



Action for Sick Children (Scotland)

Newsletter Autumn 2011

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 Scottish 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

Progress in Education for Sick Children Campaign

Our campaign to ensure equal access to education for all children and young people during times of illness is making steady progress. Earlier this year the Scottish Parliament Petitions Committee considered our petition in which we ask the Scottish Government to demonstrate how local authorities are complying with the duties imposed by Education legislation and Guidance. The Government replied that it is for local authorities to show that they meet these duties. But as we reported in our Spring Newsletter accessing education at times of illness is a problem for many families. We were recently contacted by a desperately worried parent whose 13 year old son has not received education for nine months while he has been absent from school due to ill health. We need things to change so that this no longer happens. The Guidance on the **'Education of Children Absent from School**



through ill-health' is **10 years old and in February** the Petitions Committee agreed to seek a response from the Scottish Government to our request that the Guidance be reviewed. In August we met with Scottish Government officials and are optimistic that the Guidance will be reviewed and that we and other stakeholders will be part of this process. The latest news is that the Petitions Committee decided on 20 September to continue the petition and to ask further questions of the Scottish Government about the review and a request that a sample of local authorities report on what they are doing to ensure that families know what education their child can expect when absent from school due to ill health. Read our petition on: <http://www.scottish.parliament.uk/business/petitions/docs/PE1381.htm>

Special Boost for Dental Project



Children at Kelbourne Park School in Glasgow learn through playing with Special Smiles Dental Resources

Inspiring Scotland has invited ASC(S) to join the initial portfolio of the Early Years Early Action Fund!

This new Fund run by Inspiring Scotland in partnership with the Scottish Government, aims to improve outcomes for vulnerable children, families and communities in Scotland. This funding success will enable our Special Smiles Dental Project to extend its work to more special needs schools in

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Helping sick children and young people meet their healthcare needs



ASC(S) Welcomes New Chair Professor Richard Olver



At our recent AGM, ASC(S) thanked Gwen Garner who stepped down as Chair after a period of six years. Over the last 29

years Gwen has been involved in ASC(S) as a volunteer, committee member, Strathclyde Fieldworker, EACH representative and as Chair. We are delighted that she will continue to support us over the next year in an advisory capacity. ASC(S) now welcomes Professor Richard Olver as its new Chair. Richard has been an Executive Member since 2008 and has brought a wealth of paediatric experience to our organisation. From 1985 -2007 he was the James Mackenzie Professor of Child Health at the University of Dundee and during 2001-06 he worked on the **establishment of Tayside Children's**

Hospital. In 2007 Richard became Emeritus Professor of Child Health at the University. His clinical interests are general paediatrics, cystic fibrosis and arthritis and his research interests are the adaption of the lungs at the start of breathing, lung development and cystic fibrosis. He discovered the system of pumps and channels that clear the lungs of fluid at birth and then keep the lung interior dry but the lung lining moist. In 2000 he co-authored an undergraduate textbook '**Core Paediatrics and Child Health**' published by Churchill Livingstone. During his career he has played a role on various bodies including as a founding fellow of the RCPCH and a former President of the Scottish Paediatric Society.

Richard was born in Ayr and lives in St Andrews with his wife Susan. They have four children and five grandchildren – the youngest only a few weeks old. Richard is a hands-on grandfather and with Susan, enjoys looking after his grandchildren on a regular basis.

Would you like to have your voice heard in relation to child healthcare services in Scotland?

Action for Sick Children (Scotland) has been described as *the bridge* between user and provider, enabling **families' views to be heard by key** policy and decision makers in order to shape planning and delivery of health services.

If you would like an opportunity to have your voice heard, please complete our Participation Questionnaire. Click <http://www.ascscotland.org.uk/default.asp?page=51> to download or contact a.wilson@ascscotland.org.uk to be sent a copy by email or call 0131553 6553 if you would like us to post a copy.

Scottish Patient Safety Paediatric Programme

The Scottish Patient Safety Paediatric Programme launched in June 2010; it aims to support paediatric staff in Scotland to improve the quality, reliability and outcomes of paediatric healthcare. This is part of the wider Scottish Patient Safety Programme, coordinated by Healthcare Improvement Scotland (HIS).

In 2009, Action for Sick Children (Scotland) (ASC(S)) was approached to provide voluntary sector representation on the Steering Group; this group was responsible for overseeing the development of the paediatric programme. Amy Joss, Project Officer represented ASC(S) at the Steering Group and now sits on the Professional Advisory Group. In addition, two public partners from the patient focus public involvement unit of HIS support the programme.

The key aim of the programme is to reduce adverse events by 30% by June 2013. Another is to reliably implement early

warning systems to detect changes that might lead to deterioration. In addition, the programme has workstreams and aims specifically linked to improving outcomes in surgery, critical care, paediatric wards and the management of medicines.

Improving and promoting open communication is a key element throughout the programme. Daily goals involve children, young people and parents/carers taking part in planning care alongside paediatric ward staff. ASC(S) would be interested to hear your views if you or your child/young person has been asked to take part in daily goal -setting.

If you would like to know more about SPSPP, please visit the website:

<http://www.patientsafetyalliance.scot.nhs.uk>

or contact: Julie Adams, National Facilitator Paediatrics, julie.adams5@nhs.net



Supporting First Time Teenage Parents

We talk with the Family Nurse Partnership



The Family Nurse Partnership programme (FNP) is a preventive programme for first time mothers aged 19 and under. It offers intensive and structured home visiting, from early pregnancy until the child is two. FNP has three aims: to improve pregnancy outcomes; child **health and development; and parents' economic self-sufficiency**. It is a licensed programme, developed in the USA at the University of Colorado, by Professor David Olds. Over 30 years research has shown significant benefits for vulnerable young families in the short, medium and long term. The programme was implemented in 2007 in England and has since been introduced in NHS Lothian and has recently been launched in NHS Tayside.

Gail Trotter is the National FNP Implementation Lead for Scottish Government and was interviewed by Area Coordinator, Fiona Bartley-Jones who has worked with young and vulnerable families as an integral part of her remit since 2008.

How will the success or failure of the Tayside FNP be measured?

FNP is a licensed programme and there is requirement that we are to adhere to the fidelity requirements of the programme set by Professor Olds in University of Colorado. There is an intensive and extensive system of data collection and monitoring that ensures that we capture and record the qualitative data but in **addition we will be taking account of the clients' stories too**. The overall benefits for clients receiving the FNP programme are often not evident for a long time after the programme is completed. We are therefore fortunate to have the opportunity for FNP clients in NHS Lothian to opt into the longitudinal study, Growing Up in Scotland (GUS) Programme. The Department of Health is currently undertaking a national Randomised Control Trial of FNP in England, the results of which will be of great interest to us here in Scotland.

What will decide the continuation of the Programme beyond its contracted period?

There is a manifesto pledge to roll FNP out across Scotland and we are in the early days of looking at progressing this extension of FNP nationally. NHS Tayside will be looking at the sustainability of FNP in the future and how this programme augments current support for young families in Scotland.

Given that the programme is very structured and there is a strict requirement to adhere to the principles and format, is there scope for 'tweaking' to suit the individual needs of each region and is there scope for development?

FNP is a manualised programme based on 30 years of robust evidence, so any 'tweaking' must not compromise the fidelity requirements. We are able to 'contextualise' FNP to fit in with local arrangements. For example the referral pathway of pregnant teenagers into the programme may differ from area to area.

How does such a structured programme manage to suit the needs of all types of geography? For example, it is hard to see how something can fit the needs of an inner city area such as say, Manchester, but also fit the needs of a rural town such as Pitlochry?

We are fortunate to be able to learn lots from our FNP colleagues in England who have three years more experience ahead of us here in Scotland! Our own Family Nurses and Supervisors are part of a national learning network where such challenges can be addressed and experiences shared. We have learned particularly from Cumbrian and Cornish FNP sites that have similar geographical challenges in FNP implementation. We are keen to learn from NHS Tayside about how best to deliver FNP in a rural Scottish context.

The Programme has a proven track record in the USA of impacting and reducing instances of child maltreatment, smoking during pregnancy and drug abuse. Furthermore it also improves outcomes for child health and well being. It also improves the **mothers' self efficacy and economic self-sufficiency** and reduces repeat pregnancy rates. All of these things are as relevant in the rural context as they are in the urban context, particularly where there is economic deprivation and there are young parents living in poverty in rural areas as well as in inner-city areas.

I am concerned that a girl becoming pregnant at 14 will still need quite high levels of support at 16 when the programme will cease being there for her. How will she be expected to make the transition at 16 from having intensive support from the FNP, to having no support?

The USA research findings show that the mother is likely to be stronger than she would have been without the support of the programme, so she will be better placed to cope. The evidence we have is that the best benefits for children and families are before the child reaches their second birthday. But it is important to understand that there will be a transition period **and that she won't simply be abandoned as the Public Health Nurse/Health Visitor (PHN/HV) becomes the key support for the family alongside any other agencies who may also already be on board in supporting the family**. The programme works on **'agenda matching with the client', working towards the goals or 'heart's desire' of the young parents**. This is jointly reviewed before the programme ends and a handover to PHN/HV service will ensure that future support for the family recognises the achievements reached previously and looks at how best to support this family in the future.

Is there anything you would like to add?

With a contribution from NHS Tayside, The Scottish Government has funded the NHS Tayside FNP £3.2m to deliver the programme to 295 first time teenage parents. Commitment to supporting young families in the Early Years is a key agenda for this Government. The planned roll out of FNP demonstrates in real terms a desire to test evidence based models in supporting children to have the best start possible.

EACH Child and Young Person's Health Matters

Who looks after me when I am ill?



Foster Carer Training

Following a successful series of workshops delivered in 2010-2011, we are now extending this training to other areas in Lothian and Forth Valley to include carers looking after children/young people with a disability, long term conditions, complex or exceptional healthcare needs. This will be of special interest to disability/respite care teams as, in addition to the core training sessions, encompassing

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Glasgow. Through the use of our specially developed dental play resources we can help improve the overall oral health of children with complex and additional support needs, help reduce dental anxiety and support school staff **and parents/carers to look after their children's teeth.**

Organisations will be funded for one year although the hope is that funding will continue beyond that period. We are absolutely delighted to have been successful in our application and look forward to becoming part of the Inspiring Scotland Portfolio. Most of all we are delighted to be able to continue to make a difference for this vulnerable group of children.



Thanks to Standard Life plc for printing this Newsletter

access to services and health care rights for children and young people, we have added:

- Dental Play Specialty as exemplified in our Special Smiles Dental Project (for children with additional health support needs)
- Consent and confidentiality issues
- Communication needs for children with complex healthcare needs
- The emotional impact of tube feeding
- **Carers' physical and emotional wellbeing.**

During 2011-2012, we aim to develop and deliver a programme for carers based on specific needs to enable them to become more confident and resilient in their caring roles.

Seasons for Growth (SFG)

After successful evaluation of the SFG programmes, the Project Officer has become an accredited SFG companion and following completion of the training as companion for the Adult SFG programme, hopes to use this to assist carers to develop strategies to cope with the physical and emotional impact on themselves and their families of caring for their child.

For more information contact Anne Wilson on 0131 553 6553 or a.wilson@ascscotland.org.uk

Stay Well Lanarkshire is our generic self management programme for young people in Lanarkshire, aged 11-18, living with long term health conditions.

Since October 2010, the project has completed five programmes. Four were community based and one was school based, with guidance staff referring young people into the programme. Young people have really enjoyed the workshops and say that these have increased their confidence and communication skills. They also enjoy the fun activities which ends each workshop session. One young person commented, **"I liked it all and it was good how you could get someone to come in and do stuff like drums."**

The current programme began on 3 September 2011 and continues on 1 October and 5 November. A final workshop programme will take place after the New Year and the project is taking referrals now. The project is also piloting one hour awareness-raising workshops for community youth groups in North Lanarkshire in the next few months.

Young people, parents/carers or interested professionals in Lanarkshire can find out more or make a referral to the project by contacting Amy Joss by text/phone 07935 305930 or by email amy.joss@nhs.net More information on the project is also available on <http://www.ascscotland.org.uk/default.asp?page=56>