



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

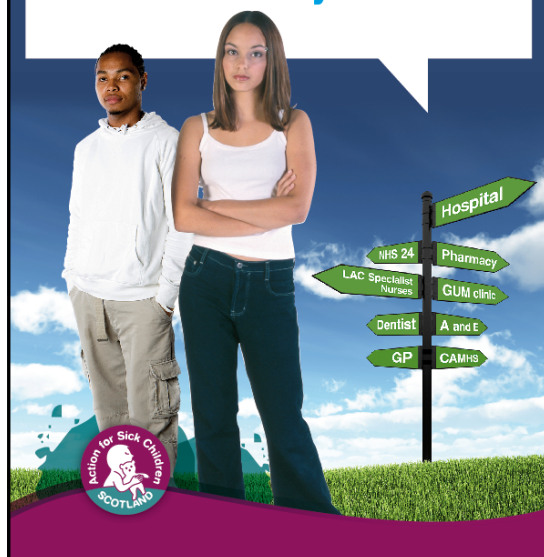
Raising awareness and representing children's needs and concerns within government, healthcare committees and other non-governmental organisations

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 2010

EACH Child and Young Person's Health Matters: who looks after those in care when they are ill?



better supported at times of illness and enabled to access appropriate healthcare services.

Seasons for Growth

Over time the project has become increasingly aware of the adverse effect on young people's physical and mental health, resulting from the additional stress of coping with the change and loss of their care situation, and of the need for support strategies to help them manage this. The project will now develop a dedicated programme using approaches from Seasons for Growth in collaboration with teachers, LAC Nurses, educational psychologists and others. This will help ensure that young people, who are vulnerable by virtue of the fact that they are in care and also coping with significant health care needs, are helped to develop increased confidence, self-esteem and resilience. For more information on this or on foster carer training contact Anne Wilson on 0131 553 6553 or a.wilson@ascscotland.org.uk

Over the past three years Action for Sick Children (Scotland)'s Children and Young People in and leaving Care project has examined the healthcare needs and issues of children and young people in care. The development of a toolkit to help meet these needs is now complete with the addition of six podcast interviews with relevant healthcare professionals, examining their role and promoting best practice. View on <http://www.ascscotland.org.uk/default.asp?page=85>

Foster Carer Training

'These Are Our Bairns' (Scottish Government 2008) recommends that young people, either as individuals or through carers, have equitable access to healthcare services. In order to promote this, our project has developed a series of workshops to help foster carers and others gain a deeper understanding of the health needs and rights of children and young people, so that these young people can be



The LAAC toolkit includes:

A4 poster for healthcare professionals

A6 postcard linked to the poster

Young People's EACH Charter - the 10 EACH Charter points and young people's interpretation of these

Young People in Hospital - a guide to help young people prepare for a visit to hospital

The GP Service for Children and Young People - a guide to help carers understand and access GP services

What to Expect when a child goes to hospital - a guide for carers

Podcasts with professionals involved in the healthcare of LAAC

Contact 0131 553 6553 to order



INSIDE - ASC(S) Conference Report - Special Smiles in Egypt - Education Rights - Stay Well Lanarkshire - Hospital Play - Community Play - News from Tayside

Helping sick children and young people meet their healthcare needs

ASC(S) Conference Asks the Difficult Questions

ASC(S) conference 'Each Child and Young Person's Health Matters: Asking the Difficult Questions' took place in Glasgow on 14 September. The event was chaired by **Dr Kate McKay**, National Clinical Lead for Children and Young People's Health in Scotland who opened with an overview of what's new in child health in Scotland. Dr McKay said that health services should be responsive to the needs of all, especially vulnerable families and that all children should have access to services with the skill mix necessary to offer high quality services. She also talked about the need to demonstrate effectiveness of interventions to allow further investment in child health services and the need for a quality infrastructure to ensure that health interventions are integrated, aligned and managed appropriately.

Ros Moore, Chief Nursing Officer for Scotland in 'Nursing Our Future: The Policy Landscape,' spoke about the challenges facing Children and Young People's health care provision and the role of GIRFEC in improving joint working between agencies. She talked about nursing issues and said that what children, young people, families, carers and NHS staff want is caring and compassion, collaboration, continuity, confidence, a clean and safe environment and clinical effectiveness. She talked about some ways to achieve this eg improving patient services, including primary care developments; supporting change, providing quality care and investing in the workforce.



Some of the exhibitors at ASC(S) conference

Dr Una MacFadyen, Consultant Paediatrician at Stirling Royal Infirmary asked, 'Do Babies Have Rights?' She said that while Scotland has contributed to the WHO Health Promoting Hospital for Children and Adolescents project and most Scottish Maternity Units have committed to the WHO UNICEF Baby Friendly Hospital Initiative, newborns may be denied their rights due to lack of planning of the neonatal unit environment and competing priorities in care planning, resource allocation and environmental awareness. She talked about evidence to support the adoption of developmental care principles for preterm infants which can result in improved signs of stabilisation, more rapid growth and earlier discharge. She also talked about evidence that premature infants are vulnerable to over and under stimulation of sensory pathways and that noisy bright hospital wards may impact adversely on them.

Maggie Tierney, Deputy Director Support for Learning, (Scottish Government) spoke about the policy context relating to the education of children and young people with health needs. Legislation and guidance are in place to ensure that Education Authorities secure learning for children and young people in hospitals but this is not prescriptive. Maggie noted that tensions are best resolved through partnership working between Education Authorities, Hospital education staff and parents.

Julia Whitaker, Play Specialist at Royal Hospital for Sick Children in Glasgow asked, 'Does Play matter?' She said that children visiting or staying in hospital have a basic need for play and recreation that should be met routinely in all hospital departments providing a service to children. She described play as a child's first language and those who have play support at hospital experience less anxiety and pain, need less analgesia and anaesthesia and recover faster. Julia included case studies which illustrated how play had helped children and young people in Yorkhill.

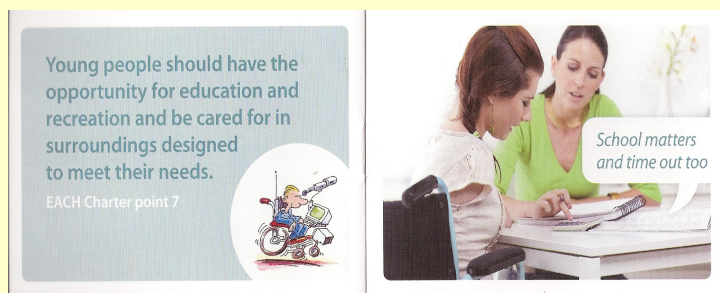
Dr Vic Larcher, Consultant in General Paediatrics and Clinical Ethics at Great Ormond Street Hospital presented on 'Ethics in Action: How Much Should Children Count?' He raised a series of questions including, How do we make ethical decisions? How should we regard children? Does moral status matter? What are the best interests, and who decides the best interests of the child? He talked about the ethical and legal requirements for valid consent and the need to encourage children's involvement in decision making.

Dr Janet McDonagh, Senior Lecturer in Paediatric and Adolescent Rheumatology at Birmingham University and the Clinical Lead for Adolescent Health and Consultant Rheumatologist at Birmingham Children's Hospital NHS Foundation Trust gave a talk on 'Better Health, Better Care: Are Young People There?' We learned of the 32% increase in emergency admissions in England in the 16-19 age group between 2002-07 and that chronic illness increases through adolescence. Dr McDonagh spoke about the development of the adolescent brain and of adult abstract thinking and social development. She emphasised the need to raise adolescents' awareness of their developing strengths and the role they can play in their health and well being; the need to motivate and assist them to do so, to promote their strengths, to model respect and kindness to the young people and to convey belief in them.

ASC(S) showed how its projects demonstrated in practice children and young people's healthcare rights as outlined in the EACH Charter. **Inspector8, Young People's Participation Group** from Dumfries & Galloway's Youth Unit delighted the audience by delivering a sketch showing how healthcare professionals and young patients should (and should not!) communicate with one another. Presentations can be accessed on <http://www.ascscotland.org.uk/default.asp?page=72>

Who Teaches Me When I am Sick?

Education Rights for Sick children and Young



Young People's EACH Charter Point 7

At our conference Dagmar Kerr, Area Co-ordinator in NHS Greater Glasgow & Clyde, summarised ASC(S)'s efforts, challenges and achievements in relation to campaigning for education rights for sick children and young people.

Dagmar was delighted to tell delegates that one of the most reluctant Local Authorities to support hospital teaching has now agreed to pay for all young people who need treatment at hospitals outside their area. She said that while there has been a general improvement in awareness that sick youngsters need access to education during illness, several areas of concern remain. She talked about how ASC(S) is in a strong position through its independent, apolitical status to campaign for the right of

privately educated sick children to access education during illness. These children are considered to have 'opted out' of state education so as a result Local Authorities don't feel they have an obligation to support them during illness. However private schools don't pay for hospital education or home tuition either, so these children's right to education is not being met by anyone. Dagmar also explained that ASC(S) wants to encourage sharing of excellent practice which is happening in some areas, for example when children have to go for complex hospital treatments and their return to school or home tuition is planned well in advance of hospital admission to make sure there is no gap in their education. ASC(S) believes that good practice like this needs to happen in all areas of Scotland. At the present time young people who are being treated in adult wards don't always have access to education and provision varies greatly depending on the local authority.

We were delighted to have Maggie Tierney at our conference who suggested that the 2001 Scottish Executive guidance on 'Education during absence due to ill health' may need to be up-dated to improve access for all sick children and young people. If that becomes the case, we would look forward to taking part in such an important review.

Special Smiles in Egypt

An interesting development in the last few months has been the introduction of our Special Smiles dental resources



Volunteer demonstrates resources in Cairo school

to schools in Egypt! ASC(S) provided a Special Smiles Playpack and training to a team of volunteers before they headed off to work in special schools in Cairo. The team leader told us that this work

was very successful, demonstrating the versatility of Special Smiles and the ability of our resources to cross boundaries of age, gender, ability and culture.

'The Dental Play Kit will be well used with special needs children in Cairo. Due to translation available, our team worked with older children. They really enjoyed the experience of play with different items in the kit and each received a toothbrush and toothpaste. The younger children will be given an opportunity with the kit in kindergarten as we showed the staff how to use it. The kit will be shared between two different schools for special needs children. Thank you so much for your donation of a dental play kit. The Egyptian children will enjoy it for a long time to come.'

in Renfrewshire

Special Smiles in Renfrewshire ended in June after working in four special schools since January 2010. The project was highlighted during National

Smile Month at a successful inter-school event held in the Mary Russell school in Paisley.



National Smile Event at Mary Russell School

and soon in Glasgow!

More recently we have been looking for funding to continue this excellent project and we hope to roll out Special Smiles in Glasgow from November. It would be wonderful if more vulnerable children could continue to benefit.

Community Play Pilot in Forth Valley draws to close

ASC(S) has long championed the importance of specialised play in healthcare. So ASC(S), with support from the Miss Agnes H Hunter Trust funded a two-year pilot project in October 2008 to scope the demand for community play support and to formalise its provision. Registered Hospital Play Specialist, Amy Joss, was appointed part-time and has been based with the Community Outreach Paediatric Nursing Team at Stirling Royal Infirmary for a period of 18 months. During this time, the project provided referral pathway information to 84 health professionals and organisations in NHS Forth Valley and specialist centres (such as the Royal Hospitals for Sick Children in Edinburgh and in Glasgow). It received 47 formal referrals and requests for play specialist input; developed resources; provided information for parents/carers and health professionals and delivered therapeutic play sessions.

The Project is being evaluated by two researchers completing dissertations for an MSc in Health Psychology at the University of Stirling. A final project report by the Project Officer will be available on ASC(S) website after the evaluation is published in November.

Play works: helping children on the road to recovery - Play in Hospital Week 2010



Balloon Launch

Community Play Specialist, Amy Joss joined Stirling Royal Infirmary play staff Lynda Allen, Seonad Hopkins and Kate Riddock in celebrating a balloon launch to begin Play in Hospital Week, 2010. Events held in paediatric wards throughout the country included messy play days, face painting fairies and music and magic shows.

The special week, organised this year by National Association of Play Staff in Wales, is held to highlight the essential service provided by trained and registered hospital play specialists, play assistants and volunteers in hospitals where children and young people receive healthcare services. Specialised play in hospital is known to reduce stress and anxiety, provide an outlet for feelings of anger and frustration and helps children and young people understand treatment and illness. For more information: www.nahps.org.uk.

Thanks to Standard Life plc
for printing this Newsletter

New Faces at Stay Well Lanarkshire Project



Project Assistant Lysia Abercrombie

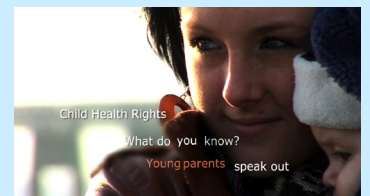
Project Officer Amy Joss

Stay Well Lanarkshire is an innovative self management programme for young people in Lanarkshire, aged 11-18, living with long term health problems such as diabetes, asthma, arthritis and chronic pain. We welcome new Project Officer Amy Joss and also new Project Assistant Lysia Abercrombie, who brings experience in community arts and youth work to the project.

The Project will begin the next series of workshops in late October 2010 to help young people explore issues of living with a long term health problem such as realities of illness, coping with change, managing emotions and feelings, communicating with professionals, peers and parents and moving on with life. The learning is fun and interactive and all material is developed specifically for young people. For information, phone: 07935 305930 or email: amy.joss@nhs.net.

Tayside Young Parents DVD

The Tayside Child Healthcare Rights Project DVD 'Child Health Rights, What do You Know? Young Parents Speak Out' is proving popular. Midwives in Tayside are distributing it to young mothers and it has been used as a teaching resource with midwifery students at Dundee University. Project Officer Fiona Bartley-Jones has now developed workshop plans for those using the DVD with groups of young people and these will be soon be available on our website. The DVD is free to young parents, midwives and health visitors in Tayside, otherwise order for £8 + £2 (p & p) from ASC(S) on 0131 553 655.



View on <http://www.ascscotland.org.uk/default.asp?page=83>