



Action for Sick Children Scotland

Newsletter

Winter 2014

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

ASCS's conference on 14 November was packed with information, emotion, confrontation, participation and pledges.

ASCS Chair Professor Richard Olver welcomed delegates and introduced Dr Kate McKay, the **Scottish Government's Senior Medical Officer**, as Chair of the morning session.

Bob Fraser, Scottish Government GIRFEC Health **Lead** and **Tam Baillie, Scotland's Commissioner for Children and Young People**, set the scene in their keynote presentations, outlining the challenges in tackling health and wellbeing inequalities and how the Children and Young People Act 2014 might help address some of these challenges.

Tam made the point that professionals should be able to express love for the children and young people they work for and that sometimes professional boundaries get in the way of humane relationships. He ended by proposing that all health boards should have a Rights of the Child Group similar to the one established in NHS Greater Glasgow & Clyde nearly 20 years ago.

After the keynote speeches, delegates debated the question Does the NHS provide person centred care for young people? Dr Una MacFadyen, Consultant Paediatrician presented the case for and Laura Wiggins, Continued on page 2

Person Centred Health Care for Children and Young People Myth or Reality?



Conference 2014 issue

Happy Birthday UNCRC!



20th November was the 25th anniversary of the UNCRC and **ASCS took part in a campaign by the Office of Scotland's Commissioner for Children and Young** to raise awareness and understanding of children's rights and the UNCRC. **SCCYP's campaign** included tweeting out every letter to spell 'Happy Birthday UNCRC' giving the opportunity to highlight key developments in children's rights in Scotland. **ASCS Chair Richard Olver was featured holding the letter C for 'Care and Compassion** - recognising the important contribution of health and social care staff involved in providing for the needs of all children.

The State of Children's Rights Report 2014 was also launched that day. It provides a non-governmental perspective on the extent to which children in Scotland are able to enjoy their rights enshrined in the UNCRC. The report was compiled by **Together following consultation with children's organisations**, including ASCS, across Scotland. Read the report at <http://www.togetherscotland.org.uk/>

Helping sick children and young people meet their healthcare needs

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Principal Physiotherapist argued against. After lively debate, talking about partnerships between agencies, patients and carers; the need for better transition pathways; the need to listen to one another and better involvement, delegates cast their vote. While policies, guidelines and strategies exist in abundance, the votes made it clear that the majority of delegates felt that the NHS had a long way to go before it could say it had implemented person centred health care for children and young people.



Delegates vote in the debate

Dr Linda Clerihew demonstrated in her presentation how children and young people fit into the Scottish Patient Safety Programme and how the training of families in infection **control and activities like 'What matters to me' give children and young people a stronger voice.**

Community Nurse Team Leader, Susan Milne talked about how to support seriously ill children and young people at home, and Caroline Johnstone, a parent, gave a very moving account about what it is like to look after her child at home and how the excellent nursing support her family receives, allows her child the right to stay at home as much as possible.

Comments at the end of the morning session demonstrated the importance of good relationships between agencies, patients and carers. Questions raised included:

- How do district nurses cope with complexities if they are not **registered children's community nurses?**
- **Would there be value in having 'generic nurses' in the community?**

One comment was that nursing staff in hospitals need to be aware of the amount of care already being given at home before

a child is admitted into a ward - **we need good 'hand-overs'**. In some health boards the community nurses visit the wards to ensure this happens.

Professor Richard Olver started the afternoon off with questions, **'Should we make sure that every new mother is given a copy of the United Nations Convention on the Rights of the Child and an EACH Charter which explains these rights in the context of healthcare of children and young people?' and 'How can we ensure better training of GPs in matters of child health?'**

Professor George Youngson, the afternoon Chair, set the scene with a presentation on age appropriate care. He talked about good models of provision including some in the United States and areas where we need to improve in this country such as safer transition to adult services.

The next session was on education and health - a civil partnership. David Watt, Senior Education Officer, Education Scotland, spoke of the entitlement to personalised support and how the soon to be published *Guidance on Education for Children and Young People unable to attend school due to ill health*, together with existing legislation and guidances, such as Curriculum for Excellence, and the Additional Support for Learning Act should support this.

Sally Cavers, Enquire Manager, then gave an overview of the kind of enquiries they receive in relation to pupils missing out on schooling because of health issues. She described the type of interventions that are helpful, like counselling support at school, peer support and effective coordination of services. Ann Burnett, Edinburgh City Council Hospital Outreach Teaching Service, talked about the development of hospital teaching services, progress and challenges.



Caroline Johnston talked about Care at Home

Three inspiring young people demonstrated just how important education was for them – especially at times of illness. Imogen Wilkinson, a 1st year university student talked about having diabetes and how different schools gave her varying support due to lack of understanding of her condition and needs. Kirsty Gardiner of the Scottish Youth Parliament and in her sixth year of school, told of the impact a hospital admission had on her higher studies. She underpinned her talk by expertly quoting different legislation and guidance that outlines the need for and



Tam Baillie



Mark Stewart



Education Panel presenters take questions from the floor, Professor George Youngson (right)

right to education. Finally, 3rd year school student and youngest speaker, Mark Stewart, gave an account of the long period he spent in hospital, how he received education during this time, what happened when he returned to school and later, when he moved on to secondary education. He finished by saying that his experience of the NHS has inspired him to want to become a doctor. Here are some key points from the discussion following this session:

- Should there be advocates for young people at schools?
- What about information sharing between health, education and peers?
- **Who owns a young person's information?**
- **How are young peoples' voices represented in the Scottish Government's Person-centred Collaborative?**

Dr Lance Sloan opened the session on **'Should every hospital have a youth strategy?'** He described the **'Fife Model'** of transition which he had developed and which is built on good partnerships between paediatric and adult agencies, social work and education. To work at its best this model needs the commitment of key lead professionals.

Morag Moore, charge nurse at the Teenagers and Young People Cancer Unit at the Western General Hospital in Edinburgh talked about the development of the Unit and how well it works in supporting young people with cancer. Feedback from delegates later highlighted the wish for all young people in hospital to have equally good facilities whatever their condition.

Dr Liza Morton, of the Somerville Foundation spoke of the importance of appropriate psychological support, promoting resilience and empowering patients. She also drew on her own experience as someone who has lived with a heart condition since birth.

The final talk came from 21 year old youth worker and service user. Kieran explored whether every hospital should have a youth strategy. He noted that **GIRFEC should not just 'get it**

right' for children, but also for families and friends. He felt that health workers could not achieve this on their own but that they should have access to youth workers with a remit to **'open doors'**. **They could act as link workers to help build** confidence and self esteem in young people through a holistic approach while recognising individual need. They could use basic pathways which should be available in all hospitals and personalise them for each young person, asking the young person what they need.

After final questions Professor Olver reminded delegates to fill in pledge forms indicating what they intend to do to **enhance the implementation of children's and young people's** rights in their area of work. At least two delegates pledged to try and form a Rights of the Child Group in their health board area. Ideas of new partnerships were voiced and the impression was that many of the delegates were inspired to take the rights agenda to their colleagues and implement it.

Professor Olver concluded by telling the audience about **ASCS's campaigning pledges. These are for:**

- A ROC (Rights of the Child) group in every Health Board
- The right of every child and young person to
 - continued education at times of illness
 - not be admitted to adult wards
 - appealing and nutritious food
- The right of families to know about the child and young **person's experience of their local GP practice.**

Professor Olver closed the meeting by thanking speakers, chairs and audience for their contribution to such an interesting, informative and inspiring day.

To listen to an audio recording of proceedings and/ or to view conference powerpoint presentations visit

<http://www.ascscotland.org.uk/default.asp?page=89>





New Education Guidance for children and young people unable to attend school due to ill health



Readers of this newsletter will know that in December 2009, ASCS launched its campaign at the Scottish Parliament - **EACH Child and Young Person's Health Matters**. One strand of the campaign was to highlight the right for children and young people to education during times of illness and to demonstrate where provision of this right was not being met.

In February 2012, the Scottish Government invited ASCS to be part of a stakeholder group convened to review the 2001 *Guidance on education of children absent from school due to ill health*. Other stakeholders included the Association of Directors of Education in Scotland, the Convention of Scottish Local **Authorities, NHS Scotland, Scotland's Commissioner for Children and Young People, the Scottish Council of Independent Schools, Education Scotland, the National Parents Forum for Scotland and Hospital and Outreach Teaching Services**. The new *Guidance on education for children and young people unable to attend school due to ill health*, is soon to be published. Please look out for information about it on our website, facebook and twitter. Here are some of the key points of the new Guidance:

- Local authorities are urged to pro-actively inform children and young people and their families about the right to education during times of illness by including this information in school handbooks.
- The need to appropriately train education and health **care workers about children and young people's right** to education and about how to help them access education is highlighted.
- The rights and needs of young people who are treated in adult hospitals are also mentioned.

ASCS is grateful to the Scottish Government which provides Third Sector Early Intervention Core and Project Funding.



- The position of children and young people who are educated in independent schools is explained.

The Guidance clearly explains the rights and duties of local authorities, parents, carers, pupils and the health service and is written with reference to relevant policies and legislation such as GIRFEC and the CYP Act 2014. It describes processes and provides links to useful information and organisations and case **studies such as: "Supporting Learners: Children too ill to attend school: A conversation, 2014"** which can be found at this link: http://www.educationscotland.gov.uk/resources/s/genericresource_tcm4827442.asp

12th European Conference of EACH: Prague, September 2014

ASCS attended the 12th European Conference of EACH (European Association for Children in Hospital) in the Czech Republic in September. ASCS Executive Committee member Gwen Garner attended as the UK representative along with representatives from 12 other European countries and Japan. The member associations of EACH aim to have the principles of the EACH Charter incorporated in health laws, regulations and guidelines in their respective countries and the activities of member associations are adapted to the needs of each particular country. The final resolution of the EACH General Assembly approved by members is as follows:



'Referring to clause 2 of the EACH Charter for Children in Hospital we are calling on all governments and providers to see to it that:

Children and young people in hospital and other health care

services shall have the right to have their parents or parent substitutes with them anytime, anywhere, any place, 24 hours a day, regardless of the age of the child or young person.

This applies whether or not the children or young people are being treated and/or examined, with or without local anaesthesia or sedation and before and after general anaesthesia. This also applies whether they are within neonatal or paediatric intensive care units, ambulance transport services, accident & emergency departments, isolation rooms, medical imaging rooms, recovery rooms, maternity services and all other health care settings in and outside of hospitals.

<http://www.each-for-sick-children.org/>

To order copies of the EACH Charter contact ASCS on 0131 553 6553.

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