



Action for Sick Children Scotland

Newsletter

Spring 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

Transition to Adult Healthcare a Priority Issue

For a young person, the transition from paediatric services to adult services can pose problems, worries, frustration, anxiety and all too often a reduction in services.

This can affect the young person's wellbeing in many ways. Their relationship with parents and professionals as well as their physical and mental health may suffer. Many organisations, both statutory and voluntary, have recognised this for years. Many publications, recommendations and research around transition exist.

Why is it then that young adults and their families still feel that their needs are often not met when they move into adult services?

The Scottish Parliament Health and Sport Committee invited a number of experts to give written and oral evidence on the question of transition between adult and paediatric services in the NHS. ASCS was one of the organisations invited to the Committee meeting on 4 March and Dagmar Kerr attended on our behalf. The broad consensus at the meeting was that the principles of good transition are well known within paediatric services, for example the need for early planning; good communication; a key worker; a person centred approach; self management support; adherence to GIRFEC



Young people can struggle when they move to adult services

principles. There was also agreement that some excellent models of good practice exist. The principles of good transition are not however always applied in adult services. The reasons are complex. Some conditions are not well known to adult physicians, such as conditions which in the past would have resulted in the death of the child at an early age, but where improvements in survival rates are now being made. There is no generic Consultant for Adolescents role in adult services to take over from a paediatrician. Young people who have seen one consultant in paediatrics may now have to see multiple specialists, for example someone with cerebral palsy may have to see different specialists for their knees, spine and feet, and these specialists may be located at different hospitals. The young **person's family who supported them through childhood** may no longer be taken into account when appointments are made or treatments discussed. Paediatric services will have been able to provide a more holistic approach to care than adult services where the adult environment in many instances may not be age appropriate.

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Action for Sick Children Scotland Conference

Friday 14th November 2014

Royal College of Physicians, 9 Queen Street, Edinburgh

Minister for Public Health Michael Matheson MSP and Scotland's Commissioner for Children and Young People Tam Baillie are two of the speakers contributing to this event which will focus on the question, 'Is there person-centred care for children and young people?'

Further details and booking information will be available soon

Helping sick children and young people meet their healthcare needs

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Person centred care is promoted as something that will greatly benefit all patients and the approach is generic. ASCS fully supports the principles of person centred care and is working to ensure that significant focus and energy is invested in age appropriate care for adolescents and young adults. There have been many conferences about transition over the years and much research into the need for better transition care, driven mainly by people from the paediatric side. ASCS now feels that a more focussed effort needs to be made to engage with adult professionals if we are to create environments and opportunities to support young people at a very vulnerable time. Each Health Board should have a lead person to produce and implement a youth strategy which would include a transition policy. This post would of course need to have dedicated time and resources allocated and be of sufficient seniority to be able to implement policies. The lead person would work towards a set of transition standards which should be set by the Scottish Government. Health boards should be assessed against these standards and would be expected to monitor and evidence their activities.

Another important message from the evidence session is that Health needs to work in close partnership with Social Work, Education and the Voluntary Sector. GIRFEC

principles should be applied in the 'adult world'. We should aim to get it right for everyone. Many interesting points were raised at the Health and Sport Committee; various examples of good practice highlighted and many suggestions on how to achieve better transition were made.

Visit <http://www.scottish.parliament.uk/parliamentarybusiness/28862.aspx?r=8983&mode=pdf> for the meeting transcript.

Duncan McNeil, MSP, Convener to the Health and Sport Committee has now written to Alex Neil, Cabinet Secretary for Health and Wellbeing, asking for his views and an update on progress on transition since the publication of *Better Health, Better Care: Hospital Services for Young People in Scotland* in 2009. A decision was also taken at the meeting to ask the territorial health boards, to provide details of what arrangements they have in place to support the transitions process. All of this is positive and constructive and ASCS hopes that as a result, the issue of transition from paediatric to adult services might enjoy an increased priority.

The Royal Hospital For Sick Teddies

The Royal Hospital For Sick Teddies was formally launched **at Yorkhill Children's Hospital** on 6 February this year.



The Play Service identified a room that could be decorated into a Teddy Hospital environment that was both child friendly and clinically non-threatening. The room was divided into the different departments children might encounter when coming into hospital. There is a reception desk, ward area, anaesthetic room and a diagnostic department with a working teddy sized CT scanner and wall murals of X-Ray equipment.

Children are either referred or can drop in to a session based on preparation or distraction. On arrival

the child's own teddy (or supplied to keep teddy) will go through registration which involves asking what Teddy is coming in for today.

The Hospital is staffed by a specialist teddy doctor and teddy nurse (Play Specialists and Play Assistants) who examine the teddies using real medical equipment – and then encourage the children to do the same. For inpatient children, the teddy doctor and teddy nurse will usually follow up any visit during their weekly ward round when teddy will be re-examined.

In addition to the Teddy Clinics, therapeutic play sessions take place weekly and children are able to use the equipment and play the role of doctor or nurse. Teddies and dolls with nasal gastric tubes, stoma bags, plasters and splints are placed around the room normalising a variety of procedures and conditions. Children who are new to the hospital environment can be prepared for admission by visiting the Teddy Hospital and having their questions answered in a friendly place.

Post-procedurally, play in the Teddy Hospital gives an opportunity to observe children acting out any previous experiences. Parents, worried about how their child is coping with hospitalisation can come for advice, or can be referred on to the play service for therapeutic work needed to help the child cope in the future.

The new Teddy Hospital highlights the role of the Play Services Team. It has proved to be a great therapeutic tool which the team are continuing to develop to ensure all children have a positive hospital experience.



Information provided by Coral Brady, NHS Greater Glasgow & Clyde



ASCS was invited to present at the 10th annual conference of Eurochild: *Building an inclusive Europe – the contribution of children’s participation*, held last November in Milan, Italy. The Conference centred on the United Nations Convention Rights of the Child (UNCRC) Article 12: Respect for the views of the child.

Amy Joss presented on our Stay Well Self Management Project which worked in NHS Lanarkshire between 2009 and 2012. Stay Well helped young people with a range of long term illnesses to cope better by taking part in a self management programme. We developed and delivered the programme in collaboration with over 50 young people with long term conditions. Their feedback showed increases in self confidence, communication, social inclusion and in their understanding of how to live more healthily with a long term condition. Some participants became peer supporters through a bespoke training session and produced a toolkit DVD and information for young people with long term conditions and for professionals who work with them.

At its heart, the project promoted the healthcare rights of children and young people as set out in the European Association for the Welfare of Children in Hospital (EACH) Charter Article 5

(Children and Parents have the right to informed participation in all decisions involving their health care), underpinned by UNCRC Article 12.

We thank Eurochild for the opportunity to highlight our work and ask all our colleagues working with sick children and young people in Scotland to challenge their own **attitudes to children’s views.**

What are you doing in your area to facilitate and support real opportunities for the participation of children and young people in their healthcare?

What have you done to make participation beneficial and effective in developing your service?

To read about the Stay Well project, visit: <http://www.ascscotland.org.uk/default.asp?page=56>
For information about the EACH Charter, Eurochild and the conference: <http://www.each-for-sick-children.org/each-charter.html>
<http://www.eurochild.org/>



ASCS Executive Committee member Frances Barbour is raising funds for ASCS through a sponsored walk of the Great Wall of China. To read more or to sponsor Frances go to www.virginmoneygiving.com/team/barbour

Parents and Teachers Report Reduced Child Dental Anxiety

The Special Smiles Dental Project is currently working in 24 additional support for learning schools in Lanarkshire, where it has been well received by teachers, children and parents. Petersburn School in Airdrie had this to say:

‘Special Smiles is a fabulous project. Our school has a Language and Communication Support Centre and some of our children find brushing their teeth and visiting the dentist very challenging. Having the resources given to us by Special Smiles has reduced the children’s anxieties about visits to the dentist and brushing their teeth. The children really enjoy role playing being at the dentist, playing with the games and toys and watching the DVDs.

The training for all our staff was great as we spent quality time learning about the need for such projects and we were able to investigate all the resources that were being made available to us. We were also able to discuss ways in which we would use the pack.



Although we have not long had the resources, our nursery class parents have already started using the home packs. Like us, our parents think this is a fabulous initiative and think that learning through role-play is extremely beneficial to children who have language and communication issues. A few parents have reported that their child is becoming less stressed about brushing their teeth and trips to the dentist.

We would highly recommend this project to other schools that cater for children with ASD.’

Influencing Child Health Policy Makers and Providers



Participation Seminar at RCPCH office

A recent aspect of ASCS's participation work was to hold an event for parents and carers so that they could learn more about influencing policy makers and providers. We were therefore delighted to team up with the Royal College of Paediatrics and Child Health (RCPCH) and its Parent and Carers Group in a joint Participation seminar on 19 March at the RCPCH office in Edinburgh. The RCPCH has recently recruited more than 20 voluntary organisations with an interest in child health as a reference group to inform its work in Scotland.

Sixteen people attended the session and around half were parents or carers. Participants had the opportunity to hear about the work of the College, the activity of its Youth Advisory Panel and the recently formed Parent and Carers' Group. After a working lunch, Anne Wilson, Action for Sick Children Scotland's Development Officer, conducted a session looking at the theory and principles of Participation. This gave delegates an opportunity to define what is meant by Participation, discuss the benefits, explore the challenges and share examples of best practice. One group defined participation as:

Engaging in a meaningful way with feedback being used to improve things: Asking, listening and doing

Perhaps the most valuable part of the day was meeting others and hearing firsthand about their experiences.

Action for Sick Children Scotland is now on Facebook



Find us on FACEBOOK



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



Learning Resource for Carers

Almost every ASCS healthcare workshop session for Foster or Kinship Carers throws up another burning issue or question, from *How do I get a LAC nurse?* to *Should I wear gloves if I am not sure of the health status of the child in my care?* Other questions have focused on hereditary worries; who gives consent; asking for a second opinion; **finding out about the child's medical history and records.**

ASCs is producing a learning resource to include frequently asked questions, a podcast interview with a Foster Carer and a description of the workshop content for distribution across agencies and networks such as CELCIS and The Fostering Network (TFN).

Areas of activity for the financial year 2014/15 include Perth and Kinross, Dumfries and Galloway and Glasgow.

Managing Me!

West Lothian Child Self Management Pilot
Our 14 month Pilot Project was completed in March, 2014. It established links and consulted with children, statutory groups, parents/carers groups and the voluntary sector in West Lothian to develop and pilot a self management program for children (8-12 years) living with a long term health condition. The project team developed and tested age-appropriate activities with children and information for parents and carers. These were found to be helpful and well-received. Three pilot sessions, jointly held with the children and their parents, were delivered at Bathgate Partnership Centre. Parents also had separate sessions and were provided with information and support relevant to their caring role.



The group enjoyed a final session family outing to The Five Sisters Zoo at West Calder to wrap up the pilot. Highlights included feeding the lemurs, handling some of the more interesting animal residents and learning about the work of zoo in rescuing animals such as circus bears, to give them a happier life.

Many thanks to the Project Funders:

BBC Children in Need, Moffat Trust, Widower's Trust, Robertson's Trust, and Miss Agnes H Hunter's Trust.