



# Action for Sick Children (Scotland)

Newsletter Spring 2011



## 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 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

## Losing out on Education The Unexpected Side Effect of Illness



Connie - missed school for seven months

When Connie needed several operations, the last thing she and her mum expected was a problem getting back to school.

Connie had to have a metal frame on her leg for a few months and needed a wheelchair to get around. Two months after her operation she felt well enough to go back to school, but no-one had told her that returning to school with a frame and wheelchair needed a lot of planning to sort out a special desk, to undertake health and safety assessments and to organise transport to and from school. In the end it took seven months before she was able to go back. Connie was about to choose subjects for standard grades. Her mum found out that her daughter was entitled to home tuition during recovery but their local authority told her it had no available home teachers and there was a two year waiting time. Connie lost a lot of



Happy to be back at school

confidence and became depressed about falling behind and not seeing her friends. She did eventually make a good physical recovery and returned to school. Her strong personality and determination helped her to catch up on most of her school work, but her mum says she is still trying to rebuild friendships.

Better pathway planning would have helped Connie to continue her education during this period and her confidence wouldn't have taken such a knock.

***'Cases like these highlight why ASC(S) is campaigning about the right for children and young people to receive appropriate, equitable access to education when absent from school because of illness.'***

A year ago Tom had to travel outside his local authority to Yorkhill Hospital three times a week for dialysis. His local authority would not pay for the hospital teaching service so Tom had to watch other youngsters get taught by hospital teachers, without being able to take part. His mother realised her son was missing out and contacted ASC(S). We helped her find out about her rights and she challenged her local authority. After discussion and the involvement of a journalist, the local authority changed its practise and is now paying for hospital tuition for its children. Tom is now preparing for standard grades and still receives hospital tuition when at Yorkhill. His mum says he could do with more help, but she is glad that at least he gets some.

Cases like these highlight why ASC(S) is campaigning about the right for children and young people to receive appropriate, equitable access to education when absent from school because of illness.

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Helping sick children and young people meet their  
healthcare needs

# Self Management Programme Rolls Out



*'Even with illnesses you can enjoy everything'*

**Stay Well Lanarkshire** is our innovative self management programme for young people in Lanarkshire, aged 11-18, living with long term health conditions (such as diabetes, irritable bowel disease, asthma, arthritis, epilepsy and others). The project is run in partnership with NHS Lanarkshire and with funding from BBC Children in Need, The Robertson Trust, Lloyds TSB Foundation for Scotland and The Self Management Fund for Scotland.

In October and November 2010, the Project Officer Amy Joss, Assistant Lysia Abercrombie and volunteers welcomed five young people to the *pilot* self management programme in

Hamilton. The six workshops explored issues around living a healthy life with a long term health condition. These included the realities of illness, coping with change, managing emotions and feelings and communicating with family, friends and healthcare staff. One young person learned that 'even with illnesses you can enjoy everything'.

The active learning sessions included dvd-making, cooking and African drumming. One parent said her daughter, 'could talk about dealing with her illness in a fun way'. Another participant, when asked what part of the workshops they enjoyed the most, said 'All of it'.

**A project OPEN DAY will be held on Saturday, 19 March from 2-4 pm in Motherwell.** Young people, parents, carers or professionals can drop in and find out more. For more information contact the Project Officer or see the poster on our website.

Another two workshop programmes are in progress and will be completed by the end of March. A further programme is scheduled to begin in May and the project welcomes referrals at any time.



Young people, parents, carers or professionals can refer by contacting Amy Joss by text/phone 07935 305930 or email [amy.joss@nhs.net](mailto:amy.joss@nhs.net). More information is available on <http://www.ascscotland.org.uk/default.asp?page=56>

## Peer Review Visits - A Positive Initiative

The Association of Paediatric Anaesthetists of Great Britain & Ireland (APAGBI) has developed a process of 'peer review visits' whereby a small team of children's anaesthetists from various UK hospitals visit another department for a constructive review of their paediatric anaesthetic service. It is important that a 'lay reviewer' (a non-medical person) is part of the visiting team and Dagmar Kerr our Area Co-ordinator in Greater Glasgow & Clyde has been a lay person on a few peer visits.

Dagmar writes, 'Several years ago I visited a specialist paediatric hospital on a peer review visit. Now the APA has decided to visit anaesthetic departments in district general hospitals (DGHs). The DGH team prepares a comprehensive portfolio of self assessment before the visit and makes paperwork available to the visiting team so that they can get the chance to prepare any questions. The paperwork usually includes any information leaflets in use. During the visit we can ask the local team questions and we

are shown round all areas where paediatric work might take place. We usually see the children's ward, day surgery, theatres and A&E. We can speak to nursing and medical staff, meet the play team and find out about the pain management service. As a lay visitor I can ask my own questions about information leaflets, pre-admission practice, family support services, age appropriate care and in particular children's healthcare rights according to our EACH charter.



After the visit a report is written to which all 'visitors' contribute. This process encourages sharing of good practice and is an excellent initiative to help ensure the highest standard of care for children and young people across Scotland. The review team organisers in Scotland would be delighted to hear from anyone interested in becoming a 'lay reviewer'. If you are interested, please contact the Scottish Paediatric Anaesthetic Network via its website ([www.span.scot.nhs.uk](http://www.span.scot.nhs.uk)).

## Community Play Specialist Report

ASC(S)'s end of project report considers the concept of hospital play and the role that Registered Hospital Play Specialists have in supporting a quality play service in healthcare settings. The pilot project looked at the need for play as a method of communication for children and young people who have difficulty accessing appropriate information through hospital pre-admission visits. It was introduced due to the realisation that many are not given the opportunity to access specialised play services with regard to hospital procedures and admissions. The aim was to consider how effective this service can be when a Play Specialist works as part of the outreach nursing team.

The report includes a detailed overview of how play can be used as a communication tool in community and home settings, to alleviate fears and anxieties that children may be experiencing. Several case studies discuss the work of the Community Play Specialist and show clearly the positive outcomes for the child, family and staff members.

An evaluation of the project conducted through dissertations by two Psychology Students from Stirling University shows that the children benefitted greatly from having access to a Registered Community Play Specialist. It normally takes time for a new service to be fully embedded into an existing area of practice. However, the project shows that, in a relatively short space of time, and with a restricted number of hours, the benefit to children and young people and their families who had input from this service was significant.

**ASC(S) would advocate that specialised play, delivered by Registered Hospital Play Specialists, should be central to the care offered to children not only in hospital settings, but also in the community.** Read the report at <http://www.ascscotland.org.uk/default.asp?page=55>



*Worry stones helped children alleviate fears*

## Dundee Family Nurse Partnership

Our Tayside Project Officer, Fiona Bartley-Jones has worked hard over the last two years to raise awareness of the issues affecting young parents in the area and for improved access to services for both the young parents and their children.

ASC(S) is therefore delighted to welcome the introduction in NHS Tayside of the new Dundee Family Nurse Partnership (FNP). The launch took place on 11 January at the St Andrews Project in Dundee. Fiona reports that this was an enjoyable event attended by Cabinet Secretary for Health & Wellbeing Nicola Sturgeon and many strategic lead staff from NHS Tayside.

The FNP is a preventive programme for young first time mothers, which offers intensive and structured home visiting, delivered by specially trained nurses (Family Nurses), from early

pregnancy until the child is two. The FNP has three aims, to improve: pregnancy outcomes; child health and development; and parents' economic self-sufficiency.

Fiona is looking forward to working with the team who will be implementing the Partnership.



*Young parents will benefit from the Dundee Family Nurse Partnership*

## Special Smiles in Glasgow



Our Special Smiles dental project has now launched in Glasgow and will work with special schools across the city until May 2012. Catherine Nelson, Project Co-ordinator, reports that it has already been enthusiastically welcomed in schools in Garthamlock, Gorbals, Baillieston and Castlemilk with comments like:

*'Very relevant and a great resource for the school'*

*'Very appropriate to children with additional learning needs'*

*'The presentation was brilliant! Thanks'*

There are many areas of Glasgow where the Scottish Government's target of 60% of school age children being free from decay by 2010 has not been achieved. 54% is the average figure for Glasgow, but this figure is lower still in relation to children with additional and complex needs and in areas of deprivation.

For this reason, Childsmile, the Government's programme, is targeting all Glasgow schools with their Core toothbrushing programme and has had 93% take-up. **However neither Childsmile nor the National Dental Inspection Programme operates in special schools, so our project is a very valuable resource for this vulnerable group of children.**

We are confident that we will achieve our aim of improving the oral health understanding and practices of children and young people with additional and complex needs by promoting learning through play using our dental play resources.

# EACH Child and Young Person's Health Matters

## Who looks after me when I am ill?



In our last newsletter, we outlined the resources we would be developing for children and young people in care namely the Foster Carer workshops and the Seasons for Growth sessions.

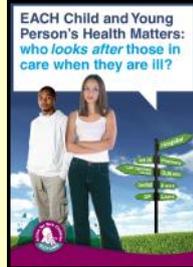
### Foster Carer Training

Working in partnership with Foster Plus and a local authority, we have delivered training to carers in Livingston, Edinburgh, Paisley and Ayr on topics ranging from the healthcare needs and rights of children and young people at times of illness to dental care for children with additional support needs. These interactive workshops have been well received with participants commenting as follows:

*'A whole new experience – enlightening'*

*'Very informative, interactive and a team effort'*

*'Focused my thinking, enabling me to look at what a child would need to be prepared for...'*



workshops incorporating these topics, to roll these out in other areas and subsequently make training available online.

### Seasons for Growth (SFG)

SFG programmes have now taken place in Alloa and Stirling in three different settings, primary school, young people in foster care and residential. These have been conducted in collaboration with the Primary School Teacher, an Educational Psychologist and a Specialist LAC Nurse respectively with 15 children and young people taking part.

The programmes are still evaluating due to delays because of severe weather and we will report on this in a future edition. Initial findings, however, indicate a positive response from the children and young people who were able to derive support from the sessions which included games, story-telling, guided imagery and kite-making.

*'You will never get these young people to open up!'*

*'I liked the way the leaders delicately helped us to feel better'*

*'When can we get to do another one of these?'*

Participants have expressed a preference for further topics such as consent and confidentiality and mental health and wellbeing. We plan to develop further

## Continued from page 1. Losing Out on Education

In January the Scottish Parliament Petitions Committee considered our petition in which we ask the Scottish Government to demonstrate how local authorities are complying with the duties imposed by Education legislation and Guidance. The Government replied that it is for Local Authorities to show that they meet these duties. But the problem of access to education for youngsters at times of illness keeps coming up and we need to try and change the system in order to achieve much better compliance. The Guidance on the 'Education of Children Absent from School through ill-health' is 10 years old so we then asked the Petitions Committee to ask the Scottish Government to review this Guidance. At its meeting on 22 February, the Petitions Committee agreed to seek a response to this issue from the Scottish Government and to invite, in its legacy paper, the Session 4 Public Petitions Committee to further consider our petition. Our petition will be considered by the new Public Petitions Committee set up after the Scottish Parliament election of 5 May. Read our petition on:

<http://www.scottish.parliament.uk/business/petitions/docs/PEI381.htm>

## National Delivery Plan Implementation Group to look at the impact on families travelling for specialist care for their child

Action for Sick Children (Scotland)'s membership on the Scottish Government's National Delivery Plan Implementation Group (NDPIG) has been an important way to keep a focus on the impact specialised and centralised services can have on sick children, young people and their families.

ASC(S) is pleased therefore to be involved in NDPIG work which will look at the financial and emotional cost for a family when they travel for treatments and assessments for their child.

We hope to collaborate in the development of a pathway which will support families during these stressful times. We will look at how families should be reimbursed for expenses, how siblings can be supported, how travel could be avoided (eg by using technology like video conferencing) at the same time as providing the best possible specialist care.

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