



Action for Sick Children Scotland

Newsletter Autumn/Winter 2013

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

Hospital Survey Findings Revealed

Action for Sick Children Scotland's latest Parental Access and Family Facilities

Survey, the seventh since 1985, has looked at access and facilities for families who have a sick child in hospital, in order to highlight progress and determine where improvements still need to be made. Sixty-six hospital wards within the 14 Scottish Health Boards took part in the survey.



Scottish Parliament Event to announce findings of Survey: Speakers from left: Hazel Wotherspoon, Richard Olver, Zoe Dunhill, Rachael McCully, Ros Moore, Alison McInness MSP, Hannah Gray

The findings were assessed against the European Association for Children in Hospital (EACH) Charter, which sets out standards of care for children in hospital. The Scottish Government recommends that NHS Boards use the Charter, which is underpinned by the United Nations Convention on the Rights of the Child, to benchmark their child health provision.

Professor Richard Olver, ASCS Chair says: **'While the survey has found many examples of good practice, the picture is uneven within NHS Boards and across the system. On the plus side it is very encouraging to see improvements in open visiting and overnight accommodation for parents and other carers, and the increased availability of play specialists and family support workers who are key to helping children and families to cope with their hospital experience. It is disappointing**

though that some arrangements, such as the availability of a dedicated named nurse for the child or young person and allowing parents to remain with their child until they are anaesthetised, are not being implemented in many wards. It appears that some shortcomings, such as the continuing practice of admitting children under 16 to adult wards or failure to make timely educational provision for all admitted children, are due to a failure to implement and monitor Scottish Government policy and guidance. ASCS is also very concerned that children and young people are being admitted to adult-focused environments which are not geared up to meet the specific needs of children and young people, or their carers.'

The Survey highlights a number of other key issues which need to be addressed to ensure continued improvement in the provision of **children and young people's services.**

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Helping sick children and young people meet their healthcare needs



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These include information about ward facilities and procedures; parental facilities; young people aged 12-16 having the choice of being in a children's ward or adult ward; and the provision of play.

The Survey findings were presented by ASCS Executive Committee member Dr Zoe Dunhill to a capacity audience at an event hosted by Alison McInness MSP at the Scottish Parliament on 9th October. The Survey was funded by the Scottish Government Health and Social Care Directorate so ASCS was delighted to **welcome Scotland's Chief Nursing Officer Ros Moore** as one of the speakers. Ros welcomed the findings saying that while many improvements in parental facilities and access had taken place since she started her career as a paediatric nurse there is still more to be done. She talked **about the Scottish Government's aim** for person centred care to be at the heart of its 2020 vision. Ros also talked about the importance of families as partners in care and as agents in the recovery of their child.

Hazel Wotherspoon from ASCS's Family Participation Group talked about her experience as a parent of four children with disabilities, all of whom have had multiple hospital stays. She talked about the mental and emotional, physical and financial impact, **'It is draining and tiring sitting in hospital with a sick child. You are**

worrying about the child in front of you and the children at home.' She said that health professionals need to be more **holistic**, *'My child is not just the infection she presented with but is much more and should be treated as such. They also need to take into account the whole family and its dynamics.'*

Rachael McCully a Member of the Scottish Youth Parliament talked about her hospital experiences and her petition to Scottish Parliament which proposes that Scottish hospitals **have dedicated young person's wards and rooms and that staff receive adequate training to support young people's mental and emotional needs.** Rachael talked about young people as the forgotten group in the health care system and about the difficulties they face in adult wards where the next youngest person in the ward could be 50 years older. She talked about the dedicated ward for young people in University College London Hospital and Teenage Cancer Trust wards and said that facilities such as these are what every young person going through hospital is entitled to.

Hannah Gray, Chair of the Royal Hospital for Sick Children (Edinburgh) **Young People's Advisory Group** talked about having regular hospital admissions throughout her teenage years. Many of the things that made hospital bearable for Hannah were not hinged on money or facilities but on

treating her as an individual and with flexibility. She talked about being able to have a long lie and being **able to use the parents' shower room** because the one in the ward lacked privacy and was always busy. **'This meant I could go and dry my hair, be a teenage girl, put on my make up and have some privacy.'**

Chair Richard Olver concluded by announcing that our campaigning priorities will focus on abolishing the practice of admitting young people under 16 years to adult wards and providing appropriate ward facilities for them; the right of all children to have a parent or other carer in the anaesthetic room before surgery and afterwards in the recovery room; the right of children and young people to nutritious food in hospital.



To read the report <http://www.ascscotland.org.uk/default.asp?page=19>

Memorable Parent Perspectives

In June ASCS's Dagmar Kerr and Anne Wilson delivered what was described as 'memorable parent perspectives' at the **Royal College of Nursing's 2nd PNAE Congress** on Paediatric Nursing in Glasgow. The new RCN Best Practice Guidelines 2013 – *Supporting parents and healthcare professionals when breaking bad news* were launched at this event. Dagmar and Anne talked about the need for news to be given in a private setting and for health professionals to contact parents/carers a few days later to check that they have remembered the information provided and to ask if they have any other questions. They also said how important it was for health professionals to refer to the child as a person not a medical case, and to look at the wider picture from the whole family perspective.

The Managed Clinical Network for Children with Exceptional healthcare Needs (CEN) Conference in September focused on *Care Closer to Home*. **ASCS's Anne Wilson spoke at a session** dedicated to the memory of children with complex needs whose lives have ended early as a result of their health condition. Delegates heard about the **importance of celebrating not only the baby's birth but their whole life's journey, and how much families** appreciate the empathy, care and compassion shown by professionals working with them. The depth of loss felt not only by the family but also by the practitioners looking after them was also acknowledged. Other **presentations included Children's Hospice Association (CHAS) outreach support; Self Directed Support; Guardianship; Incapacity Law and Medical Treatment; and Transition.**



Person Centred Care for Children and Young People in Scotland

The Scottish Government has committed its health service to ensuring that every individual receives person centred care and a policy for Person Centredness was published in 2012. ASCS campaigns for the needs and rights of children and young people who are sick and particularly for those whose voice may not readily be heard in expressing their needs and who may not fully understand or claim their rights. The Scottish Government strategy document on Person Centredness does not specify how the care of children and young people will experience this approach to health care. ASCS therefore wrote to health boards to ask how they planned to implement person centred care for their youngest citizens. Eleven regional and two special health boards replied.

NES (NHS Education for Scotland) has clearly defined what is meant by person centred care and has developed resources to assist health professionals to deliver care in a person centred way. NES responded to our enquiry with enthusiasm and described how young people are involved **in the work of their Children and Young People's team** as participants in developing projects and advising the team.

Activity around the Person Centredness agenda varied among health boards that replied. Some were at the start of considering implications for their service planning and others were examining where their existing activities were relevant to this new requirement. Those health boards that have embraced the concept of person centredness have well established groups or projects that provide feedback on the experience and opinions of users of health services.

Examples of good practice in soliciting the views of children, young people and families include:

- A youth project where 12 young people led surveys of the health knowledge and experience of hundreds of their peers. The information gathered is now being used to identify need for change and improvement with clear aims and measurable outcomes. The priorities given by the young people to mental and sexual health services, access to information and advice offer a clear message to service planners on elements of person centred health needs that are currently not effectively met.
- Addressing the challenge of a wide spread of communities and health care facilities and developing a **strategy for children and young people's health care that incorporates patients and their families in public involvement activities**, with both long and short term aims clearly defined and progress measured. Ongoing success in delivering services close to the home community is sustained through its relevance to person centred care.

- Making efforts to ensure that families of children with additional needs are included in planning and assessment of services. A local respite centre for children with complex needs has held an open day to **demonstrate its work and to gather families' views** on how they would wish the service to develop.
- The setting up of a multi-disciplinary Rights of the Child Group and the policies and teaching that the Group provides; a Family Support team; a group to ensure written material is readable and a Youth Voices group. These are well established in at least one region and already provide a strategic person centred focus for staff.

With all this good work underway and future plans being developed we hope children and young people will be **well provided for in Scotland's NHS. However, it is** important to note that, although some activities described by respondents involve relatively accessible groups, those most in need may not have their voices heard. We hope there will be specific guidance on how the needs and wishes of young children can and should be solicited within any health service they access.

NHS Scotland has endorsed the EACH Charter for children in hospital yet our 2012-13 Family Facilities Survey shows that many children are admitted to adult wards. While children need to have a parent or carer with them at times of stress or fear, many carers are denied access as their child recovers from anaesthesia.

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ASCS has updated two useful Guides for parents and carers with funding from the Yorkshire Building Society. Helping Children Cope with Pain contains sections on helping a child cope without drugs; pain control with drugs; questions young patients may ask.



Helping Children Cope with Needles shows how parents and carers can help their child to cope; how to prepare the child; and the use of techniques such as distraction and relaxation and supervised play. Both Guides signpost to helpful organisations and information. They can be downloaded from <http://www.ascscotland.org.uk/default.asp?page=20>
Single copies are free. For bulk orders contact ASCS.



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Parents or carers who feel they cannot leave their child's bedside have little opportunity to obtain the food they need while in hospital when adequate nutrition at realistic cost could help them cope and reduce their anxiety over finances. Young children and their parents or carers who are bewildered by illness, the hospital environment, complex and distressing investigations and treatments can be helped by involving a Health Play Specialist with knowledge and **skills to understand the child's developmental needs and to explain and prepare the child to be able to cope.**

With this in mind, ASCS proposes that NHS Scotland should issue guidance that, to comply with a person centred health service:

- a health board must demonstrate its implementation of the EACH Charter
- every health facility has a current policy for the care of children and young people that recognises their rights as children and complies with the UNCRC.

Furthermore, person centredness should include:

- **a means to ensure that the child's needs and wishes are considered in planning care** - every child has a right to information and explanation that is appropriate for age and ability
- the sharing of good practice among health boards and health services for children throughout Scotland so that all may benefit from the learning of others and improvement can apply to all promptly and effectively
- **participation in children and young people's service** planning and development should include all age groups with the facilitation required to ensure that younger age groups and those with learning or other disabilities have a voice
- integration with other services in line with GIRFEC principles is considered when planning and delivering health service to children and young people so that the **individual's right to education, a safe home and a community that welcomes its young members**
- involvement of parents and carers of children and young people, who have responsibilities under the Children Act Scotland when participation and feedback are sought in relation to health services, but not as a substitute for children themselves
- inclusion of person centredness in each and all services in any strategy and plans for implementation of quality improvements, including transition to adult services. Many children and young people with disabilities or chronic disease receive health and social care from many different agencies within the NHS.

Hospital Passport Coping Kit

ASCS attended the launch of the Hospital Passport Coping Kit in June, 2013 at the Royal Hospital for Sick Children, Glasgow. Developed in the Clinical Psychology service and based on a similar idea in the Netherlands, this innovative resource is designed to help reduce hospital related distress in children of primary school age. After a successful pilot in Yorkhill, the passport has been rolled out for use in hospitals across Scotland over the summer.



Gillian Saunders, Health Play Specialist on Ward 3 at the Royal Hospital for Sick Children (Edinburgh), has been working with staff, families and children to introduce the Passport to patients with anxiety about hospital visits, especially those who are frequent attenders. Gillian told us that initial feedback has been very good and families welcome the opportunity to use the Passport between hospital visits. Most importantly, it gives children an opportunity to discuss choices in their treatment and hospital stay and to have a voice in decisions about their care.

If you would like a Hospital Passport Coping Kit for your child, ask your health play specialist, psychologist, nurse specialist or paediatrician. All staff where the Passport is used are trained and aware; they are finding it to be a good conversation-starter and a great communication tool. For more information on the Kit click: [http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/psychology-\(paediatric\).aspx](http://www.knowledge.scot.nhs.uk/child-services/communities-of-practice/psychology-(paediatric).aspx)

ASCS Project News in Brief

Funding from BIG's Third Sector Early Intervention Fund has enabled our **Special Smiles Dental Project** to extend into new local authority areas. The project is currently being offered to 24 ASL schools in Lanarkshire and is already working in 13 schools where it has been well received.

The **Children in and Leaving Care Health Project** continues to deliver healthcare workshops to Foster and Kinship carers. It is currently collecting frequently asked questions to form part of a learning resource toolkit designed to support the health needs of looked after children and young people.

The **West Lothian Child Self Management pilot project** team has now developed themed activities and information to pilot with families and children arising from feedback from NHS and Education professionals and parents/carers who support children with long term health conditions. The Project will now deliver pilot workshop sessions for children with a long term condition in January/February. Contact Project Officer Amy Joss on 07712542849 amy.joss@virginmedia.com for information.

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