



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

Action for Sick Children (Scotland)

Newsletter Autumn 2009

Tayside Pupils Promote Special Smiles



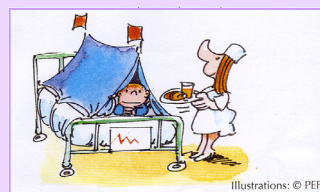
Photo: Courtesy of Arbroath Herald

Action for Sick Children (Scotland) helped spread the message of good oral health by organising events to mark National Smile Month in Hayshead School, Arbroath and Robert Douglas Memorial School in Scone. Both schools are involved in our Tayside Special Smiles project. (Continued on page 2)

EACH CHILD AND YOUNG PERSON'S HEALTH MATTERS CAMPAIGN LAUNCH

A date for your diary!

Action for Sick Children (Scotland) is hosting a Garden Lobby event at the Scottish Parliament on Wednesday 2nd December 2009 from 6 to 8pm. This event, 'EACH Child and Young Person's Health Matters', will be hosted by Christine Grahame, MSP and Convener of the Health & Sports Committee. It will mark the start of a year-long campaign on the healthcare rights of children and young people at times of illness, promoting our work through the medium of the European



Association for the Welfare of Children in Hospital (EACH) Charter by showcasing our

local projects as practical examples of how the Charter standards apply in practice.

We will send out invitations nearer the time, but for now please note this for your diary. We hope that as many people as possible will be able to come along and hear about the campaign and our work. If you would like your name to be added to the invitation list please email enquiries@ascscotland.org.uk or call 0131 553 6553.

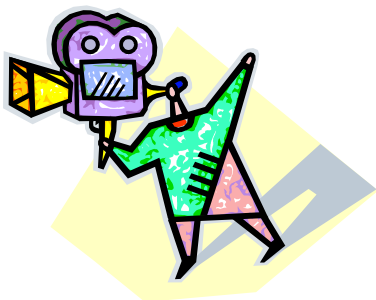
Helping sick children and young people meet their healthcare needs,
in partnership with parents, carers and professionals

TAYSIDE CHILD HEALTH RIGHTS DVD

Fiona Bartley-Jones, Project Officer writes:

The DVD project is moving ahead and we have some new young mothers coming on board who are excited and enthusiastic about the opportunity to take part in the project. Producer/Director Emma Olver will start filming in November and I look forward to working with her. She has some great ideas about how to convey the messages we wish to give on how to help teenage parents to access healthcare services and information about their babies' health rights.

Work is also underway compiling a directory of services and resources that may be of assistance to young parents across Tayside. We welcome contact from any local organisations who wish to be included, especially those in rural areas. If you would like to know more, please email asc.eastscot@dsl.pipex.com



for Scotland's Disabled Children From good intentions to better lives



Kate Higgins, Policy Manager, for Scotland's Disabled Children Liaison Project, writes: for Scotland's Disabled Children (fSDC) is a coalition of disability and children's organisations campaigning for rights and justice for disabled children and young people in Scotland. The aim is to translate the good intentions of government policy and legislation into better lives for families with a disabled child. The coalition focuses its efforts on improving the design, planning and delivery of four key service areas - short breaks, transition support, childcare provision and education.

As part of the coalition's work, a liaison project has been funded by the Scottish Government to act as a conduit between government and key players in the sector. The project has a simple but challenging aim - to enable families with a disabled child to enjoy the same quality of life as other families. Our engagement programme, called Three years to make a difference, will harness families' experiences and work with decision makers to determine what 'different' looks like in terms of designing, planning and delivering more flexible support better suited to families' needs. Families will be invited to keep diaries during the three years to help us chart progress.

fSDC is also about to start campaigning on issues connected to its four areas of concern. But they will need the help of fSDC supporters on the ground to reach Councils and Health Boards. Campaigns will be designed to make it easy for people to get involved as and when suits them.

If you are interested - in being kept up to date with fSDC activities or taking part in Three years to make a difference or getting involved in fSDC campaigns - please sign up as a supporter. Disabled children, young people, parents and other family members, professionals and practitioners in all sectors, are all welcome to join. Just Email donna.tomlin@cafamilly.org.uk or call 0131 659 2939.

Volunteer with Stay Well Lanarkshire



Stay Well Lanarkshire, our self management project for young people with long term chronic conditions, needs volunteers to help out at its workshops. These workshops will run over a period of eight weeks starting from 22nd October and we are looking for volunteers to help to run the sessions for a few hours a week. Full support will be given and if you have particular skills in working with young people we'd love to hear from you. An interest in drama, creative story telling, healthy eating and exercise is desirable, but the most important attribute we are looking for is a commitment to helping young people get the most out of life despite their having a long term health condition.

Our workshops are aimed at young people in three age ranges 11-12; 13-15; and 16-18. The sessions will run over the next two years and will cover communication, problem solving, moving on with life, coping with changes and confidence building. Each workshop will last for around two hours and will involve fun learning activities and a chance to acquire some new skills and get involved in activities such as drama, drawing, creative writing, healthy cooking, fun exercise, relaxation and stress management techniques.

If you'd like to volunteer, or want to refer to the project, please contact Project Officer Karen Martin on 07935 305930 or email ascsc@btconnect.com Check out the project web page on <http://www.ascscotland.org.uk/default.asp?page=56>

Karen Martin, Project Officer Stay Well Project

Special Smiles: Continued from front page

One pupil delivered a PowerPoint presentation on looking after your teeth as his response to Special Smiles. Games, DVDs and planting carrot seeds followed - all highlighting the importance of 'Brushing for Health', the theme of National Smile Month.

All of us at ASC(S) are sorry to lose Project Officer Gill Sutherland who has taken up a new post with NHS Tayside. However we have now enlisted the help of Amy Joss, Community Play Specialist Project Officer and George Hutchison, from our Project Advisory Group. Both Amy and George will liaise with schools this term, to offer support and collect feedback.

We have recently appointed a team from the Dental Health Services Research Unit at Dundee University to carry out an evaluation of Special Smiles. The team will report in January.

Catherine Nelson, Special Smile Dental Project Co-ordinator

Community Specialist Play Project Underway

The Community Play Specialist *pilot* project is well underway with Amy Joss, our Project Officer and Hospital Play Specialist, continuing to take referrals from child health professionals or directly from families in the Forth Valley area. Amy has also been providing support and hospital play ideas for child health professionals.

This project provides a service that is **in addition** to the NHS hospital play services already available when a child is an inpatient at Stirling Royal Infirmary or one of the specialist hospitals visited by children and young people from the NHS Forth Valley area.

Hospital Play Specialists are trained in child development and specialised play for children and young people experiencing ill

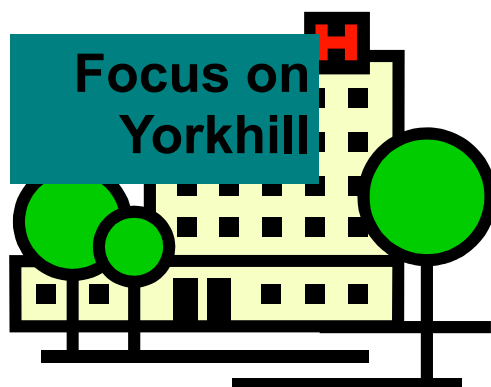
health. They can provide play ideas and support for families and they provide children with age-appropriate information about hospitals, those who work there and medical procedures they are scheduled to have. Specialised Hospital Play support might include: diversion/distraction/relaxation; play preparation for upcoming hospital stay or procedures; post-procedure or post-hospitalisation play; playbag; short-term loan of medical-theme toys and books; and other information for example on family/child facilities in specialist centres, patient/parent rights and using other community agencies.

For more information contact: Amy Joss, Community Play Specialist, Community Outreach Nursing Service, Stirling Royal Infirmary, Stirling FK8 2AU

Email: amy.joss@nhs.net Message Phone: 01786 433675 or visit: www.nhsforthvalley.com
Hospital Play Specialists: www.nahps.org.uk



ASC(S) hospital playbox in use in Glasgow



Dagmar Kerr, our Co-ordinator in Greater Glasgow & Clyde highlights the work of two groups she attends.

The **Family Council** at Yorkhill meets quarterly to discuss issues that affect families attending the hospital. Topics have included the catering service, parking, the hospital's play service, the young people's service, the hospital school amongst others. The group also receives regular updates about the progress of plans for the new Children's Hospital. Speakers are invited and at a recent meeting guests from 'WestMARC' who provide wheelchairs and special seating for children and adults in the West of Scotland, talked about improvements to their service and their plans for the future. They said, 'Having recently received approval for the £3.7million redesign programme in wheelchair and seating services, WestMARC aims to make further significant changes over the next three years, to its Repair and Clinical

Services.' Azhar Akram has been appointed to take forward WestMarc's commitment for user involvement.

Tel: 0141 232 7901, Email: Azhar.Akram@ggc.scot.nhs.uk Web: www.nhsggc.org.uk/westmarc

The Family Council next meets on 16 November in Yorkhill at 10.30am. All are welcome to come and hear about the Yorkhill Children's Foundation, the medicinema and the new children's hospital and to bring issues to the attention of the hospital.

The **Rights of the Child Group** ensures that children are treated according to their rights as defined in the UN Convention of the Rights of the Child. The group addresses a wide range of issues, from the need to provide appropriate staff training to making sure sick children's and young people's right to education is observed when they are ill and unable to attend school; from age appropriate care to emotional and physical support during any illness; from ensuring that information, participation and involvement are granted, to the right to be safe and protected, and many others.

The group has an excellent multidisciplinary membership from all areas of Greater Glasgow & Clyde Health Board and is chaired by Rory Farely (Director of Nursing for the acute sector). For more information contact Dagmar via ASC(S) or email dagmar.kerr@ntlworld.com

Partnerships and Family Participation

ASC(S) is often described as **the bridge** between the provider and the user in health services and we have selected from a wealth of examples, three recent pieces of work which highlight this key role.

The National Delivery Plan (NDP) was launched in March 2009 following a review of Specialist Services carried out by the Scottish Government's Children and Young People's Health Support Group in which we played a key role. Following the launch we were invited to become part of the NDP Implementation Group (NDPIG), set up to ensure that all 55 recommendations made are acted upon, and most importantly to ensure that the funding of £32m is invested appropriately. Since joining this group we have contributed to its first newsletter 'Better Health, Better Care: Update on the NDP for Children and Young People's Specialist Services in Scotland'. To read the article visit: <http://www.climb.org.uk/PDF/ScotlandBHUpd.pdf>

We are currently collaborating with National Services Division on a scoping paper for the NDPIG setting out the case for increased and more equitable financial support for families when their child is in hospital. *Continued on back page*

Their Health Matters: Meeting the Health Needs and Rights of Children and Young People in and Leaving Care Project



In our Spring newsletter we mentioned **These Are Our Bairns** (TAOB) (Scottish Government 2008), which gives guidance to Community Planning Partnerships on being a good corporate parent and a series of recommendations on health service provision for Health Boards which include:

- Health Boards should identify a lead or champion for looked after and accommodated children and young people (LACYP) and care leavers in their area
- Ensuring that young people are able to access primary medical care and specialist health services and

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Review of National Managed Clinical Networks (NMCNs)

As ASC(S) had been involved in the development of two MCNs, we have been invited to take part in the National Managed Clinical Network Review designed to assess the extent to which each NMCN is achieving its original designated objectives ie improving patient care, and contributing to sharing good practice, education and development, and to consider the extent to which they continue to meet the needs of their stakeholders and add value to healthcare in Scotland. For more information click on: <http://www.nsd.scot.nhs.uk/Publications/currentreviews/nmcnpid1.1.pdf>

The National Managed Clinical Network (NMCN) for Children with Exceptional healthcare Needs (CEN)

launched on 17th June, attracted considerable interest from a host of key professionals and other stakeholders, parents, carers and the voluntary sector. ASC(S) had been an active member of its forerunner, the Scottish Complex Needs Group (for children/young people with very complex health needs e.g. severe cerebral palsy, neuro-degenerative conditions, muscle disorders and other life-limiting conditions). Delighted to have been part of this successful application to become a NMCN, we look forward to continuing to assist as a member of the steering and service users' groups.

- A charter approach in which the rights of LACYP are set out to ensure that services are designed to meet their needs.

The overall aim of ASC(S)'s project is to identify the needs and priorities for this group and subsequently adapt and develop our resources to meet these. Here we outline some of the work we have been doing to meet those objectives in line with the recommendations in TAOB.

We had just started to survey different healthcare professionals at the time of our last newsletter and there has been a very encouraging response with over 70 questionnaires returned. The inspiration for this arose from the concept described in TAOB of the **corporate parent** and the **champion** for LACYP. As well as identifying needs and priorities, we wanted to establish how each professional saw their role and how they could help LACYP. The findings of this survey will be available shortly on our

website. As a result of this work we were invited to contribute an article to the Scottish Journal of Residential Child Care, Special Health Edition (Autumn 09). (Article on www.ascscotland.org.uk.)

Using our Children and Young People's Healthcare Resource Pack, our work with young people in residential schools in Fife and Forth Valley has focused on interactive activities and games which introduce young people to health services and explain how to access these and their healthcare rights.

These rights were further promoted by considering how the 10 healthcare standards in the EACH Charter could be adapted for this setting.

Our recent information booklets, **The GP Service for Children and Young People** and **What to expect when a child goes to hospital** have been designed with all carers in mind and help to promote easier access to healthcare services.

Anne Wilson, Development Officer

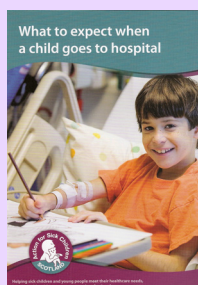
What to expect when a child goes to hospital

This new booklet gives information on the following:

Going into hospital:

What is it like? What do I tell the child? Top tips for a happier stay; What happens if I stay? **On the Ward:** who looks after the child? What is the daily routine? What about eating and drinking? How can I help? How can I have a break if I stay? **Staying and Visiting:** What if I can't stay? Can relatives or friends help? Managing the rest of the family? **Having an Operation:** What should I tell a child beforehand? What if a child wants to know more? What will happen on the day? What happens afterwards? Going home; Follow-up appointments? **Getting back to normal:** At home; At school; A child's view on hospital care; Your feedback; Information about Helpful Organisations.

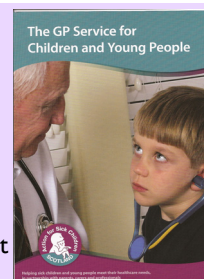
Both information booklets are available free for parents/carers and cost 30p plus postage for others, or download from www.ascscotland.org.uk



The GP Service for Children and Young People

Gives information on:

The GP Service: What can I expect? How do I register a child with a GP? What should I look for in a GP? Can I change my GP? How can I get an immediate appointment for a child? **Seeing the GP in the surgery:** How can I make the best use of our consultation time? Can I refuse recommended treatment for a child? Can I ask if my child can be referred to a specialist? Can I choose which specialist I want my child to see? **Seeing the GP out of the Surgery:** Can I get advice over the phone? When is a child entitled to a home visit? What do I do when a Surgery is closed? How do I cope in an emergency? **GPS and Confidentiality:** Access to medical records by children, young people and their parents/carers



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