



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 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

Action for Sick Children (Scotland)

Newsletter Spring 2009

SELF MANAGEMENT PROJECT FOR YOUNG PEOPLE LAUNCHED



Living with a long term health condition can be challenging for a young person. These issues can include remembering medication routines and medical appointments, interruption to schooling and coping with the effects of illness amongst others. In addition to all that, young people have to cope with the physical and emotional changes of adolescence. They are moving from primary to secondary school; worrying about relationships; getting on with their parents or carers; while of course wanting to do all the same things as their mates. These changes and challenges can seem insurmountable and many young people diagnosed with long term health conditions can experience a mix of emotions ranging from loss and grief - *'I'm not the same as my pals'* - to anxiety about the future, - *'Will this affect me getting to university?'*

Stay Well Lanarkshire is our innovative new three year project which aims to empower young people to live well and healthily and to manage their lives during this period of change, so that their health condition is only a part of and not the main factor in their life. Project Officer Karen Martin and trained volunteers will work with groups of young people between the ages of 11 and 18 who have a chronic condition or illness. Our project is not disease specific and the self management programme will be suitable for and open to any young person whatever their chronic condition. It aims to promote resilience, coping resources and to develop life skills in young people. Specifically we will look at developing skills in communication, decision making and problem solving.

All self management sessions will be held in community venues easily accessible by public transport, and will take place over an eight week period. Each session will also include a fun activity chosen by participants. At the end of the programme we hope that young people will go on and contribute to further self management/peer support activities and there will be an opportunity to meet again six months after the initial course to catch up with each other. There will also be a chance for participants to take part in our awareness raising work with schools and fellow peers. This will inform people of their

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New Community Play Specialist Project Pilot in NHS Forth Valley



We are delighted to announce our exciting new project in NHS Forth Valley.

This two year pilot Community Play Specialist project is believed to be the only one of its kind in Scotland.

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VISIT OUR NEW WEBSITE

on www.ascscotland.org.uk to read more about our projects, how we can help, how to get involved and to download our leaflets and publications.

Helping sick children and young people meet their healthcare needs,
in partnership with parents, carers and professionals

Fun is a word that keeps cropping up!

Special Smiles Dental Project



Trainee dentist at Robert Douglas Memorial School, Scone!

The Special Smiles Dental Project has now been rolled out to 28 schools or centres across Tayside. Schools taking part in Perth & Kinross, Dundee and Angus include specialist nursery, primary and secondary schools, a sensory service and units in mainstream schools with specialist provision for pupils with additional support needs. One playpack has also been placed with the Consultant in Paediatric Dentistry at the Dundee Dental Hospital and School, for use when treating children with additional support needs who do not attend any of the schools participating in the project.

Project Officer Gill Sutherland, is now visiting schools on a regular basis to hear about progress and to observe children using the play resources. Our two inflatable dentist's chairs are being loaned to various schools in rotation when they are making a particular focus on the resources. We've now purchased a camcorder for recording how the play resources are being used in particular settings and we've issued disposable cameras to some schools.

It is only when you see the resources in action that a project like Special Smiles comes to life. Now that the playboxes and playpacks are being used in schools, we are starting to get some very positive feedback. Robert Douglas Memorial School in Scone has a base supporting a number of children with Autistic Spectrum Disorder. One class particularly enjoyed dressing up as dentists and administering treatment using the Play-Doh Dr Drill and Fill playset. Great fun! 'Fun' is a word that keeps cropping up and it's wonderful to think that while children and adults are having fun, they are also developing a better understanding of how to care for their teeth and becoming less anxious about attending the dentist. Hopefully these are skills that the children will carry with

them into adulthood.

Schools have been coming up with fantastic ideas on how to use the resources and these ideas are being shared with other schools via a monthly update. A flyer advertising the playpack is currently being distributed to all the schools for children to take home. We hope this will encourage more parents to borrow the pack to use with their child at home, reinforcing the learning already taking place in school.

Special Smiles is attracting a lot of interest and the Project team, Catherine Nelson and Gill Sutherland, have been busy speaking about the project and demonstrating the resources to various groups across Scotland. Community Dental Officers, Community Nurses, Oral Health Officers, Paediatric Dentistry Consultants and Play Specialists are amongst those who have expressed interest in the project, recognising its value and potential usefulness in a variety of settings, thus affirming both the need and the demand for a project such as Special Smiles.

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Community Play Specialist Pilot Project

The aim of the project is to work with children, young people and families who live in the health board area and need Play Specialist input to support their care before admission to or after returning home from **specialist or tertiary** health centres. The project funded by Action for Sick Children (Scotland) is welcomed by the Community Outreach Nursing Service based at Stirling Royal Infirmary and the project will receive referrals from the hospital. Play support will include:



Amy Joss

- Diversion/distraction
- Play preparation for upcoming hospital stay or procedures
- Post-procedure or post-hospitalisation play
- Short-term loan of playbag - medical-theme toys, books and/or equipment
- Provision of support such as information on family facilities in tertiary centres, patient/parent rights, community agencies.

Amy Joss, a registered Hospital Play Specialist, is our Project Community Play Specialist working 15 hours weekly. Information from: Amy Joss, Community Play Specialist, Community Outreach Nursing Service, Stirling Royal Infirmary, Stirling FK8 2AU

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Their Health Matters: Meeting the Health Needs and Rights of Children and Young People in and Leaving Care Project

In our Spring 2008 newsletter, we talked about the Scottish Government's report **We can and must do better** (2007) which sets out the way forward in relation to looked after children and young people. Since then we have seen their publication of **These are our bairns** (2008) which gives guidance to community planning partnerships on being a good corporate parent. This also includes recommendations on health service provision by which authorities and health boards will collaborate to identify these children and young people in their area, ensure they receive assessments and help them to access the health services they need, including GP and dental registrations.

We were delighted to take part last Autumn in the **Who Cares? Scotland** conference helping them celebrate 30 years of working with young people in care by conducting a workshop on their health care needs and rights. It was attended by a range of professionals all involved in caring for looked after and accommodated children and young people and many from residential settings.

In December an invitation from the Scottish Child Health Commissioners group allowed us to showcase the work of the project to professionals from all over the country. There was a lot of interest and we have been invited back to report on our project findings.

Conference season seems to be all year round these days and the last couple of months have been no exception. In January, Development Officer Anne Wilson attended the conference, **Looked after children and young people: ensuring the achievement of potential**, where she learned about key developments in the field and made some important networking links including a foster care network who are very interested in being involved. One of the key messages from Kathleen Marshall, Scottish Commissioner for Children & Young People, was that while the numbers of children and young people in care continues to grow (14,886 in 2008),

'A modest vision is to strive for the same outcomes we would expect for our own children.'

The Scottish Association for Community Child Health held their annual conference in early March on the theme of **Children in Poverty**, and we were very pleased to be invited to present on *Helping looked after children and young people cope when they are ill*. In the words of one of the speakers, Harry Burns Chief Medical Officer for Scotland, **'It's about affection . . . we can afford to show it . . .'**

and in the words of one of the young people who was interviewed, **'I like it ken, when they've got that look on their faces that says, 'we do care what's going on wi' people.'**



The project has an advisory group with representation from Acute, Community, Children's Community Nursing, Through Care and After Care, LAAC (looked after and accommodated) Nurses and GP Services.

We are currently conducting a survey round a variety of different health professionals involved in the care of LAAC children and young people when sick, using professional specific questionnaires. The feedback obtained will enable us to prioritize key action points to take forward.

Exemplar Areas – Forth Valley - We have forged links with a residential school in Stirling where we have conducted sessions on young people's healthcare needs and rights using our healthcare rights resource pack with both staff and the young people themselves. There are plans in place to visit another school in a different setting, the Community Health Partnerships (CHPs) and the local authority Social Work Departments. Meanwhile there are valuable examples of good practice in the **Compass for Health project** which supports very vulnerable and homeless young people.

Fife - Fife is different from other areas in that it does not have LAC Specialist Nurses whose role falls to Public Health Nurses. The project will shortly begin work with Falkland House School which supports 25 young people unable to live at home. In addition, Maxine Moy, nurse consultant in NHS Fife for vulnerable children and young people has been instrumental in linking us to the Public Health Nurses in the three CHPs and the newly formed Corporate parenting board within Fife children and families.

TAYSIDE CHILD HEALTH RIGHTS



The high teenage pregnancy rate in Tayside provided an impetus for our Child Health Rights project. As part of this we will over the next few months be producing a DVD to assist teenage mothers to effectively access healthcare services and to raise awareness of their babies' health rights. Project Officer, Fiona Bartley-Jones, is collaborating with the St Andrews Young Families Project in Dundee on the DVD. So far Fiona has researched the content with the young mums themselves and spoken to several film companies.

'Speaking to the young mums and hearing their experiences has been the most interesting aspect to date. However, learning about DVD production has also been fascinating. Of course funding the project has always been an issue too and ensuring that the work comes in on budget is a priority. The girls who wish to participate are now eager to get started and we are all looking forward to the experience as well as the finished product.'

Many thanks to the Scottish Community Foundation Women's Fund and NHS Tayside for financial support for the DVD.



Children and Anaesthetics

Association of Paediatric Anaesthetics Conference March 2009

Dagmar Kerr, our Area Co-ordinator for Greater Glasgow and Clyde, was invited to speak at the annual conference of the 'Association of Paediatric Anaesthetists of Great Britain and Ireland' held in Brighton in March.

Dagmar talked about the parent/carer perspective when children don't cope with going for an anaesthetic. Her talk was one given during a session about preparation for anaesthetics. She shared experiences about her own daughter as well as those of some carers who had talked to Action for Sick Children (Scotland). The key message was that good preparation and knowing about what might happen in hospital helps both parents and their children to cope. Children who may previously have struggled to cope were often helped by a hospital play specialist or by attending a pre-admission programme, including one or more

visits to the department. Involving children in decisions and treatment helps them to feel more in control and empowers them to cope. These points backed up what some of the research presented by anaesthetists and psychologists has found. Dagmar also asked the audience not to forget that procedures they consider small or routine might feel big and special or even frightening to children, young people or parents who are unfamiliar with the hospital system.

Dagmar was delighted to address this group of professionals and her talk was very warmly received. ASC(S) is particularly heartened that doctors are becoming more and more interested to hear the views of parents and carers. Other presentations included a talk about the need for age appropriate care by Morgan Jamieson, National Clinical Lead for Children and Young People's Health in Scotland and some research about how to best inform children and young people about their anaesthetic. For more information about the conference please visit the APA website: www.apaqbi.org.uk

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own age and those who work with young people about the realities of living with long term health problems and how they can help the young person cope.



Karen Martin

Information about the project is being developed and will be distributed initially, through outpatient clinics, schools and youth projects throughout Lanarkshire.

Young people interested in taking part can get in touch with the Project Officer for further information about self management sessions etc. In the meantime for more about the project, or about volunteering as session worker, contact:

Project Officer Karen Martin on ascs@btconnect.com

Phone 07935 305930.

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