in more detail in this section. The main factors identified were:

- Access – to the right medicines and the right people
- Caring, sympathetic staff – who are understanding and patient, and who have a good relationship with the child
- Appropriately trained staff – including qualifications, where appropriate
- An understanding of the child's condition – by school staff and peers, including knowing what to do in an emergency
- Continuity – of care, including staff who help
- Good communication between home and school
- Privacy.

4.1. Access – to the right medicines and the right people

Parents identified that access to the right dosage of the right medicine at the right time was paramount to the safety of their child. They also reported that access to appropriately trained staff who were able to offer a consistent approach to supporting their children was similarly of great importance. It is difficult to overstate the importance of the relationship between a child with health care needs and the person(s) providing support, which holds true across parents' accounts and regardless of the nature of the child's health care needs. The information provided revealed that, at a fundamental level, children needed to know *who* would provide help and support to them when they needed it. Particularly when the administration of medicines or health care procedures happened in an emergency, children needed to be very clear about *who* to approach and *how* to find that person.

4.2. Caring, sympathetic staff

Parents commented on the importance of a caring, sympathetic approach, stating that 'to be listened to' was important to their child. One parent explained that patience and respect are fundamental aspects of good practice:

"I believe the office staff are very patient when he is trying to communicate his needs. He suffers from processing problems and his speech can be a bit jumbled if he is stressed."

Another parent claimed that current arrangements for help and support at school have had a positive impact:

"This makes it easier knowing the school is sympathetic and understanding."

Effective healthcare practice in schools ultimately supports the inclusion of children with health care needs in all aspects of school life. As one parent explained:

“I’m very pleased with my child’s school and what they have done to accommodate him. He loves going to school and gets included in all activities, even though he has lots of procedures needing to be done every day.”

4.3. Trained staff

Several parents stated that staff who administer medicines or health care procedures must be appropriately trained. A few parents expressed the view that an appropriate qualification was important, but overall training *to meet the specific health care needs of their child* was identified as an important part of good practice.

4.4. Understanding the nature of the condition and its impact on the child

Many parents expressed the view that having an understanding of their child’s condition and how to help them was a critical aspect of good practice. Several parents reported that workshops or awareness sessions about common conditions should be part of ongoing staff development; in fact, many parents expressed surprise that this was not already an essential part of good practice in all schools in Scotland. In a number of cases, parents reported that they took an active role in supporting school staff’s understanding of their child’s medical condition, explaining which practices were helpful (and not so helpful) for their child.

4.5. Continuity and consistency of care

Parents were clear that continuity of care was an essential element of good practice. This meant having the same member(s) of staff involved in their child’s care; agreeing and consistently following procedures; regular communication, or at least the willingness to communicate with the parent (and the child); and regularly reviewing and updating health care plans.

4.6. Good communication between home and school

Many parents reported that feeling welcome to contact the school with any issues or concerns was very important. Approachability and willingness of school staff to listen to the parent (and many also said to their child) was identified as helpful practice. In some parents’ accounts, one key member of staff was identified as central in establishing ongoing good communication. Indeed, some parents suggested that one key point of contact was critical to good practice in schools. One parent stated:

“Good communication is paramount. Not being made to feel like we are wasting staff time when we approach with information when the asthma is playing up. Knowing we can approach the school with any concerns and our son can do the same is invaluable. Having to fight past a member of staff who is putting barriers in the way of my child is very stressful.”

Another parent explained that a daily diary is a good form of communication between home and school, to write about any concerns or changes in the child's health care needs, as well as which procedures have been carried out in school.

4.7. Privacy

Some parents highlighted the importance of privacy in meeting their child's health care needs at school. The parent of a child with Crohn's explained that:

“School has been very supportive and allows access to any toilets and also rest periods when needed. This makes it easier on the days the illness is active. Privacy is paramount for Crohn's sufferers.”

Another parent stated that there had been *“a few incidents about privacy when toileting, but they seem to have been sorted out”*. Having access to suitable, private spaces in which to receive help and support and to self-manage their medication is important for all children and young people.

4.8. Summary

When health care practices in schools were effective, the impact on the child's overall health and wellbeing and quality of life was significant, as one parent explained:

“It means the world! It means that I am reassured to know that my daughter will be cared for during school hours (application of creams and bandages at lunch time), therefore she doesn't become uncomfortable and is able to concentrate better. Also she is less likely to get flare-ups due to the consistency of the treatment during the day, hence, less infections, less antibiotics and a better attendance rate. The plan benefits her health, education and our quality of life as a family. It also means we feel supported by the school and this is very important.”

One of the main objectives of this research study was to ascertain to what extent health care practices in schools enable children to participate as fully as possible in their day to day education. What was striking, from parents' responses, was the extent to which parental involvement in the management of their child's health care needs at school prevented them from engaging in employment or education opportunities, as was clear in one parent's statement:

“As parents we need to be readily contactable for my child to ask for help managing diabetes. Before my child was able to do injections independently, we had to attend school every lunchtime to administer the insulin. This meant one of us giving up work.”

Yet when effective health care practices were in place, the benefits for parents were palpable. One parent explained that:

“We have 6 hours during the school day when we don't have to worry about my child's procedures needing to be done.”

It is clear to see from the parents' responses that when effective practices are in place in school, the health and wellbeing of the child and the right of the child to receive a full education are being met, and crucially parents are able to participate more fully in their own work and education experiences. In this way, the wellbeing of the family is supported and enhanced when effective practices are in place at school.

5. Factors which hindered effective practice and parents' views about how to improve practice

In section 2, it was reported that 27.9% of parents felt their child's needs were *sometimes* met at school and 11.6% felt that their child's needs were *not being met* at school. This section contains a detailed discussion of the factors which parents identified as hindering effective healthcare practice in their child's school. The main factors identified were:

- Unsafe practices – storage and administration of medicines and food allergens
- Concerns about adequate staffing – including lack of staff confidence, training or qualifications; provision of appropriate staff
- Lack of awareness of the medical condition, and how it affects the child
- Unsympathetic attitudes and approaches
- Lack of or failure to follow policies and procedures.

5.1. Unsafe practice - storage and administration of medicines

Several accounts of difficulties with medication were reported which highlight clear risks to the child's safety and wellbeing. One parent described an incident in which the administration of medicine was forgotten:

“Following a severe medical incident where medication was forgotten, our son became very ill. We then had to require the school to fax us 3 times per day to confirm what and when medication had been given. Over 6 different medications were NOT given in the incident. It was serious negligence.”

Another parent reported instances of mismanagement of EpiPens:

“Sometimes the pens have been locked away; not passed on to the relevant teacher; left in school overnight and taken out of the special box and not replaced.”

Other parents reported failure to administer medicines in schools, resulting in medicine being administered at home only:

“My child is often sent home if she has any medical needs of any kind, they did not give her the medicine she needed when she needed it, so now I have to come pick her up from school to administer the medicine myself.”

5.2. Unsafe practice with food allergens

Food allergies are common, and becoming increasingly so, yet some dangerous practice was evident in parents' accounts. Nut allergies can be fatal, but there was evidence of nuts in some school environments, in the following statements from two parents:

"As they refused to remove nuts from all cookery classes she cannot attend home economics."

"In my daughter's primary school they made bird seed from peanuts even after being told of the nut allergic children. There was a 6 year old with a nut allergy in the class and they still continued to use peanuts. When approached they said nothing to do with them. My child suffered from severe anxiety because of problems with her primary school and yet no help from school or NHS were available to us."

Another parent reported that there should be:

"Clear lines from the school that all teachers are fully aware of his condition (as was the case in primary school), this has caused some issues particularly in home economics where he can be exposed to his allergens and the teacher was unaware."

The lack of clear, consistent policies and procedures about food allergies was of concern to another parent:

"I worry that my son might be given something to eat that is unsuitable. He will usually ask if it is OK, but I have had to write to the headteacher to ask that the school inform me if the school are planning to give the children something to eat. Although individual teachers are great, there are no procedures in place in the school management."

Food sent in by other parents, which contains or may contain food allergens, was also seen as problematic:

"Other parents [are] sending in snacks with nuts despite being told repeatedly cake and candy type events are problematic."

Meeting the needs of children with food allergies requires a consistent approach and clear guidelines about which foods are not allowed in the school environment. These comments suggest that enabling full participation in all aspects of school life is central to the principle of inclusion, as noted in parents' responses.

5.3. Concerns about adequate staffing

Concerns about staffing were common in parents' accounts, specifically issues about appropriate training and qualifications; the effects of staff absence on health care practice in schools; and the provision of specialist staff, when required.

One parent expressed confusion about the common practice (supported by the findings of this study) of learning assistants administering medicines and health care procedures in schools:

“It is difficult to understand why the administration of medicines is left to the least qualified member of staff in the school. Learning assistants are not being asked to oversee complex educational issues, so why are welfare assistants overseeing complex healthcare issues?”

Another parent explained that their son was not supervised or supported during indoor break times, when the learning assistant was absent:

“After an operation, my son was not to go out in the playground at break (i.e. no running or PE). As the learning assistant was off sick there was no one available to watch my son indoors as the other learning assistant was required for playground supervision.”

A child's health care needs might be particularly acute following surgery, so the need for close support and supervision would have been crucial at that time of enhanced vulnerability. The absence of a learning assistant in this case perhaps should not have been a barrier to help and support at break time.

Just as having no replacement staffing is an issue for parents, so too is that of temporary staff who need to be aware of the health care needs of children in their care. One parent explained:

“I worry about supply teachers not being as aware school trips and camps are a worry.”

Frustration with the current framework, in which the administration of medicines and health care procedures is undertaken on a voluntary basis in schools, is evident in one account of barriers encountered by parents and carers:

“I know too many families who either struggle to get an arrangement with the school in terms of medication or simply do not know they are entitled to it so never ask and miss out, while their child is not properly looked after during school hours. Guidance should be clearer for carers and schools. There should be no barriers to medication at school, such as 'no staff has volunteered to do it'; 'we don't touch the kids'; 'we don't have the training or the funding to do it'.”

Transportation to and from school was another area of concerning practice for parents. One parent reported that their daughter:

“... cannot access her school bus transport because bus staff have refused to help in an emergency. A taxi was offered and the escort in the taxi agreed to be EpiPen trained but not administer it! ... So no alternative was provided and I have been getting ignored from [the council] for months now.”

The provision of nurses to support children with complex health care needs

Parents of children whose complex health needs are best met by (specialist) nursing staff identified the inadequate provision of nurses as a factor impeding good practice.

Lack of appropriate nursing staff resulted in one child missing a great deal of his early education, as their parent explained:

“He has frequently not been able to attend school when he is well to do so. He has missed the very large percentage of his primary schooling.”

Frustration was palpable in the parent’s account of why they felt this situation came about:

“Nurses are provided by the health board. They claim they cannot recruit sufficient nurses to attend school with my son. However, they refuse to fund training shifts so nurses are expected to attend school with a child with the most extreme of health problems without ever having had the opportunity to visit the school with my son. They also [know] my son needs nurses who know him well to attend school with him, but as they will not fund training for nurses, no nurses can get to know him well, so the problem continues. As the nurses are agency nurses the health board has a vested interest in nurses not being available, as if no nurse is available, no payment is made for a nurse.”

5.4. Lack of understanding of how the condition affects the individual child

Some parents expressed concerns about school staff’s lack of understanding of their child’s medical condition. One parent described “widespread ignorance” of their child’s condition. Another parent gave a stark account of how ignorance about diabetes made their child’s early school experience very difficult:

“My child has had to be self-reliant, and although this is less of a problem now it was very challenging at a younger age. It was easier for my child to simply not take insulin injections and not test blood glucose levels rather than constantly approach teachers to explain why the schoolbag should not be locked away, why it really matters if lunchtime is 20 minutes delayed for class detentions or why lunchtime sports meetings that leave 5 minutes to eat are complicated.”

Parents reported that many children find having to regularly remind school staff of their health care needs challenging, a process which consistently singles them out as different from their peers.

A third parent gave an account of unhelpful practice associated with another common condition, asthma. Having a better understanding of how asthma presents in individual children was advocated:

“An awareness amongst teachers that asthma doesn't always present as wheezing or breathlessness, but can also be a dry persistent cough. Telling my children to get a drink of water rather than use their inhalers is not helpful.”

Another parent described a similar concern about the lack of understanding of anaphylaxis, a common condition:

“I wish they would understand the difficulties presented with this illness there is a lot of ignorance surrounding anaphylaxis and quite frankly people can be very dismissive of it.”

The importance of regular treatments for eczema, another common condition, is cause for concern for another parent:

“Don't think they fully understand how important his creams are. Without them his hands become sore and cracked leading to infection and bleeding.”

5.5. Unsympathetic attitudes

School staff who lack a caring, compassionate approach were seen by many parents as a barrier to good practice. Some parents reported concerns about the effects of unsympathetic attitudes on their children's wellbeing, including one parent's description of a difficult experience at their son's secondary school:

“After bouts of pneumonia resulting in long term steroid and antibiotic use we found the support was not there. Teachers were less than sympathetic about the illness and the side effects of the medication. They failed to listen to my son's explanations of absence. His pupil support teacher often refused to gather work from subject teachers to send home and if any was gathered it was not clear where it could be collected from. Communicating information to subject teachers about his condition was also not forthcoming and I was made to feel like I was wasting her time.”

Another parent explained:

“She is very self conscious about it and finds that teachers can sometimes be very unsympathetic and indiscreet. (She sometimes feels that they think she is 'chancing it' whilst others are 'over protective').”

Children’s concerns about not being listened to were mentioned by several parents. For example, one parent explained:

“She feels as if she is not listened to. There is widespread ignorance about the condition.”

Frank, open discussions with other children are perceived to be important, too, in creating awareness of health care needs and in preventing or ameliorating unhelpful attitudes. One parent stated that it was important:

“That the staff are open and honest about his condition and ensure that the other children know they can't catch it.”

5.6. Missed schooling

In a previous section, parents’ concerns about inadequate provision of specialist nurses preventing their children from attending school, even when they were well enough to do so, were discussed. Parents gave other reasons for missed schooling: failure to administer medicines or health care procedures at school; inability to participate in school activities; and perceived over-reactions to minor health complaints.

Two parents expressed the view that the school contacted them to take their child home, when the child might be well enough to be there. One parent stated:

“I would prefer I wasn't called to the school, every time my child coughs or sneezes. I doubt any other child who doesn't have a disability is sent home every time.”

Another parent explained:

“Most times if my child is unwell I am sent for to take her home ... she has missed quite a bit of school because of this.”

The school’s inability to follow agreed procedures was the reason for one child missing school, and he *“remained at home from 31 November until 30 January as the school could not uphold [the] care plan”*.

Although it was not clear from the data just what the activities referred to were, one parent explained:

“I have taken him out when activities are being staged which he cannot participate with.”

One parent's account drew on the experiences of other parents, for whom missed schooling had serious implications for their own employment:

“Not mine, but I do know of many children with the same condition who do not get the appropriate care at school, which stops them from attending and also stops their parents to work as they have to care for them at all times.”

5.7. Up to date policies and guidelines for schools

A few parents identified the absence of, or outdated, policies and guidelines about meeting health care needs in schools as a factor hindering good practice. One parent explained that a policy document about the needs of diabetic children in school was needed, in conjunction with “*proper support*” from the local authority. Another parent expressed the view that practice could be improved “*if there was a willingness to follow up to date guidance from more specialised sources*”. One respondent identified consistency as an important reason for clear guidance in schools and across local authorities, and for better information for parents about additional help and support available at school.

5.8 Parents' views on how practice could be improved

Parents were asked to identify what would be *more helpful* to their child at school and a summary of their responses shows clearly how they felt practice could be improved for children with health care needs:

- Safe storage, access and administration of medicines
- Allergen-free learning environments
- Appropriately trained, qualified and informed staff
- Caring, compassionate staff
- Provision of specialist nurses, when required
- Private spaces for health care
- Up to date school and local authority policies
- Agreeing health care procedures in a health care plan (and adhering to them).

5.9. Summary

Despite a high level of agreement that their children's needs were being met, parents in this study provided much more information about factors which (in many cases *previously*) hindered rather than helped effective practice, indicating that ineffective practice remains of real concern to parents. This study has also found that ineffective practice in schools can result in loss of employment and/or educational opportunities for parents, when they are required to provide regular help and support for their child at school.

6. Key findings

This research has highlighted the complexities of practice around administering medicines and health care procedures in schools. Parents' views were sought, following concerns raised with the Commissioner's office about current arrangements in schools. This study has found that many parents were happy with the current arrangements for their child in school, and there was ample evidence of good practice. However, parents have also described some concerns around unsafe practices, which will have an impact on the wellbeing of children with health care needs in schools.

The main findings in relation to the main research aims are summarised below.

6.1 Current practice around the administration of medicines in schools

A wide range of health care needs were identified by parents, from common conditions requiring occasional support to complex needs requiring regular and skilled support. A detailed list of conditions identified, with definitions, appears in Appendix 1.

Half of the parents in this study reported that their children required medicines to be administered in school and almost 40% reported that their children sometimes required medicines to be administered. Only a small number of children (18.6%) were reported to self-manage; the large majority (65.1%) did not, as reported by their parents. This research highlighted the variable nature of provision for children requiring help and support in schools.

More than half of the parents in this study reported that their children required health care procedures in schools. The overall picture was of highly varied, individualised health care procedures to meet children's complex health care needs.

Many parents identified the need to be proactive about securing help and support for their children at school, with many indicating frustration about this.

Learning assistants most often provided help and support, even when a high level of need and care was required. Parents identified the importance of adequate training for support staff, as well as staff competence and confidence.

There was considerable confusion around reasonable adjustments for children who had a disability, suggesting that parents require further support in understanding their legal rights.

6.2 The extent to which parents believed the medical needs of their children were being met

Almost two thirds (58.1% or 24) of parents who participated in this study reported that their children's health care needs were being met at school and nearly one third (27.9% or 12) felt that their children's needs were sometimes met at school. Key reasons reported for children's needs being met were:

- good, regular communication between themselves and school
- willingness to work in partnership with the parent
- a sympathetic attitude and helpful approach to the child
- good staff training
- consistency in carrying out health care procedures.

A small number of parents (11.6% or 5) stated that their children's needs were not being met at school. There was evidence that parents felt the need to take an active role in ensuring that the school met their children's health care needs, and some were clearly frustrated by this.

6.3 The extent to which parents believed their own and their child's views were taken into account by their child's school

The majority of parents (64.3% or 27) felt that the school took their views into account. Those parents reported feeling happy about existing arrangements and communication, and satisfied that if they did need to contact the school with any issues, these were listened to and dealt with.

Around one fifth of parents (21.4% of parents or 9) felt that the school sometimes took their views into account; just under a tenth (9.5% or 4) felt that school did not take their views into account; and 7.1% (or 3) were not sure. Parents reported concerns that the school might not be fully aware of the seriousness of their child's health care needs, and some also reported not feeling listened to.

There was a marked contrast in the number of parents reporting that the school took their *children's views* into account (38.1%). This suggests that although children have the right to express their views freely in matters affecting them, their voices were not being heard as consistently as parents' voices.

6.4 Factors which parents felt helped effective practice

The main factors identified were:

- Access – to the right medicines, on time
- Access – to the right people who could help, when it was needed
- Caring, sympathetic staff – who are understanding and patient, and who have a good relationship with the child
- Appropriately trained staff – including qualifications, where appropriate
- An understanding of the child's condition – by school staff and peers, including knowing what to do in an emergency
- Continuity – of care, including staff who help
- Clear health care plans – and knowing that these should be in place for children with health care needs
- Good communication between home and school
- Privacy.

There was evidence that the need for regular parental involvement in the management of their child's health care needs at school prevented them from engaging in employment or education opportunities. This research showed that when health care practice in schools was effective, the impact on the child's overall health and wellbeing and quality of life was significant, and the impact on family life was also positive.

6.5 Factors which parents felt hindered effective practice

The main factors identified were:

- Unsafe practices – storage and administration of medicines and food allergens
- Concerns about adequate staffing – including lack of staff confidence, training or qualifications; provision of appropriate staff
- Lack of awareness of the medical condition, and how it affects the child
- Unsympathetic attitudes and approaches
- Lack of or failure to follow policies and procedures.

Parents provided much more information about factors which they felt hindered effective practice, some of which related to previous experiences, even though nearly two thirds reported that their children's needs were being met at school. This suggests that barriers to their children's health and wellbeing at school are a source of long term anxiety to parents.

6.6 Parents' views on how practice could be improved

One of the main research aims of this study was to ascertain parents' views about how practice could be improved. Parents were clear about what helped their children and what did not but there was less direct information about how practice could be improved. Parents did suggest the following:

- Safe storage, access and administration of medicines
- Allergen-free learning environments
- Appropriately trained, qualified and informed staff
- Caring, compassionate staff
- Provision of specialist nurses, when required
- Private spaces for health care
- Up to date school and local authority policies
- Agreeing health care procedures in a health care plan (and adhering to them).

7. Reflections on policy and practice

This report has produced a number of issues which might be of interest and/or concern to practitioners. This section raises a number of discussion points emerging from the study.

Communication

One of the main objectives of this study was to ascertain the extent to which parents believed their views were taken into account by the school. A significant number of parents and carers who participated in this research study expressed the view that good, open communication was an essential part of effective practice for children and young people who require medicines or health care procedures to be administered. Parents who reported difficulties with or uncertainties about contacting the school to discuss arrangements and concerns said that they felt:

“cheated”

“frustrated”

“feel a little dismissed at times or spoken over”

“I do not feel I have a voice”.

There is clearly a need for schools and families to work towards finding better and more consistent ways to communicate about children’s health care needs. One parent reported the value of a daily diary, in which school staff recorded which medicines or procedures had been administered and the parent wrote about any concerns or issues with their child’s health care needs. Given that several parents of children who required creams to be applied because of eczema reported uncertainty about whether such applications were actually happening, the use of a daily diary or similar shared communication tool seems like a simple way to enable effective practice. The benefits to the child’s overall health and wellbeing indicate that consistent communication about health care procedures be considered as part of good practice in all schools.

School culture

It is recognised that many schools promote cultures of compassion and caring, and that staff members will be sympathetic to the health care needs of all children and young people in their school community; however, several parents in this study reported that unsympathetic attitudes and approaches in their child’s school led not just to unhelpful and in some cases harmful health care practices, but also had a significantly negative impact on the child’s feelings of wellbeing. Getting it right for every child means meeting all of their wellbeing needs, and ensuring that all children are *safe, healthy, active, nurtured, achieving, responsible, respected and included*.

Pastoral peer support

The right for all children to have an uninterrupted education is paramount, and it is not intended that peers are used as a substitute for the provision of adult help and support in schools; however it is accepted that many children and young people with health care needs do already receive a great deal of particularly emotional support from their friends. Especially when children and young people prefer discreet, unobtrusive help, peers might be better able to provide such support than a learning assistant or other adult member of staff. It is not intended that peers should miss any of their schooling to provide help and support, but rather that they could be seen as an effective way to support children and young people with health care needs as part of an inclusive approach. Discussions to determine how peer support practices for children and young people with health care needs can be implemented and sustained could be held with children and young people, their parents, education staff and health staff.

Involving children and young people with health care needs

There is evidence that children and young people with health care needs want to be involved in wider discussions about best practice and in developing policies around the administration of medicines and health care procedures in school, and that they have clear beliefs about what constitutes good practice²¹. Indeed, children and young people have the *right* to express their views freely in matters affecting them²². Therefore, it is important to consider how children and young people could be actively involved in setting and reviewing those policies and practices which affect their health care experiences at school.

Provision of appropriately-trained staff

This research study found that learning assistants most commonly provided help and support to children and young people with health care needs in school. Although it seems entirely appropriate that learning assistants should provide support to children and young people with health care needs in certain situations (such as providing discreet support with certain procedures or reminding a child to take medicine), some concerns have been raised by this study about the suitability of learning assistants to deal with complex health care needs. Learning assistants often provide excellent support to children and young people with a range of needs, but may not always be the most appropriate staff to carry out health care procedures, especially in complex situations. Although there is no legal requirement for school staff to undertake the administration of medicines and health care procedures, it can be written into a learning assistant's contract that they are required to do so. It might also be possible that learning assistants, who are often employed on temporary contracts, might feel

²¹ Information provided by the Commissioner's office, from a focus group of children and young people with health care needs. Participants agreed that clarity was needed in the use of inhalers in school, and one child advocated that all relevant parties should get together and 'all talk about it and what is best'. Participants also had clear ideas about procedures, suggesting for example that Primary 4 is the best age to independently manage an inhaler.

²² United Nations (1989) *United Nations Convention on the Rights of the Child*, Article 12.

coerced into undertaking health care provision in order to retain employment, and there is evidence from other research that this is the case²³.

This research study has found that appropriately trained, qualified and confident staff are seen by parents as an essential element of effective practice. Other research has shown that many workers providing health care in schools do not feel adequately trained, confident or comfortable in providing such care²⁴; thus there is good evidence that this practice requires to be reviewed to ensure that the needs of children and young people with health care needs are being met in schools.

Raising awareness about health care needs

Many participants in this study raised concerns about school staff's lack of awareness and understanding of their child's health care needs, with some using the word "*ignorance*" to describe the lack of knowledge of common conditions. There is evidence, also, that children and young people feel that their health care needs are not taken seriously enough²⁵. Schools which are not already doing so could consider how best to share information and raise awareness about common conditions as well as any complex health care needs.

Awareness raising might take the form of:

- workshops
- presentations by children and young people, health care professionals or school staff to whole school cohorts at staff meetings, In-service days or other training opportunities
- organising awareness days/weeks around certain health care needs (posters displayed prominently throughout the school, events).

Opportunities such as those listed above place the needs of children and young people with health care needs at the heart of their own school community; when they feel comfortable about discussing their health care needs, they are directly involved in educating and informing others about their health and wellbeing. It is recognised that although some children and young people with certain health care needs would actively seek to be involved in presentations to school staff, to guide their understanding of how the condition affects them personally, presentations at school assemblies or in front of their peers might be a more sensitive matter, with the potential to embarrass children and make them feel singled out.

²³ RCN and UNISON (2012) *Supporting pupils with health needs in schools – RCN and UNISON survey*

²⁴ Ibid.

²⁵ Information provided by the Commissioner's office, from a focus group of children and young people with health care needs. Participants agreed that clarity was needed in the use of inhalers in school, and one child advocated that all relevant parties should get together and 'all talk about it and what is best'. Participants also had clear ideas about procedures, suggesting for example that Primary 4 is the best age to independently manage an inhaler.

Using the Health and Wellbeing curriculum to raise awareness and develop knowledge

Mainstreaming learning about the common conditions which many children and young people have could help to reduce concerns about “*widespread ignorance*” of those conditions, and consequently lead to increased understanding and acceptance. Including issues about health care needs and care in formal learning and teaching could help children and young people with health care needs feel included by seeing that their needs matter and are taken seriously as part of the ‘official’ curriculum, and help all children and young people to better understand their own and others’ right to be safe and well.

Allergen-free learning environments

Children have the right to be safe from harm when they are at school. It is recognised that banning or eliminating all possible allergens from all school environments would be extremely difficult; however, the presence of potentially fatal food allergens (such as nuts) in classrooms is a highly unsafe practice. This study has found evidence of nuts and other allergens still being used in home economics classes, which is potentially very harmful to many children and young people. Future review of policies should reflect the need to restrict harmful food allergens as completely as possible.

Proper storing, handling and administration of medicines

Managing medicines appropriately in school is essential; issues of access, storage and administration are central to keeping children and young people with health care needs safe. This research study found evidence of unsafe practice, where the safety and wellbeing of children and young people was compromised. There is evidence from other research with workers who administer medicines in schools that they, too, have concerns about competently storing, handling and administering medicines²⁶.

In order to resolve this issue, policy-makers need to look more closely at this area to improve practice. The safety and wellbeing of children and young people depends upon getting their health care right at all times and in all settings.

Encouraging and supporting self-management

It is increasingly recognised that children and young people with health care needs should be encouraged to self-manage their medication and care wherever possible²⁷, from as young an age as is seen appropriate²⁸. The previous recommendation highlighted the need for proper storage of and access to medication; if children and young people with health care needs are to be successfully supported to self-manage, practices such as locking away medication will not be effective.

²⁶ RCN and UNISON (2012) *Supporting pupils with health needs in schools – RCN and UNISON survey*

²⁷ Scotland’s Commissioner for Children and Young People (2012) Research specification: The administration of medicines and health care procedures in schools, p. 4.

²⁸ Scottish Executive (2001) *The Administration of Medicines in Schools* p.16

Privacy

Evidence from this research study showed that nearly half of respondents identified that the administration of medicines or health care procedure happened in a private or semi-private space in school, such as the medical room, or designated space within the classroom. Some parents highlighted the importance of privacy in meeting their child's health care needs at school, with issues around privacy and toileting mentioned specifically. Having access to suitable, private spaces in which to receive help and support and to self-manage their medication is important for all children and young people who require it and is part of effective practice in all schools.

Reasonable adjustments

Almost 60% of parents who took part in this study reported that their child had a disability. Much of the information provided revealed that many of those parents were not aware of their rights with regard to reasonable adjustments. Several parents were of the view that being aware of their child's rights and active about ensuring that these rights were met was necessary. It would be useful for parents to be signposted to appropriate information about reasonable adjustments, including helpful websites²⁹.

Health care plans

Some participants in this study reported that agreeing a health care plan prior to the child starting in a new class was part of effective practice. It might seem an obvious point, but health care plans which are not known about, referred to or used to inform and review health care procedures, do not support the child's health and wellbeing. Also, health care plans which are too broad or general in scope will not support effective practice. Instead, health care plans need to clearly show what the child's health care needs are; how the child is affected; and what needs to be done to help and support the child when required. As a school's duty to provide reasonable adjustments is an anticipatory one, schools need to think in advance about what disabled pupils require and what adjustments would need to be made for them, and plan accordingly.

²⁹ The Equality and Human Rights Commission provides excellent information and can be accessed at:

<http://www.equalityhumanrights.com/advice-and-guidance/education-providers-schools-guidance/key-concepts/reasonable-adjustments/>

Next steps

Some of the issues for policy and practice raised in this discussion section have indicated how they might be addressed, and some require action. Where unsafe practice poses risk or harm to children and young people, it is important to consider how action might be taken at policy and practice levels to make it safe for children to be in school. Where learning assistants are undertaking health care procedures without training, confidence, or support, ways to improve practice should be explored.

At local authority and school levels, updating and adhering to local policies around the administration of medicines and health care procedures in schools should be prioritised.

Finally, it is suggested that the national guidance on the administration of medicines in schools needs to be updated. The findings of this study may contribute to any review of the guidance.

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Appendix 1 – Conditions, treatments and interventions described by parents, with definitions

Anaphylaxis is an extreme and severe allergic reaction. The whole body is affected, often within minutes of contact with the substance that causes the allergic reaction. Because severe allergic reactions can happen rapidly, the adrenalin injection must be available at all times. <http://www.anaphylaxis.org.uk/what-is-anaphylaxis/signs-and-symptoms#1>

Asthma is a condition affecting the airways in the lungs, irritating them and making them narrower, and reducing the flow of air in and out of the lungs. Children with this condition can have attacks of breathlessness and wheezing triggered by a variety of different things. <http://www.who.int/respiratory/asthma/definition/en/>

Asthma Attacks are when symptoms get worse and make it very difficult to breathe. In a severe attack, sometimes not enough oxygen reaches the blood and this is dangerous and needs immediate medical care. Inhalers are used to relieve asthma symptoms. <http://www.asthma.org.uk/about-asthma/what-to-do-in-an-asthma-attack/what-is-an-asthma-attack/>

Beals Syndrome is a genetic condition that causes problems extending joints such as fingers and knees, as well as problems with the heart and other muscles. <http://www.marfan.org/marfan/2347/Beals-Syndrome/CCA/>

Cerebral palsy is a broad term describing conditions caused by disturbances in brain development. Symptoms vary depending on which part of the brain is affected, and might include movement and speech difficulties as well as problems with muscle tone. Every person with cerebral palsy is affected differently. <http://www.scope.org.uk/help-and-information/cerebral-palsy/introduction-cerebral-palsy>

Crohns's Disease is a chronic inflammation of the digestive system, especially the small and large intestines. Symptoms can be more or less severe and include diarrhoea, weight loss, pain and tiredness. http://crohns.org.uk/crohns_disease/what-are-the-symptoms

Diabetes (type 1) is a condition caused when the body stops producing insulin. Without regular insulin (given by injections or an insulin pump), the glucose levels in the blood become very high and cause serious damage to many organs in the body. http://www.diabetes.org.uk/Guide-to-diabetes/Introduction-to-diabetes/What_is_diabetes/

Eczema is a dry skin condition, causing redness and itching and sometimes splitting and bleeding with a risk of infection. <http://www.eczema.org/what-is-eczema>

Epilepsy is a condition where increased electrical activity in the brain causes seizures (sometimes called fits). There are different types of seizures, some last for a

few seconds and others last for several minutes. Seizures might cause lack of awareness and disorientation or loss of consciousness. http://www.epilepsyscotland.org.uk/what-is-epilepsy-/info_13.html

Food Allergies are caused when particular foods trigger an immune system response. Typical symptoms are rash, wheezing, and itching. Occasionally reactions can be severe, see **Anaphylaxis**. Food intolerance is different and has less severe, more generalised and often more delayed symptoms. <http://www.allergyuk.org/what-is-food-allergy/what-is-food-allergy>

Gastrostomy is a surgical opening through the abdomen into the stomach. This allows liquid food to be given directly into the stomach. It is used when there are feeding and/or swallowing difficulties and can be permanent or temporary. <http://www.gosh.nhs.uk/medical-conditions/procedures-and-treatments/living-with-a-gastrostomy/>

Holoprosencephaly is when the front part of the brain does not develop clearly into separate halves. The condition occurs when the foetus is growing in the first few weeks of pregnancy. Symptoms vary depending on how severely the brain is affected, but can include epilepsy, heart and bladder problems. <http://www.soft.org.uk/Trisomy13-18/Related-Disorders/Holoprosencephaly-HPE>

Hydrocephalus is a build-up of fluid in the brain, usually treated by surgical insertion of a shunting device that drains fluid away from the brain so it can be absorbed by the body. The shunt can sometimes become blocked or infected, requiring medical attention. http://www.ssba.org.uk/content/hydrocephalus_definition/

Intrathecal Baclofen Pump is a battery-operated device that gives medication without the need for injections. The medication (baclofen) is administered through a small tube directly into the body and helps to loosen severely tight muscles. <http://www.medtronic.com/patients/severe-spasticity/therapy/what-is-it/index.htm>

Oesophageal Disconnection (Oesophageal Atresia, Tracheo-Oesophageal Fistula) is when the oesophagus (food pipe) is not connected properly either to the throat or to the stomach. Surgery is needed, and problems with breathing and feeding can sometimes persist. http://www.tofs.org.uk/index.php/what_is_tof_oa/

Pierre Robin Sequence is characterised by a combination of small lower jaw and cleft palate (abnormal opening in the roof of the mouth) pushing the tongue backwards. It can cause breathing and feeding difficulties, and although the condition often resolves as children grow, sometimes surgery is required. <http://www.pierrerobin.org/>

Spina Bifida is a fault in the spinal column (backbone) that causes damage to the nervous system. There are different forms of spina bifida. The more common form is also the most serious and causes some paralysis as well as bladder and bowel problems. http://www.ssba.org.uk/content/spina_bifida_types/

Stroke is when the blood supply to part of the brain is cut off and some of the brain cells are damaged or die. A stroke can cause problems with mobility, speech, thought processes and/or emotions. The effects are different for different people depending on the part of the brain that is affected.
<http://www.stroke.org.uk/about/what-is-a-stroke>

Tracheostomy is an artificial opening in the front of the neck in the windpipe (trachea). It is used as a way of aiding breathing by protecting the airway when there are problems managing food or liquid, or reduced consciousness.
<http://www.tracheostomy.org.uk/Templates/Patients.html>

Ventriculoperitoneal Shunt is the surgical insertion of a drainage tube into the brain, allowing excess fluid to drain into the abdomen.
<http://sarahcannonresearch.co.uk/your-health/?/2010817631/Ventriculoperitoneal-Shunt---Child>

Appendix 2 - Methodology

Review of the literature and data gathered by Scotland's Commissioner for Children and Young People

In 2012, prior to this research study being commissioned, Scotland's Commissioner for Children and Young People submitted a Freedom of Information (FOI) request to every one of Scotland's local authorities. The FOI request was for:

- Any local authority guidance and/or policy documents relating to the administration of medicines in schools and the management of health and care needs in schools
- Any local authority protocols and/or joint agreements with the corresponding Health Board regarding the administration of medicines in schools and the management of health and care needs in schools
- Contact details of person(s) in the local authority with responsibility for the administration of medicines in schools and the management of health and care needs in schools.

The information was published in the report entitled *The Administration of Medicines in Schools: Report on FOI responses (2012)*.

Throughout January and early February 2013, this report was reviewed, to obtain a clearer sense of current practice around the administration of medicines and health care procedures in schools. The report makes plain that there are differences and discrepancies in practice across local authorities, and highlights some examples of poor practice.

The Commissioner's office also provided data from a focus group with children and young people with health care needs; a separate focus group with school nurses in one local authority; and a transcription from an interview with one parent. All of this information underpinned the research design, and informed the survey design.

Ethical approval

A full ethical review of the research proposal and research tools was carried out by the University of Stirling's School of Applied Social Science (SASS) ethics committee. The research was conducted in accordance with SASS's ethics framework, which is based on the ESRC Framework for Research Ethics whose principal aim is, as far as possible, to protect all groups involved in research. At the header of the online survey, all participants were fully informed about:

- Purpose, methods and intended uses of the research (in accessible language)
- What their participation involved
- That confidentiality and anonymity would be ensured throughout the data collection, analysis and dissemination process
- That their participation was voluntary.

Survey with parents and carers

An online survey was developed for parents and carers whose children require medicines to be administered or health care procedures to be carried out (or both) in schools. A draft survey was circulated initially within the WithScotland team, for comments and suggestions. It was then sent to colleagues at the Commissioner's office, who also provided valuable comments and feedback, and further amendments were made. Finally, the draft survey was piloted with staff at two organisations (Contact a Family and Action for Sick Children Scotland); several suggestions about the wording of certain questions were made, as well as recommendations about the addition of two questions (question 18, which asks parents/carers whether they feel their views are taken into account; and the separation of questions 22 and 23, for clarity).

A meeting was held with some staff members of Action for Sick Children, to discuss the research study and design in more detail, as well as aspects of their support and development work in this area. Survey feedback from one of their consultants, a community paediatrician, was sought in advance of the meeting.

The following networks and organisations helped facilitate the participation of parents and carers in this study, by circulating the link to the online survey:

- Enquire
- ENABLE
- Kindred
- Contact a Family
- Action for Sick Children
- The National Managed Clinical Network for Children with Exceptional Health Care Needs (CEN Network)
- Diabetes UK Scotland
- Asthma UK Scotland
- Children and Young People Allergy Network Scotland (CYANS)
- Cystic Fibrosis Trust
- Epilepsy Scotland
- Arthritis Care UK Scotland.

Unfortunately, not all organisations were able to participate in this study by facilitating contact with parents, due to the tight timescales.

A total of 44 surveys were completed, 43 online and 1 by post.

Analysis

The research team carried out the analysis of the survey data during February and March 2013. The initial deadline for completing online surveys was 28 February, however to encourage as wide a return as possible the deadline was extended for one week, and the organisations and networks named above again assisted by communicating this fact to parents.

Appendix 3 - Survey

Survey for Parents and Carers - Administration of Medicines and Health Care Procedures in Schools

On behalf of Scotland's Commissioner for Children and Young People, WithScotland is undertaking research with parents and carers of children who require medicines to be administered in schools, or who require health care procedures to be carried out in schools, or both.

Our research applies to children:

- finishing a course of medication
- with medical or long term conditions such as asthma or diabetes that if not properly managed could limit their access to education
- with conditions which could require emergency treatment e.g. severe allergic conditions (anaphylaxis) or epilepsy
- with intimate care needs, which could include invasive treatment.

For the purpose of this research, 'schools' are defined as pre-five local authority centres, primary and secondary schools (including special units in those schools), special schools and independent primary and secondary schools. It does not include private nurseries or play groups.

We want to better understand those health care practices and procedures in schools which you feel have an impact on school and family life, which is why we have invited you to complete this survey. It should take between 20 and 30 minutes. Your participation is voluntary and anonymous; there is no obligation to take part and you do not have to give us any personal information about your child, yourself or your family. The information we gather will be analysed and written up in a final report which will be published by the Commissioner's office.

1. In a few words, what is the nature of your child's medical condition?

2. Does your child currently attend (*tick one box only*)

- local authority pre-five centre
- primary school
- a special unit in a primary school
- secondary school
- a special unit in a secondary school
- special school
- independent school - primary
- independent school - secondary

3. Does your child require medicine to be administered in school? (*tick one box only*)

- yes
- no
- sometimes

Please describe

4. Does your child self-manage his/her medication? (*Self-management can include any or all of these aspects: remembering to take the medication, going to get it, dealing with the dose and taking it.*)
(tick one box only)

- yes
- no
- sometimes

Would you like to tell us anything more about this?

5. Does your child require health care procedures to be carried out in school?
(tick one box only)

- yes
- no
- sometimes

Please describe

6. How many times per day does your child require help and support at school (*such as medicines to be administered or health care procedures to be carried out*)?
(tick all that apply)

- once
- twice
- three times
- more than three times
- in an emergency
- other (please specify)

7. Who usually helps and supports your child at school (*the administration of medicines or health care procedures*)?
(tick all that apply)

- learning assistant/classroom assistant/auxiliary
- nursery nurse
- school nurse
- class teacher
- depute head teacher
- head teacher
- health care professional not employed by the school (e.g., specialist nurse, community paediatric nurse)
- you
- your partner/spouse
- your child
- other person
- not sure
- other (please specify)

8. Do you know whether the same person(s) generally helps and supports your child at school (*the administration of medicines or health care procedures*)?

yes
no
not sure

How do you feel about this?

9. Did you request to help and support your child in school (*administer medicines or health care procedures*)?

yes
no

If so, what were your reasons for doing so?

10. What do you think is helpful for your child at school (*regarding the administration of medicines or healthcare procedures and practices*)?

11. What do you think could be more helpful?

12. When during the school day does your child get help (*the administration of medicines or health care procedures*)?
(*tick all that apply*)

before school starts
in the morning during class time
during morning break
at lunch time
in the afternoon during class time
after school
other (please specify)

13. Sometimes help can happen in different places in school. Where in the school does your child get help (*the administration of medicines or health care procedures*)?

14. Do you feel that your child's medical/healthcare needs are being met when s/he is at school?

yes
no
sometimes
not sure

Can you explain why you feel this way?

15. Does your child have a health care plan (or a plan called by another name)?

yes
no
not sure
name of other plan

16. How often do you attend meetings at school to discuss and review your child's health care needs?

never
once a term
more than once a term
once per school year
other (please specify)

17. Does the school take your child's views into account (*about the administration of medicines or health care procedures*)?

yes
no
sometimes
not sure

How do you feel about this?

18. Does the school take your views into account (*about the administration of medicines or health care procedures*)?

yes
no
sometimes
not sure

How do you feel about this?

19. Has your child's attendance at school ever been affected because of difficulties with help and support at school (*the administration of medicines or health care procedures*)?

yes
no

Would you like to tell us anything more about this?

20. Does your child have a disability?

yes
no

21. If your child has a disability, what reasonable adjustments (for disability, under the 2010 Equality Act) has the education authority made for your child at school, in terms of the administration of medicines and/or health care procedures?

22. What, if any, impact have the current arrangements for help and support for your child at school (*the administration of medicines or health care procedures*) had on your child?

23. What, if any, impact have the current arrangements for help and support for your child at school (*the administration of medicines or health care procedures*) had on your family life?

24. Is there anything else you would like to tell us about the help and support your child gets at school (*the administration of medicines or health care procedures*)?



**Scotland's Commissioner
for Children & Young People**

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