



Action for Sick Children Scotland

Newsletter

Spring 2013



Action for Sick Children Scotland

Is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of ALL sick children within our healthcare system. Our work includes:

Working with the Scottish Government, NHS and voluntary sector to ensure that health services are planned for sick children and young people in child centred environments with appropriate ratios of trained staff

Informing children, parents and carers of their rights and responsibilities; empowering them to participate in decisions about treatment and care

Raising awareness, representing children's needs and concerns within government, healthcare committees and other non-governmental organisations

Promoting high quality of health care services at home and in hospital, while working to obtain equality of services and access across Scotland

What must it be like for a child or young person at school to

- find the toilets locked at lunchtime and they suffer from irritable bowel disease
- ask for their medicine and find it is in a locked cupboard with no one to help them
- be shown into a cupboard to administer their insulin injection and told that they are a nuisance
- be told they cannot take part in school trips and activities because of their medical/health needs and
- what about parents and carers who have to leave home or work to come into the school to give medicine to their child?

ASCS has for some time been concerned at the extent to which children's health care needs are disregarded in various school settings.

The experiences above have been described by children, young people and families through our Campaign for the right to education for children and young people absent from school through ill health, our Stay Well Lanarkshire Self Management Project and our Children in and Leaving Care Project.

Under the Additional Support for Learning (Scotland) Act 2009, health-related needs are classed as additional support needs and so Local Authorities, through their schools have a duty to provide for these needs. '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.



At present, arrangements in individual schools are at the discretion of the Head Teacher and practice varies enormously, despite the existence of clear guidance and the provisions laid down in the Act. Research has recently been carried out by WithScotland on behalf of

Administration of Medicines in Schools

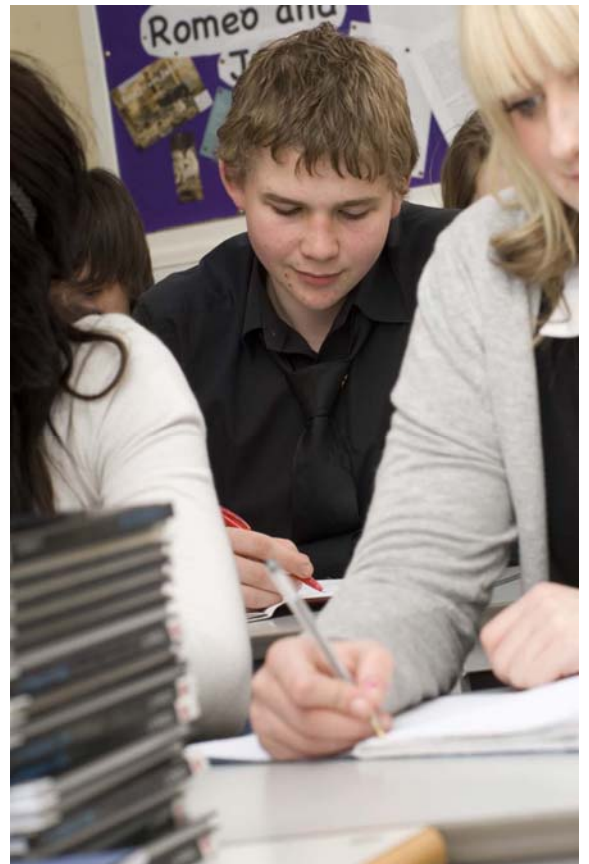


Photo: NHS Health Scotland

the Office of Scotland's Commissioner for Children and Young People (SCCYP), with parents and carers of children who need medicine to be administered and/or healthcare procedures to be carried out in schools. ASCS was delighted to work with the researcher on the draft survey questions and to provide background information to the research team.

We look forward to seeing the final report to be published shortly by SCCYP and hope that the findings will encourage the Scottish Government to review their Guidance on the Administration of Medicines in Schools which is now over 12 years old.

Helping sick children and young people meet their healthcare needs

259 Children helped by ASCS Special Smiles



Children in a Glasgow school correctly identify good and bad foods

Our **Inspiring Scotland's Early Years Early Action funded Special Smiles Project** has now been rolled out to all additional support for learning schools in Glasgow and an evaluation of the work carried out between October 2011 and September 2012 concluded that the project has successfully achieved its desired outcomes.

Over the year the project was delivered to 17 schools where 295 children up to the age of eight years used our dental play resources. Training sessions were delivered to 134 teachers and 87 parents/carers, 29 of whom borrowed a dental play-pack for home use. 72 children completed Before and After Questionnaires, enabling us to gauge change in understanding and behaviour. Results included a very healthy improvement (88%) in oral health practices and a significant reduction in anxiety as reported by the children.

Questionnaires completed by teachers, parents and carers further evidenced positive outcomes and the impact the project has had on their ability to assist ASN children.



Role play helps children deal with fears

The Play Box made a huge difference to the children with autism in my class. The role play was great fun ... they were learning without realising it, overcoming their fears, becoming familiar with the sights and smells of the dentist, so that when they went to the dentist it was not such a big deal. The Play Box made such a difference to their confidence and how they felt about looking after their teeth in general. (Teacher, St Vincent's Autism Unit)

Visits to the dentist can be difficult experiences for our children as the usual explanations given to the children are not accessible to them. This project has helped our children overcome their fears of going to the dentist. (Unit Co-ordinator, St Charles' Language Unit)

One pupil asked his mum to take him to the dentist for first time, which she did. (Teacher, Greenview Learning Centre)

It has given Ellie more of an understanding of how important it is to brush her teeth and eat more healthy snacks. (Parent)

Parents who used the home Play-pack said that it greatly helped their child to overcome dental anxiety.

It has helped my son see what happens at the dentist, what it smells like, what they wear and what they use.

More awareness and less fearful. Our dentist is now able to look in Allan's mouth and put on fissure sealants. The Special Smiles home Play-pack made a huge difference to Allan.

Children, parents, carers and teachers have all been very enthusiastic about the dental play resources. This reinforces our belief in the value of specialist play to support ASN children during their early years to care for their teeth and to help prepare them for dental treatment. To quote one teacher and one child:

This playbox has been invaluable. Children and their parents were far less stressed as a result. I sincerely hope other schools can get the benefit of this resource - it really works! (Teacher, St Vincent's Autism Unit)

It's wonderful! (Lloyd, St Kevin's School)

The Special Smiles 2012 Evaluation Report is available on <http://www.ascscotland.org.uk/default.asp?page=19>



An NHS fit for the Future - Looking at Models of Care

Our last Newsletter reported on NHS Greater Glasgow & Clyde's Clinical Services Review. The Review is looking at how to deliver a high quality sustainable service in the coming years to a changing population with a growing percentage of frail, elderly people; people with chronic diseases and more children with chronic, complex needs who survive into adulthood. The service will need to change to meet these demands. ASCS is a member of the Review's Child & Maternal Health Group and its Clinical Services Review (CSR) Group and its Patient Reference (PR) Group. These groups have discussed the care of sick babies, children and young people in hospital and in the community and the care of expectant and new mothers.

Parents of children with complex needs have voiced concerns about problems faced when their children are moving from paediatric into adult care. As a result a new group is looking at models of transition which could improve this process. Parents who have experienced the death of a baby are raising awareness about the need for the health service to support such families.

Discussion has also focused on: What services need to be delivered in a hospital? Which could be delivered in the community and where could they best be located? What support is needed if more care is delivered in the community? When does a child need to go to A&E? How and when can the GP help? How best to educate people on the appropriate use of emergency and planned services? Some of the CSR Group visited other centres to find out how they have managed to improve on appropriate use of their services.

This work is presenting lots of challenges and opportunities to design an excellent service for the future.

ASCS's Family Participation Group Influencing Policy and Practice

ASCS is involved in child health planning and policy-making, locally and nationally, with input from parents, carers, children and young people, whose knowledge, experience and needs inform and shape our work. Here we report on recent participation activity by our Family Participation Group.

- 1. The National Managed Clinical Network for Children with Exceptional healthcare Needs (CEN)** – recently conducted a survey assessing emotional support for families when tube feeding their child. This report is now available at www.cen.scot.nhs.uk
- 2. Genetic Alliance UK/Scotland working with Rare Disease UK** launched their report - *Experiences of Rare Diseases: Patients and Families in Scotland* - at an event in the Scottish Parliament Event on 26th February to mark Rare Disease Day. Visit <http://www.geneticalliance.org.uk/scotland/>
- 3. For Scotland's Disabled Children (fSDC)** is re-launching the fSDC Coalition and work is being taken forward by a Coordination Group of which ASCS is a member. As part of this, Children in Scotland is hosting a Parent Participation Project on behalf of fSDC and there will be opportunities for ASCS's Family Participation Group (FPG) to become involved in this work. <http://www.fsdco.org.uk/parent-participation-project>
- 4. The Office of Scotland's Commissioner for Children and Young People** is conducting research into parents and carers' views on the **Administration of Medicines in Schools** (including healthcare procedures carried out in schools). This is a difficult area where practice in schools varies enormously. ASCS supports the need for a national protocol to standardise practice to ensure the best interests of children and families. We have worked closely with the researcher from WithScotland on the draft survey to inform content and ensure clarity and user accessibility.
- 5. The Royal College of Paediatrics and Child Health** is looking for young people who are involved in health in their local area and interested in influencing healthcare for children and young people to join its **Youth Advisory Panel**. Click [here](#). ASCS has heard that one of the young people from Inspector8 in Dumfries & Galloway, who performed at our EACH Conference in 2010, has been selected to the Youth Advisory Panel.
- 6. Health Rights Information Scotland (HRIS) (now part of NHS Inform)** produces information for children, young people and their families on *Consent, Confidentiality and Having your say* accessible at <http://www.hris.org.uk/patient-information/> We have input to the update of their Consent <16s booklet.

Thanks to all who have contributed to this important work. If you would like to join our Family Participation Group get in touch via our Family Participation page: <http://www.ascscotland.org.uk/default.asp?page=51>

EACH Child and Young Person's Health Matters: Who looks after those in care when they are ill?

Do you know who looks after someone who is ill when you are in care? Do you have any questions relating to their healthcare?

What you should know after someone who is ill when you are in care:

- You should know who looks after you when you are ill.
- You should know who to contact if you are ill.
- You should know what to do if you are ill.
- You should know who to contact if you have any questions.
- You should know who to contact if you need help.
- You should know who to contact if you need support.
- You should know who to contact if you need advice.
- You should know who to contact if you need information.
- You should know who to contact if you need help with your care.
- You should know who to contact if you need help with your health.
- You should know who to contact if you need help with your education.
- You should know who to contact if you need help with your leisure.
- You should know who to contact if you need help with your social life.
- You should know who to contact if you need help with your future.

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Our Children in and Leaving Care Project has developed workshops to support foster and kinship carers to look after the healthcare needs of the children and young people they care for. If your agency or organisation works with foster or kinship carers and you would like to find out more about these workshops, please contact Anne Wilson on 0131 553 6553 or on a.wilson@ascscotland.org.uk

West Lothian Child Self Management Pilot underway

ASCS's new West Lothian Child self management pilot project began in February 2013. This 14 month pilot, organised by Project Officer Amy Joss, will support at least 32 children and 20 parents/carers in West Lothian to learn about self management.

The pilot follows on from our Stay Well project for young people in Lanarkshire, which concluded in May 2012.

<http://www.ascscotland.org.uk/default.asp?page=56>

Stay Well was a 3 year project which delivered a generic self management programme to 51 young people with long term conditions (average age 14). Feedback from the young participants, carers and professionals was that having self management support at a younger age would be useful and would make the transition to secondary school less challenging for children with long term conditions.

The first stage of the pilot will be to establish links and consult with families, healthcare, education and voluntary sector professionals to identify support available for children aged 8-12 with long term health conditions living in the area. The Project will then develop activities and information to pilot with families and children later in the year. The aim is to help children develop the confidence to self manage their

health condition and to take part in positive health and wellbeing activities. Parents will learn about supporting their child with a health condition and working with professionals to encourage good self management.

If you live or work in West Lothian and know of a child (8-12 years) with a long term health condition such as asthma, diabetes, eczema, IBS, epilepsy or other health condition and you would like more information, please contact:

Project Officer: Amy Joss

Email: amy.joss@virginmedia.com

Mobile: 07712542849

For more information about the West Lothian project: <http://www.ascscotland.org.uk/default.asp?page=88>

A Special Thank You to BBC Children in Need; Moffat Trust; Widowers' Children's Home Trust; Robertson Trust; Miss Agnes H Hunter's Trust for supporting this work.

Education for Sick Children and Young People - Where are we now?



Education Minister Michael Russell and Dagmar Kerr (ASCS) at our Scottish Parliament Display

Last year only one meeting of the Stakeholder Group convened to review the 'Guidance on Education of Children Absent from School Through Ill-Health' took place. This was due to work pressures on Scottish Government staff. In the meantime ASCS continued to campaign about the education issue and in early October hosted an exhibition at the Scottish Parliament on sick children

and young people's rights with particular emphasis on education and the review of the Guidance. More than 20 MSPs signed our guest book and many more gave us encouraging feedback.

Alison McInnes MSP, the sponsor of this exhibition, also submitted a parliamentary question on 25 October asking about the progress of the review (S4O-01379). As a result of her intervention the Stakeholder group reconvened in January. Members from education, health, voluntary sector, local authorities, finance and government are now working in subgroups to look at pathways, quality & standards, legal issues relating to privately educated pupils, virtual learning and the role of IT. These subgroups will report back to the next whole group next meeting.

ASCS Family Facilities Survey

Our latest Parental Access and Family Facilities survey of all Scottish NHS hospitals admitting paediatric patients is near completion. Findings from the first survey in 1985 and subsequent surveys have been used by the Scottish Government and NHS Boards in planning future service delivery. Surveys have also informed parents and carers about the availability of services in their area. Results from this survey will be available in June 2013.

Action for Sick Children Scotland is now on Facebook



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