



Action for Sick Children Scotland

Newsletter

Autumn 2012

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 others to ensure that health services are planned for sick children and young people in child centred environments with appropriate ratios of trained staff

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

Raising awareness and representing children's needs and concerns within Scottish 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

The State of Play in Scottish Hospitals: Asking the question?



On 13 August 2012 an article appeared in The Scotsman newspaper with the headline 'Want to play with our toys? Then book now, cancer children told'. In part the article discussed the re-organisation of the play service in one of the largest children's hospitals in Scotland. The rest of the article discussed the short supply of Registered Health Play Specialists in the hospital, and went on to mention limited access to toys, with comments made by a parent with regard to toys being locked away. Of course this is just one perspective of what is happening in one area of this particular health board, and it would be good to think that this was just an isolated case. However it has come to our attention that play, and play services in Scotland lead by appropriately trained people registered with HPSET (Hospital Play Specialist exam trust) appears to be on a decline. Part of the reason for this decline could be the reluctance in the past of

some health boards to support individuals through play specialist training. This has led to Scotland's only training programme being withdrawn until such times as appropriate student numbers can be guaranteed. Another reason is the lack of understanding of what 'play' means. The words play and toys are often intrinsically linked as though the two cannot be separated. Toys are of course sometimes part of a child's play, they are often the tools that a child will use to take their play to another level. For example a young child playing with a tea-set may use the experience to socialise, to act out what they have observed in their everyday world and to communicate either to themselves (to practice new words), or by using language as a means of engagement with other children and adults. The same can be said for young people with a computer game. However not all play requires toys or equipment. At the crux of all play is

Continued on back page

Education for Sick Children Update



The Scottish Government Group set up to review the Guidance on the 'Education of Children Absent from School through Ill-health'

had its first meeting in March and further meetings still have to be scheduled. It had been hoped that the draft Guidance could be put out for consultation between September and November with new Guidance published by January 2013. It is possible however that the publication date will now be deferred. In the meantime ASCS continues to raise awareness of the issue at the Scottish Parliament with MSP Alison McInnes presenting motion S4M-03932 in which she congratulates the charity

on championing the interests of sick children, young people and their families and drawing particular attention to the review of the education guidance. MSPs are being asked to support this motion.

We plan to raise further awareness about children and young people's healthcare rights at an ASCS display at the Scottish Parliament in early October. Volunteers and staff will be available to talk about our work in general and the education campaign in particular.

Helping sick children and young people meet their healthcare needs

Stay Well Project shows positive results

In May 2012, the Stay Well Self Management project finished after three years operating in Lanarkshire. With funding from BBC Children in Need, Lloyds TSB Foundation, The Robertson Trust and The Self Management Fund for Scotland the Project completed nine full programmes with six workshop sessions in each. 51 young people between 11 – 17 years of age benefited from the self management programmes, held in community centres and secondary schools. Over 400 other young people received information about the project and self management.

Results showed that young people enjoyed the workshops and learned new skills. The main benefits they told us about were huge increases in their confidence and communication skills and they felt much more socially included. They also developed increased awareness of the impact of long term conditions on **their lives and also on other people's lives.** One participant, age 12 with asthma said, **'I think it's a good project because you get to meet people who are going through similar things to you, you get to meet new friends and all that.'**

One parent liked **'the knowledge it gave my son about managing his illness and mixing with others.'**

Eighteen Stay Well young people also took part in Peer Support training specially developed by the project to explore values and beliefs about living with a long term condition and awareness of different conditions. Some of these peer supporters returned to assist the project in delivering fun and educational activities at future workshops.

A toolkit for young people who took part in the workshops and for other stakeholders was developed on a USB wristband

format. Seven peer supporters helped to create a new Stay Well **DVD for young people and a new leaflet, 'Talking about My Health Condition'** aimed at young people with long term conditions and professionals working with them. These and other information on the wristbands is available to view or download on our website www.ascscotland.org.uk

One parent, whose 12-year old daughter was recently diagnosed with Type 1 diabetes said,

'My daughter has looked at the Stay Well wristband documents that you kindly gave her. She enjoyed watching the DVD and was particularly inspired by Kayleigh talking about Type 1. I think that watching Kayleigh has helped boost her confidence. Another highlight was the Suzie e journal - she enjoyed the layout and information provided'.



Some of the young people who took part in the project

Fit for the Future - Clinical Services Review

How are we going to deliver a high quality sustainable service beyond the year 2015?

This pressing question is being discussed in seven working groups across the Greater Glasgow and Clyde Health Board. The **'Clinical Services Review'** takes place in the following groups: Population Health; Planned Care; Child and Maternal Health; Chronic Diseases/ Long Term Conditions; Unplanned, Emergency and Trauma Care; Cancer Services; and Older People. All groups also have a patient reference group which is seeking to get the best possible involvement of service users.

Our Area Co-ordinator for NHS Greater Glasgow & Clyde, Dagmar Kerr, has been invited to sit on the Child and Maternal

Health Group and is co-chairing its patient reference group. The first aim for **the groups is to make a 'case for change'** by looking at what services are being provided at the moment, looking at current population and health data and what the predictions are for the period 2015-2020. The multi-disciplinary teams are working together to find out what is sustainable and what needs to change in order to meet all needs. At a joint meeting of all the groups at the end of **September the 'Case for Change' was** discussed. Some ideas for possible answers were shared, but it became very clear that there are not going to be any simple solutions for problems which are highly complex. Before we tackle the high **numbers of 'unnecessary' hospital** admissions or the wrong use of A&E

departments, we need to understand the reasons and causes for these. Health behaviours, socio-economic circumstances, aging population are but a few of the reasons.

Dagmar sees her role in this important and complex review to make sure that the needs of children and young people continue to be considered and cared for as the Board looks at how to provide excellent service for an increasing number of frailer, older people.

For more information and to have your say please visit the NHS GG&C website <http://www.nhsggc.org.uk>



ASCS Family Facilities Survey

Thanks to funding from the Scottish Government, ASCS is carrying out its latest Parental Access and Family Facilities survey of all Scottish NHS hospitals admitting paediatric patients. Findings from the first survey in 1985 and subsequent surveys have been used by both the Scottish Government and health boards in planning future service delivery, as well as informing parents and carers about the availability of services in their area. Results from this survey should be available in April 2013.

RCPCH Spring Meeting in Glasgow

The Royal College of Paediatrics and Child Health Annual Spring Conference was held for the first time ever north of the Border in Glasgow in what was one of the hottest weeks of the year!

ASCS, working in partnership with the College in Scotland, approached ten Scottish Young People's Participation groups and brokered their involvement in the Participation Seminar at the Conference. We are delighted that four Scottish Groups were selected to present at the conference including our Stay Well Lanarkshire Project. These were:

Inspector 8 from Dumfries and Galloway
Children's Hospice Association Scottish Young People's Council
 Scottish Youth Parliament
 Stay Well Lanarkshire Project

The session was very well attended and the launch of the Stay Well DVD received an excellent endorsement from a member of the Youth Advisory Panel, RCPCH who said,

'Action for Sick Children Scotland has spotted a clear gap in the market and do a fantastic job in providing emotional support for children and young people who are really ill. There are plenty of support groups out there for adults, or parents of affected children in particular, but it is incredibly rare to see something for the children themselves. The video clearly shows how their work helps the children form a support network between themselves, providing new friends for some children who have very few, and giving them an emotional bedrock and increase in confidence that will aid their day-to-day lives long after their sessions with Action for Sick Children Scotland'.

Dental Project extended a further six months

Our Special Smiles Project is currently operating in seventeen Glasgow schools which cater for children with additional support for learning needs. It aims to improve oral health and reduce dental anxiety through play with our specially designed resources, and the Special Smiles Team have provided support in their use to over 200 staff, parents and carers receiving very positive feedback.

'I was astonished at the diversity of materials supplied, including the fabulous chair! Many of our children suffer from real sensory issues which impact on their day to day lives. Going to the dentist with the sounds, smells and touch issues surrounding it can cause severe anxiety and stress to children and their extended family. Being able to expose them to these resources hopefully allays some of their fears. The parents who used the pack with their children at home have been most complimentary and grateful that their children's needs are being recognised and they are being supported through this material.'

Head Teacher, Sunnyside Speech & Language Unit

National Smile Month at two schools, showcased the project in June to parents and professionals. The children entered enthusiastically into all the activities as pictured here.



Funding has been extended for another six months, enabling us to work in 12 more schools so that more children like Eva can benefit: **'It has given Eva more of an understanding of how important it is to brush her teeth and eat more healthy snacks. She is less anxious about going to the dentist.'** Parent

ASCS Project supports Kinship Carers



Photo: NH Health Scotland

www.ascscotland.org.uk/default.asp?page=85

The project subsequently designed healthcare training based on this resource for foster carers and in the course of this, we became aware of the very considerable needs and health issues of children and young people in kinship care.

Looked after children in general are likely to have poorer health outcomes than those not in care. This can be for a range of reasons such as early trauma, neglect, missing

ASCS works on behalf of ALL children and young people and this includes some of the most vulnerable children in Scotland today – those in kinship care, children cared for by families and friends. In 2010 our Children in and Leaving Care Project produced a toolkit designed to support staff and carers looking after the health needs of children in care.

<http://>

health records, missed medical appointments, gaps in treatment. These factors can all be present for a child in kinship care but often additional complex issues impact on **them around the birth parents' mental health; fear of inherited conditions; the challenges relating to consent and confidentiality for kinship carers and interfamilial tensions relating to the reason for the child coming into care.**

To support kinship carers the project has developed and delivered workshops to carers in East Lothian and Lothian on healthcare rights; issues for carers; mental health and consent and confidentiality. It has also delivered a Seasons for Growth Programme to help kinship carers address the adverse impact arising from their situation on their physical and mental health. This was very positively received.

'I was so upset – I did not think I could come back after the first session but I am so glad I did as it has helped me cope. It should be mandatory for all carers.'

Our kinship care activity also includes collaboration with Mentor UK on their Kinship Care Guide where we feature as a source of advice and information.

The State of Play in Scottish Hospitals: *Continued from page 1*

communication and to be given the opportunity to be listened to. Unlike most adults who have had years of experience practicing and acquiring new language, children and young people often need to be given time to find the language they need to express themselves. What must it be like for a child or young person when they are sick, in an unfamiliar environment with people they do not know, who often carry out unpleasant and painful procedures? Children need to use play (which may or may not include the use of toys), to communicate how they are feeling and to learn about new things. For this reason we need **dedicated ward based play specialist's** team who are trained in understanding **the nature of children's play and who** have the skills to support children and young people in a holistic way in healthcare settings. Health care boards in their bid to save money often see play as an easy money saving

target. There is a growing culture in some hospitals to use play staff on a referral basis for preparing children for procedures and distraction purposes. Successful play preparation and distraction can only be ever be successful if the child has had time to ask questions and listen, this is often brought about through relationship building using play as a medium, sometimes this needs to be carried out over a period of time. How can we hope for a successful outcome if the staff member does not know the child or has just recently met them? Other health care boards are using registered play staff as part of a skill mix team training individuals to take bloods. How can children define when a person is coming to play with them or to carry out a procedure? Children in healthcare systems need to feel that not everyone is going to carry out procedures. In a bid to save money are health



boards offering our children and young people a second rate service with regard to their right to play? In the words of one Mother (The Scotsman 13th August 2012) the medical treatment is excellent but the facilities are poor.

Frances Barbour
ASCS Executive Committee

Thanks to Standard Life plc for printing this Newsletter