



Action for Sick Children Scotland

Newsletter

Spring 2017



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 the Scottish Government, NHS and voluntary sector to ensure that health services are planned for sick children and young people in child centred environments with appropriate ratios of trained staff

Informing children, parents and carers of their rights and responsibilities; empowering them to participate in decisions about treatment and care

Raising awareness, 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.

A Child's Anaesthetic Experience - A Brighter Future?

In last year's Summer Newsletter,

I reported on the results of our survey into the experiences of parents and carers whose children (0-18 years) had been given a general anaesthetic in the previous three years in a variety of hospital settings across Scotland <http://www.ascscotland.org.uk/default.asp?page=16>

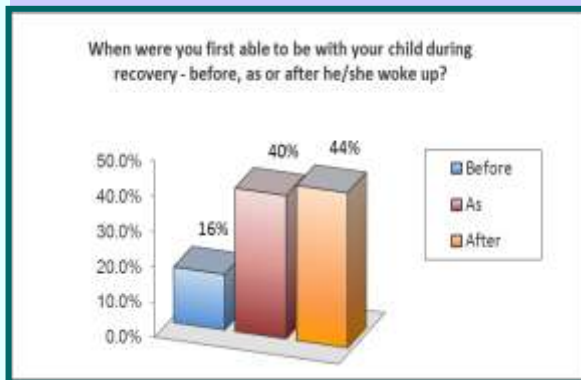
We found that, although satisfaction levels with their experiences in the anaesthetic room were high, this was not replicated during recovery. Many parents and carers reported that they were not encouraged to be with their child as they were waking up and one in ten told us that they and their child were upset because they were not present at the time of waking.



Children have the right to have their parents or parent substitutes with them at recovery

We wrote to all Scottish Health Boards with the results of our survey pointing out that, by denying a substantial proportion of children the right to have a parent or carer present at recovery, their healthcare rights are not being met. This is in breach of Articles 3 and 9 of the United Nations Convention on the Rights of the Child and Article 2 of the Charter of the European Association for Children in Hospital (EACH) which states that 'Children in hospital shall have the right to have their parents or parent substitutes with them at all times'.

All 14 Health Boards replied. The majority were very positive, stating that they would review



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Child Healthcare in Scotland: Overcoming the Challenges to Equality

Action for Sick Children Scotland Conference
Friday 10th November 2017

Royal College of Physicians, 9 Queen Street, Edinburgh
Minister for Childcare and Early Years, Mark McDonald MSP and Scotland's Chief Medical Officer, Dr Catherine Calderwood are two speakers who will be contributing on the day.

Further details and booking information will be available soon

Promoting the Healthcare Rights and Needs of Children and Young People



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A Child's Anaesthetic Experience - A Brighter Future?

their procedures and, as one Health Board put it, 'explore opportunities with clinical staff of how we can meet the expectations of parents ... and provide a service that meets their expectations for this patient centred approach to care'.

Arising from this interaction with Health Boards, a meeting with the lead paediatric anaesthetist in NHS Tayside, with ASCS Area Officer Tayside, Deborah Brown and me representing ASCS, provided an opportunity for a discussion about children's anaesthesia and recovery issues in particular. Together we made a decision to share information and seek a collaboration with the Scottish Paediatric Anaesthetists Network (SPAN). The aim being to jointly develop information for parents and carers about the induction of anaesthesia and the recovery process, with a stated principle of parental presence in recovery (ward or recovery room) as soon as it is safe to do so for the 'awakening child'.

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It's great to be able to report that, with SPAN's engagement with the issues, there seems to be a real prospect of improving the anaesthetic experiences of children and young people, their parents and carers. The current state of play is that an anaesthetic information sheet for parents and carers has been drafted and is out for consultation within ASCS and SPAN. Publication and distribution should take place later this year.

Professor Richard Olver, ASCS Chair

A Rights-based Approach to Dental Care - **Let's Play!**

Moving forward with Special Smiles, our team has been working successfully in partnership with NHS Education Scotland (NES) to deliver training to dental teams across Scotland. By March 2017, 122 oral health staff including dentists, oral health improvement managers, Childsmile nurses, extended duty dental nurses (EDDNs), hygienists and dental health support workers (DHSWs) have enjoyed play-based, interactive training days.

Annette Johnson, NHS Grampian Childsmile Co-ordinator, said, *'I really enjoyed it, it was really helpful and a great opportunity for me as a co-ordinator to review and refresh my thinking about how we communicate with children and parents.'*



Training session in Glasgow

It also addresses service planning and delivery as well as working with children and parents as partners.

A child's right to play (Article 31) is reflected in the United Nations Convention on the Rights of the Child (UNCRC) and supports the aims identified in Scotland's Play Charter. <http://www.playscotland.org/resources/policy-scotland-supporting-play/> **Scotland's Play Strategy (2013)**, encourages those working with children to embed playful opportunities into working practice, thus enabling children to thrive. Amy Joss, one of our dental project officers and co-presenter says; *'This is important for dental healthcare staff. Children explore and learn to express their feelings through play and we know that play can really make a difference to everyone's experience of the dental surgery.'*

Using the European Association for Children in Hospital Charter (EACH) and in discussion groups, the oral health



teams consider how they are already approaching children's rights in their workplace and how they can improve

practice, either through policy change or individually through re-thinking their approach to situations. Feedback resulted in some very positive comments, such as the following:

'Great insight and new ways to make sure children's rights are always heard and valued'.

'We will hope to achieve better communication with parents and carers before they come to clinic with (the) child. This preparation will benefit the child'.

'Very worthwhile, enjoyable course and so relevant to the work EDDN's and DHSW's do in the Childsmile sessions'.

Mary-Flora Ferris, our other dental project officer and co-presenter, believes that this training has a real **possibility of reducing children's anxiety** and raising their self-confidence, while creating more confident dental teams who can build closer relationships with children and families. She said, *'Supporting staff to change their working practice and become more rights-focused will naturally facilitate them to become more patient-centred'*.

Elizabeth May, ASCS National Coordinator, thinks the way forward is to continue to train oral health professionals in partnership with NES and to develop a community-based project working with parents and pre-nursery children. This would give the best chance of developing good oral health habits as early as possible to minimise the effects of social disadvantage. *'Such a project would make the greatest difference and would provide a way of supporting communities to prevent dental disease in our youngest children'*.

Mary Boyle _____ A Champion of Children's Rights



All of us at ASCS are still coming to terms with the untimely death of our fantastic Vice Chair Mary Boyle who died in March. Mary worked tirelessly for ASCS and for children and young people's health rights. She will be missed in so many areas where children and young people need her kind of expertise and positivity.

Children's Rights Day at Glasgow's Royal Hospital for Children - A Great Success!

The UK signed the United Nations Convention on the Rights of the Child (UNCRC) in April 1990, ratified it in December 1991 and it came into force on 15 January 1992. To mark this 25th anniversary, Glasgow's Rights of the Child Group (RoC) decided to hold a Children's Rights Day at the Royal Hospital for Children. What better way to showcase children's and young people's healthcare rights than using the EACH (European Association for Children in Hospital) Charter which was adopted in the UK even earlier, in 1988!

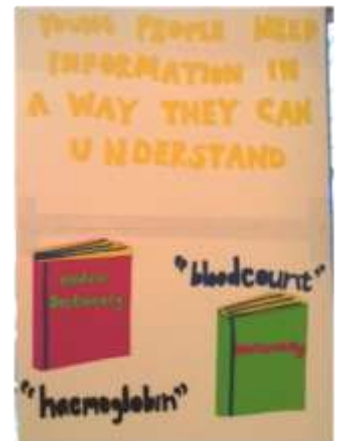


Supported by ASCS, the Play Service, the Young People's Service and the Children's Hospital Charity, we decorated the hospital foyer, organised craft activities and conducted a

questionnaire to find out how much children and young people, their parents and staff knew about the EACH Charter and healthcare rights.

One highlight was a series of presentations held in the Medicinema. Jen Rodgers, Chief Nurse for Hospital Paediatrics and Neonates spoke about the health board's commitment to a rights based approach in children's and young people's healthcare. The 'What matters to you' approach is a very effective way to find out what young patients need and to help staff deliver person centred care. Gwen Garner, ASCS Executive member and Secretary of the EACH Co-ordinating Committee, gave a brief history of EACH. Our Area Coordinator, Dagmar Kerr then described how she helps to keep children's rights firmly on the agenda through her involvement with various workstreams across Greater Glasgow & Clyde.

Most memorable were two young people, Nayaab Hussain and Yaser Merzouki, who were supported by Sarah Barr from the Play Service. They spoke about what the EACH Charter means to them, how important education at times of illness is, and how much they benefit from age appropriate services, like Zone 12+. Good information is important too. It helps them make decisions about their health care which are right for them. They need to 'feel in control' and want doctors and nurses to understand what they need.



Throughout the day we had interesting conversations with patients, parents and staff.

The Rights of the Child group wants to build on this successful day with targeted training events on children's healthcare rights as well as organising similar public events. The next one might well be a big party to celebrate the RoC Group's 21st birthday in 2018. Watch this space!

Scottish Government's Guidance on Healthcare Needs in School

ASCS has been closely involved in the development of this Guidance in partnership with a range of key stakeholders representing children and young people, health, education and the third sector. Prior to this ASCS was involved in the Children and Young People's Commissioner for Scotland's research into concerns around healthcare in schools and the need for a review of the 2001 Guidance.

The hope is that children, young people and families will benefit from the fresh perspective and encouragement which the reviewed Guidance will bring and ensure they are well supported in school, whatever their health need.

Politically and legislatively this is not a straight forward area, with different pieces of legislation and responsible organisations all playing a part. Our hope is that with the underpinning of the Additional Support for Learning (ASL) Act 2009, coupled with the Children and Young People (Scotland) Act 2014, children and young people will have their additional healthcare needs recognised, upheld and supported and planning through GIRFEC will bring cohesion and consistency in schools' response.

ASCS has recently responded to the consultation on the draft Guidance. We are grateful to all, including our members and Family Participation Group, for their input to our response.

Linda Alexander - New Face at ASCS



'Hard to reach' - What and who do we mean when we use this term? Do we mean the **'under-represented' who are marginalised, economically disadvantaged, and/or socially excluded? The 'invisible' that slip through the net, and may have difficulty articulating their needs; or the 'service resistant' who may be unwilling to engage,**

be suspicious of services and be disengaged from opportunities? Maybe you have a different term to capture the similarity of experiences, and the different **needs of families, children and young people who don't know about our services, that we don't reach, or who can't, for whatever reason access our services?**

I started in March in a two year development officer post of 20 hours a week to do just that, to ensure we are easier to reach and better placed to know the barriers **which prevent 'hard to reach' families, children and young people achieving their child health rights.** I have a background in health inequalities, community engagement, equality and diversity which I hope will stand me in good stead as I start this work. *l.alexander@ascscotland.org.uk*

Mental Health Awareness in Tayside



ASCS was delighted to participate in the Grove Academy Mental Health Awareness Week which took place in March. Our Tayside Area Officer Deborah Brown provided a stall and chatted to around 80 pupils who were interested in what was on offer.

A working group of senior pupils, who had accepted the role of Mental Health

Champions, and staff members organised the week long programme. They created a Mental Health Awareness Week logo and used this to promote the events and activities. The aim was to raise awareness of mental health and related illnesses, help to reduce stigma and to make young people aware of where to get help.

Things on offer included activities led by tutor teachers, helpful information displayed prominently in the school; **'Advice to Teenage Self' where teachers shared their achievements and advice to pupils;** information sessions led by a range of agencies during year group assemblies; display tables and informal drop in sessions with relevant agencies during the lunchtime break; mindfulness taster sessions and a parent information evening. Workshops were also arranged for senior pupils attending local feeder primaries to learn about mental health.

Future activities will include training from CAMHS and Mental Health First Aid Training. The organisers hope this will become an annual event.

Well done Grove Academy for promoting Mental Health Awareness to your young people and thanks for inviting us along!

Health Matters for Children and Young People in Kinship Care DVD

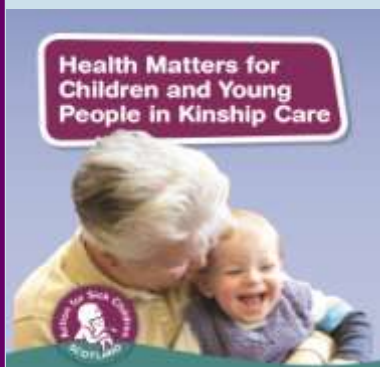
In this DVD, a group of kinship carers talk candidly about issues which concern them and include:

- challenges relating to consent and confidentiality
- **concerns around the birth parents' health**
- fear of inherited conditions and
- the ways these issues affect them and the children in their care.

There are also interviews with practitioners talking about sources of support and help.

We hope that our new DVD will be useful for kinship carers, local authorities, other agencies, healthcare professionals and all involved in kinship care.

The DVD will be available in disc format, on ASCS's



website and on websites of organisations including Mentor, Children 1st and Citizens Advice Scotland and Centre of Excellence for Looked after Children in Scotland. To obtain a copy or for further information please contact Anne Wilson at our National Office on 0131 553 6553.

ASCS is grateful to the Scottish Government which provides Children, Young People and Families Early Intervention Funding.



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