



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

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Newsletter Spring 2010

Successful Launch of Health Rights Campaign

Last December, which saw the close of the year that not only marked the 20th Anniversary of the United Nations Convention on the Rights of the Child, but also the 50th Anniversary of the publication of The Welfare of Children in Hospital Report (known as the Platt Report, after Sir Harry Platt its Chairman) it was fitting that that we launched our **EACH Child and Young Person's Health Matters** campaign, on the healthcare rights of children and young people.

Kindly hosted by Christine Grahame MSP, Convenor of the Cross Party Health and Sport Committee, this took place in The Garden Lobby at the Scottish Parliament. Over one hundred guests gathered to hear about the work of the organisation and its drive to promote the healthcare rights of children based on the European Association for Children in Hospital (EACH) Charter.



Gwen and Christine Grahame MSP (far right) with Yorkhill Youth

Many will be aware that it was the Platt Report and the influential work of a Scot, James Robertson that led to the formation of Mothercare for Children in Hospital in 1961. This in turn became the National Association for the Welfare of Children in Hospital NAWCH and in 1991 Action for Sick Children.



Chair Gwen Garner, Dr Peg Belson and Vice-Chair Bob McFarlane

Sister organisations came in to being in Europe and formed the European Association for Children in Hospital. The 1984 NAWCH Charter, based on the Platt Report, and endorsed by over 50 voluntary and professional organisations involved in child health, provided the template for the European Association for the Welfare of Children in Hospital (EACH) Charter.

Throughout this year we will be promoting our work by highlighting our projects as practical examples of how the EACH Charter standards

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Asking The Difficult Questions ASC(S) Conference Royal Concert Hall, Glasgow 14 September 2010

EACH Child and Young Person's Health Matters: Asking the Difficult Questions - will cover the Rights of babies; Rights of children to education and play at times of illness; Transition and adolescent healthcare; Ethics and the UNCRC. Speakers include: Dr Vic Larcher, Ros Moore, Chief Nursing Officer, Dr Janet McDonagh, Maggie Tierney, Deputy Director, Support for Learning Division, Scottish Government, Julia Whitaker, Senior Play Specialist, Yorkhill Hospital. Booking details and further information will be available nearer the time.

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

The Right to Education

Why would a child or young person want to learn or study when they are ill?

Even though many say that they 'hate school', when they can't attend through illness, many youngsters start to worry about missing important subjects and what might happen to their chances of passing exams. Other aspects of school, like being with friends or keeping life as normal as possible during times of illness, are also important. It is up to local authorities to interpret the law as regards if and when teaching might be provided when children or young people can't come to school. Authorities across Scotland have different rules about if and when they might pay for hospital teaching or how many days a youngster is off sick before a teacher starts helping them at home. Youngsters in a paediatric hospital or ward have a much better chance of getting taught than those being treated in an adult setting. It can be very difficult to access subject teachers to help with more than just general teaching. Those who are ill at home depend on varying local arrangements.



Our campaign calls for equal access to education for all sick children and young people, regardless of their illness, age or where they live. The **Rights of the Child Group** (Yorkhill) is also looking at this and hopes to achieve better, more equal access to education across Scotland.

Does your local authority or health care setting provide this for all sick youngsters in your area?

We would like to hear about good (and maybe not so good) practice to help us work towards better and more equal access to education for all who are losing out due to illness. Get in touch with us.

Successful Launch: Continued from front page

apply in practice, and we will be holding a conference on 14 September at Glasgow Royal Concert Hall.

We were delighted to welcome amongst the guests the Youth Panel for the new build Royal Hospital for Sick Children, in Glasgow, the young people from Hayshead Primary School Arbroath, who were involved in the Special Smiles Project, and Dr Peg Belson MBE, Honorary Fellow of the Royal College of Paediatrics and Child Health, and a founding member of our organisation. Peg is also the UK representative at the European Association for Children in Hospital.

Guests were welcomed by Christine Grahame and Chair Gwen Garner. Morgan Jamieson, Former National

Stay Well Lanarkshire

Living with a Long Term Health Condition

Stay Well Lanarkshire has tested out our self management workshop material at sessions with 19 young people and here we share some of their feedback.

'It disnae feel like work, it's good fun and I learnt so much from my pal. I didn't know half of what she went through wi her diabetes, it was really good that she could tell us.'

'I never know what to say to the nurse when we meet, then I think about all the stuff I should have said when I'm on my way home. I'd like help to remember what I should be telling her.'

'Lunch times are the hardest. I want to eat same as my pals but I have to watch because of my diabetes. Coming here tonight (workshop) let me talk about how that makes me feel; I got some good ideas for snacks from some of the others. Ta.'

One boy spoke about how people react to his illness, 'I hate having asthma. Every time I cough people just look at you, they probably think I've got swine flu!'

A girl with diabetes commented, 'I get fed up with being the diabetic one at school. Even my mum tells people I'm diabetic when we first meet – you'd think I had something you could catch!'

The project will hold workshops throughout 2010 and we are keen to hear from any young person wishing to take part. Call 07935 305930 or 0131 553 6553.

Would you like the Scottish Government to do more to empower and support young people to take responsibility for their own health and management of their chronic condition? If so join us to raise awareness of healthcare rights of children and young people through our EACH campaign.

Clinical Lead for Children and Young People, and then Rory Farrelly, Director of Nursing, NHS Greater Glasgow and Clyde Acute Division addressed the gathering and expressed appreciation for the work that we do. Our staff gave brief presentations on current projects, and then invited guests to visit the displays of work.

Although much progress has undoubtedly been made over the years, through our work we are aware that there is still room for improvement. In our Manifesto, which can be viewed at <http://www.ascscotland.org.uk/default.asp?page=46> we have identified the issues that we are concerned about. All present were invited to bear in mind the EACH Charter and to endeavour to implement it to keep the focus on the healthcare rights of children, young people and their families.

EACH Child and Young Person's Health Matters: Meeting the Health Needs and Rights of Children and Young People in and Leaving Care

Last year we celebrated the 50th Anniversary of The Welfare of the Children in Hospital Report (the Platt Report), whose guiding principle was the vital significance of support for the emotional and mental well-being of children and young people in hospital.

Children and young people in hospital shall have the right to have a parent or parent substitute with them at all times.

(EACH Charter point 2)

It seems fitting then that, at the launch of our EACH campaign in the Scottish Parliament, that the importance of support in hospital was highlighted as a major consideration for children and young people in care. Guests at the Launch heard too how much weight those young people themselves attach to the need for tact, understanding, privacy and respect. (EACH point 10) as set out in our Manifesto Item 4,

To ensure that children and young people who are vulnerable by virtue of the fact that they are in care or have exceptional health care needs, are accorded the same degree of respect, understanding and privacy as we would accord to any other child or young person.

Our Meeting the Health Needs and Rights of Children and Young People in and Leaving Care Project concludes with the launch of a toolkit at the conference, *Journeys to Health Care: Exploring Different Routes*, hosted by the Scottish Healthy Care Network and the Scottish Institute for Residential Childcare on 25th March in Dundee.

The toolkit will include:

- Poster and postcard signposting to our website with links to other helpful organisations
- Booklets on the GP Service and Young People in Hospital,
- An EACH charter booklet for young people

- Podcasts from a range of healthcare professionals
- A glossary of terms (including a who's who in healthcare)
- A credit card size aide-memoire.

Through this resource we will emphasise to all involved in the healthcare of LAC, the importance of the recommendations in **These are our bairns** (TAOB), (Scottish Government 2008). These recommendations include the need for a champion for children and young people in care, equitable access to healthcare services and above all an understanding mind.

'I like it ken when they got that look on their face that says we do care what's going on wi people.' A young care leaver

Join our campaign and tell us what your priorities are for action to implement the recommendations in 'These are our bairns'

Dental Project Evaluated a Success

The Special Smiles Project in Tayside has now come to an end, with 700 children in 29 schools having access over the last two years to our dental play resources for children and young people with complex and additional support needs.

Researchers from Dundee University have now completed an evaluation of the project and we are delighted that they have found that the project achieved what it set out to do. The evaluation report concludes that oral health understanding of staff, carers and children was improved and child dental anxiety reduced. The report further recommends that Special Smiles should be implemented in nursery and primary schools across Scotland. ASC(S) believes this could help the Scottish Government to achieve its oral health targets for children in Scotland, while ensuring that youngsters with additional and complex needs are adequately

provided for in their oral health initiatives and services. We are seeking funding to drive this forward.

Project Co-ordinator Catherine Nelson is now offering Special Smiles in selected schools in Renfrewshire until June 2010. This will allow more children to benefit from our work and give us an opportunity to take forward some of the recommendations of the Report. To read, visit www.ascscotland.org.uk/default.asp?page=19



The Tooth Team from Hayshead School at the EACH Campaign Launch at Parliament in December

What they say about Special Smiles!

'Excellent, well thought-out and comprehensive. It has been a joy to use this equipment and see the benefits to the children. The home Playpack has involved whole families which is so important for consistency of approach.' Teacher, Crieff Primary

'I noted quite a big change in the children. Even the most sensory defensive child held a toothbrush.' Nursery Teacher, Fairview School

'My child treats teeth cleaning more as a game now. It is much easier to help her.' Parent, Fairview School

'I have used the Playbox with two primary school pupils who 'couldn't work' because they had sore teeth. Neither wanted to go to the dentist. I showed them appropriate items from the box and we discussed teeth. Both subsequently had dental treatment.' Teacher, Hayshead School

DVD for Young Parents Launched

Our DVD, **Young Parents Speak Out** was launched in February in Dundee. The DVD is primarily aimed at Tayside young parents and seeks to support them in appropriate access to services, but it is much more than just a simple information film. The DVD, with commentary kindly recorded by Lorraine Kelly, features young parents talking about issues such as attendance at ante-natal classes and their relationships with healthcare professionals such as midwives and health visitors. There are messages for young parents but also for healthcare practitioners, making it suitable for use as a staff training resource for those who work with young parents, either in a healthcare capacity or social context. To view the DVD visit: <http://www.ascscotland.org.uk/default.asp?page=83> The DVD is free to young parents, midwives and health visitors in Tayside.



Organisations can purchase for £8 + £2 (p & p). To order or to have Fiona visit your group to talk about the film and work of the project, call 07810 238 663 email: ASCeastscot@talktalk.net or contact our Edinburgh office on 0131 553 655.

The film is supported by a guide **'Help in Tayside for You and Your Baby'** which gives advice on a wide range of issues from money management to baby blues, as well as signposting to additional



Fiona Bartley-Jones, Gwen Garner, Kathryn Miller (back)
Sarah Henderson and Gina Turnbull (front)

Photo: Courtesy of the Dundee Courier

sources of help and support, both practical and emotional. Read on www.ascscotland.org.uk

The Child's Right to Play Especially When Sick



The Community Play Specialist pilot project in NHS Forth Valley continues to provide hospital play services in the community for children, young people and families who are using specialist healthcare services.

This Spring, the project welcomes the involvement of two Health Psychology MSc students from Stirling University, who will evaluate the project as part of their studies.

Project Officer Amy Joss welcomed the opportunity to highlight the child's *Right to Play, Especially When I'm Sick* at the ASC(S) Scottish Parliament event in December, citing the child's right to play in both the United Nations Convention on the Rights of the Child (UNCRC) and European Association for Children in Hospital (EACH) Charter. Article 7 of the EACH Charter states 'children shall have full opportunity for play, recreation and education suited to their age and



Amy - The Child's Right to Play

condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.'

This Project is providing specialised play for children and young people in their home or other community setting, to support their individual need for play preparation or to reduce anxiety about healthcare.

What are you doing in your area to promote play for children and young people requiring health care services?

What are you doing to promote the child's right to safe and age-appropriate play opportunities in your healthcare facilities? Let us know ...

For more information contact:
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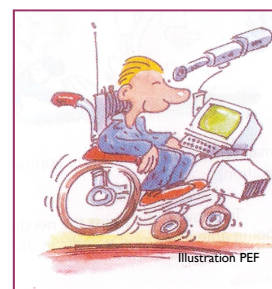


Illustration PEF

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