



Action for Sick Children (Scotland)

Newsletter

Spring 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



Dr Peg Belson MBE at the launch of ASC(S)'s EACH Campaign at the Scottish Parliament December 2010

Though they will be unaware of **it, there isn't a family in the UK** who has had a sick child in hospital that does not owe a debt of gratitude to Dr Peg Belson MBE, Honorary Fellow of the Royal College of Paediatrics and Child Health. Peg died on 2 January 2012. She was an amazing woman whose indefatigable pioneering spirit, wise words and contributions have left the world a better place for sick children, young people and their families. She had a razor sharp mind, a wealth of

expertise, knowledge and experience. The wellbeing of the child was unwaveringly at the heart of all her work.

Peg was a founding member of Mothercare for Children in Hospital which subsequently became The National Association for the Welfare of Children in Hospital (NAWCH) and then Action for Sick Children. From such beginnings similar organisations sprung up round the world from the USA, Europe and Australia. She was a member of the working group that enabled the establishment of the European Association for Children in Hospital (EACH) in 1993, and since its inception she acted as the UK delegate on its Executive Committee and as its Secretary. As recently as last November, even at the age of 90, she played an active role at the EACH meeting in Vienna.

She always took a keen interest in what Action for Sick Children (Scotland) was doing. We were delighted when she came to participate in our conferences and to the launch of our EACH campaign at the Scottish Parliament. Her last visit was to our Each Child and Young Person's Health Matters Conference in 2010 at which her questions to the speakers, as ever, went straight to the heart of the matters under discussion. We shall remember her with great affection and appreciation.

Last year Peg received the inaugural University of Sydney's UK Alumni Award for Lifetime Achievement. Please visit this website to see why she so deservedly won this Award and to read an account of her work:

www.alumni.sydney.edu.au/s/965/images/editor_documents/alumniassociations/USUKAA/usukaa_2011flyer_peg.pdf

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The Corporate Parent



Photo: NHS Health Scotland

No child, including those in the care system, should ever have to ask the question **'Who looks after me when I am ill?'**

If being a good corporate parent means giving our children the love, security and care that any good parent gives their own child when they are sick, how do local authorities and other agencies fulfil this role for children and young people in their care?

The poor outcomes for children and young people who are looked after continue to be an area of significant concern for the Scottish Government. This has prompted the Scottish Government to promote a raft of policies and other initiatives, one of which is the corporate parenting agenda, to be implemented via its Looked After Children in Scotland Implementation Group (LACSIG). LACSIG works closely with agencies and organisations such as Who Cares? Scotland and the Centre for Excellence for Looked after Children in Scotland.

The Scottish Government defines the corporate parent as: *'The formal partnership needed between all local authorities departments and services and associated agencies which are responsible for working together to meet the needs of looked after children and young people.'* (Looked after children and young people: We Can and Must do Better, Scottish Executive, 2007).

In *These Are Our Bairns* (Scottish Government 2008), we read: *'Being a good corporate parent means we should seek for them the same outcomes any good parent would want for their own children.'* This Report includes specific recommendations for health boards:

- Appointing a Director with responsibility for children and

- young people in care
- Providing equitable access to Healthcare services
- an understanding mind.



Between 2007-10, ASC(S)'s Children in and Leaving Care Project looked at the healthcare needs and rights of children and young people in care. Inspired by *These Are Our Bairns*, we looked at what corporate parenting means in a health context by surveying different healthcare professionals involved in the care of Looked After Children and Young People (LACYP). As well as finding out about LACYP needs and priorities, we learned how each professional saw their role, the challenges they face and how they helped this vulnerable group. This information informed the development of a toolkit, including podcast interviews, which aims to raise awareness of the health needs and rights of children and young people in and leaving care and provide information relevant for all staff and carers. See <http://www.ascscotland.org.uk/default.asp?page=85>

As a result of disseminating project findings to LAC Directors in Health Boards, we have been invited to the Western Isles to present on corporate parenting at a development day for Health Board members. We will co-present with Who Cares? Scotland, which is currently delivering corporate parenting training to Scottish Health Boards and local authorities. We are delighted to participate as partners in this very valuable work.

The Project is currently training foster and kinship carers to help them to look after the health of children and young people in their care. The training now includes mental health and wellbeing. A Seasons for Growth programme has also been delivered to foster carers in Clackmannanshire, and one for kinship carers is planned for later this year.

Contact Anne Wilson on 0131 553 6553 or email a.wilson@ascscotland.org.uk

Stay Well Lanarkshire

Stay Well Lanarkshire, our generic self management project for young people aged 11 – 18 years living with long term health conditions is in its final stages. Since October 2008, it has been 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.

The Project is currently delivering the last two self management programmes and working on the toolkit which will be available in June.

Over 55 young people have benefited from the programme developed with and for young people, many of whom have also received training in peer supporting. Thanks to all those young people who returned to workshops as peer supporters and **DVD developers. You've been great!**



Project Assistant Lysia and Volunteer David

The Project team Amy and Lysia would like to give special thanks to an outstanding volunteer, David Coulter from Hamilton. David has devoted many hours and Saturdays to support the workshop programmes and his special skill in providing challenging and active games has been a big favourite.

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

*We bid a fond farewell to Lysia Abercrombie, who leaves us in March. **Lysia's background in youth work and community arts has been extremely important in the development of our generic self management programme.***



Scottish Commissioner for Children & Young People visits Rights of the Child Group

The work of Dagmar Kerr, our Area Co-ordinator for Greater Glasgow and Clyde (GG&C), includes that of influencing service planning and delivery in the Health Board area. One of the key groups with which she works, is the Rights of the Child Group, which enjoys tremendous support from the NHS Board. Elaine Love, Head of Nursing for Neonatal, Children and Young People's Services at Women & Children's Directorate of NHS Great Glasgow & Clyde explains:

"It is extremely important that nurses and other healthcare staff working with children and young people understand the Rights of Children as described by the UN Convention and adopt the principles of the EACH charter in how they care for their patients and support their families.

The Health Board's Women's & Children's Directorate has a long established multi-agency and multi-disciplinary Rights of the Child Group which has provided support to the Directorate in ensuring the Rights of Children are protected. A recent invitation to Tam Baillie, Scottish Commissioner for Children & Young People, from the Rights of the Child group, resulted in a very positive visit to RHSC, Yorkhill. The Commissioner was very supportive of the work of the group and was keen to influence other Boards to adopt a similar approach.

The success of the group to date has been due to the enthusiasm and commitment of the group membership past and present, with the key objective of ensuring that children and young people feel supported, protected, safe, listened to and valued while in receipt of our services."

The Board is working across all its areas to implement the **new Patients' Rights Bill, and within this work, the Rights of the Child Group plays an important role in ensuring that children's and young people's rights are equally considered.**

NHS Greater Glasgow & Clyde demonstrated commitment and forward thinking when it decided to continue the work of the Group, which had been established in 1996 by the Yorkhill NHS Trust Board. Issues like consent, education during times of illness, staff awareness of the rights and needs of looked after children, are but a few of the topics that this group deals with. **ASC (S) hopes that as a result of Tam Baillie's visit to the Group, that all Health Boards will be encouraged to establish Rights of The Child Groups in their Board areas.** ASC(S) is grateful for the support of the Health Board and for the opportunity to share good practice between hospitals and across other Health Board areas.



Education for Sick Children Guidance to be reviewed

Readers will know that ASC(S) has been campaigning hard over the last 18 months to ensure equal access to education for all children and young people absent from school during times of illness.

In January 2011 we submitted a petition to the Scottish Parliament Petitions Committee asking the Scottish Government to demonstrate how local authorities are complying with the duties imposed by Education legislation and Guidance. We also asked the Scottish Government to **review the Guidance on the 'Education of Children Absent from School through Ill-health' which is now 11 years old.**

Our petition has been considered at several Public Petitions Committee meetings over the last year and **we've had ongoing correspondence with the Scottish Government.** We are now delighted to report that the Scottish Government has agreed to review this Guidance and has invited ASC(S) to be a member of the Review Group which will have its first meeting in March. Our public petition is now closed but contains useful background information about this important issue. It can still be viewed on <http://www.scottish.parliament.uk/business/petitions/docs/PE1381.htm>

Special Smiles Co-ordinator Speaks at Scottish Parliament Health Inequalities Seminar

On 31 November, St Andrew's Day, Catherine Nelson, our Special Smiles Dental Project Coordinator gave a presentation at the Scottish Parliament at a Seminar on 'Health Inequalities and Scottish Projects' supported by the Pfizer UK Foundation. The evening event, sponsored and chaired by Jim Eadie MSP, was hugely successful in showcasing best practice from Action for Sick Children (Scotland), CanRehab and Diabetes UK Scotland. Projects from these three organisations were chosen as great demonstrations of innovative and inspiring programmes which have improved the health of their local community through targeted, evidenced based interventions.

Those hearing about our work included MSPs and representatives from across the healthcare sector, from organisations such as Health Scotland, the Royal College of Nursing Scotland and the Association of the British Pharmaceutical Industry Scotland. Professor Susan Deacon, Early Years Champion for the Scottish Government and Pfizer UK Foundation's Scottish Board member was also present.



left to right: Catherine Nelson, ASC(S), Sarah Ward, Diabetes UK Scotland; Jim Eadie, MSP; Dr Anna Campbell, CanRehab.

New Faces in Post

Meanwhile thanks to funding from Inspiring Scotland's Early Years Early Action Fund which has enabled us to extend our work in Glasgow, Special Smiles continues from strength to strength.

Thanks to Standard Life plc for printing this Newsletter



Project Officers Grace (left) and Mary

Two new Project Officers Mary Cox and Grace Lacey took up post in December, and with Catherine, are rolling out the project to 17 special needs schools and units throughout Glasgow.

At the beginning of March we were pleased to work together with other Glasgow based Projects funded through Inspiring Scotland's Early Years Early Action Fund. We jointly showcased the work of our respective organisations at a stall at 'The Gathering' - the annual voluntary sector event held in the SECC, Glasgow. Thanks to Glasgow City Council who sponsored the cost of the stall, we were able to bring information about our work to hundreds of people who attended this popular event.



SPPA's Ian Williamson designed the Banner for 'The Gathering' which features Action for Sick Children (Scotland) along with other Inspiring Scotland Glasgow based projects