

Their Health Matters

*Annual Review and
Impact Report 2011-12*



*Helping sick children and young
people meet their healthcare needs*

Chair's Report - A Year of Significant Progress



Professor Richard Olver

As I write this report towards the end of my first year as Chair of Action for Sick Children Scotland, it is possible to identify significant progress in our work to improve standards of healthcare for sick children and young people. This has been achieved through our campaigns designed to influence public policy and directly through delivery of our projects.

Policy

It is particularly satisfying that in response to our campaign on the right to appropriate education for all sick children and young people absent from school due to illness, regardless of where they live, the Scottish Government has agreed to review the Guidance on Education of Children Absent from School through Ill-health (2001) and invited us to join the Stakeholder Group set up to progress this review. Additionally, we have continued to represent the voluntary sector on the Scottish Government Specialist Services for Children and Young People Monitoring Group and in March 2012 ASCS became a member of the Scottish Government **Children & Young People's Health Support** Group.

Projects

Our Special Smiles Dental Project has **continued to work in 'special needs'** schools training teachers to use our dental play resources designed to reduce the **children's dental anxiety and improve their oral health practices**. In September 2011 this project became one of Inspiring **Scotland's Early Years Early Action Fund** ventures which enabled us to extend its work in Glasgow.

Our three year Stay Well Lanarkshire Project to assist young people with chronic health conditions to self-manage their illness concluded successfully in May 2012

with the production of a USB wristband self-management tool kit.

We continue to develop and extend links with vulnerable groups. Our **'Looked After and Accommodated Children and Young People in and leaving Care' Project delivered** workshops to foster carers and kinship carers on the healthcare needs of those in their care. The Tayside Child Health Project supported young mothers to look after their children at times of illness.

Throughout the year staff have continued to highlight the importance of **children and young people's healthcare rights** in various NHS committees and working groups. This was a particular focus of our Area Co-ordinator in NHS Greater Glasgow & Clyde. ASCS has also offered families opportunities to influence child health policies and delivery through its Family Participation Group.

Plans for the Future

Over the year ahead our plans to enhance the healthcare of sick children and young people in Scotland include:

- A Parental Access and Family Facilities Survey of all Scottish hospitals with paediatric and adolescent admissions. In March 2013 we will report to the Scottish Government on current provision of care provided to children and their families. This is the latest of a series of periodic surveys carried out since 1985.
- Continuation of our campaign *Each Child and Young Person's Health Matters* to highlight the healthcare rights and needs of children and young people and gaps in service provision. We will continue, in particular, to campaign for the right to education for children when absent from school due to illness.
- The Special Smiles Dental Project will continue until March 2013. We hope that further funding beyond that period will be awarded to allow us to extend into new local authority areas.
- The **'Looked After and Accommodated Children and Young People in and Leaving Care' Project** and our **Child Health Project** in Tayside will continue to support parents and carers to look

after the healthcare needs of their children at times of illness.

- Further work to assist children and young people with chronic health conditions to self-manage their condition.

In addition, we will continue to provide practical support, information and advice to families with a sick child.

Thanks

We are grateful for the generous support of our funders and fund raisers. Our thanks also go to Executive Committee members Trisha Summers, Robert McFarlane and Deborah Catty who have stepped down and we welcome new members Simon Robinson and Jim Robinson.

This report would not be complete without mention of the huge contribution to the work of ASCS by Gwen Garner, who completed her term as Chair in September 2011, and of the Executive members and staff who have worked tirelessly to ensure that sick children, young people and their families get access to the support and care they need. Many thanks.

Richard Olver, Chair



Gwen Garner (left) ASCS Chair until September 2011, with Dr Peg Belson MBE, a founding member of our organisation who died in January 2012. Peg's pioneering spirit left the world a better place for sick children, young people and their families.

How we have helped to make a difference

Special Smiles

Our Special Smiles Dental Project funded by the Early Years Early Action Fund, has been working with 17 additional support for learning schools and units in Glasgow. This play-based project aims to increase **children's oral health understanding** and practices and reduce anxiety associated with dental treatment. The project has been training school staff in the use of our specially designed resources, running play sessions with children and helping **parents to support their children's dental health needs**. Between October 2011 and March 2012, we trained 102 teachers. Over 90% said this had raised their **awareness of the children's needs** and would affect how they worked with them and their families. Here are some of the **teachers' comments:**

'Children love our 'Tooth Times'. Over the past few weeks there has been a noticeable increase in participation, particularly from one boy who dislikes brushing his teeth. He appears to be much more comfortable with it, since less attention is drawn to him when we all brush together, and he enjoys focussing on the Twooth Timer. The timer keeps the children brushing for the full two minutes.'

'One pupil asked his mum to take him to the dentist for first time, which she did.'

Over 60 children have used the resources up to the end of March and for some, the impact has been considerable. Parents have said:

'It has given Jan more understanding of how important it is to brush her teeth and eat more healthy snacks. She is less anxious about going to the dentist.'



Special Smiles activities in a Glasgow school

'Allan found it very difficult to brush his teeth as he doesn't like putting anything in his mouth. I got the Dentist Box home from school. We looked

through it together, playing and dressing up with younger brother, age 3. After showing Allan the pictures of what good teeth and bad teeth look like, this helped me to explain to Allan the importance of brushing teeth. I find it much easier now to get Allan to allow me to brush his teeth. We are due to visit the dentist next week. I am sure this will be a much more pleasant experience for both of us, as dressing up as dentist was great fun.'

In the year ahead we will continue to work in Glasgow whilst rolling out the project to 12 new schools in Ayrshire.



Children play at being dentists

Greater Glasgow & Clyde

Our Area Co-ordinator, Dagmar Kerr, has continued to support families when their children are ill as the following shows:

After several weeks of being unwell, 14 year old Bob was admitted to hospital. As **it was an adult hospital his Mum wasn't allowed to stay with him**. Bob became very worried and was afraid to ask nurses and doctors what the various tests and injections were for. His anxiety increased when he was told that he had to have an MRI scan. His Uncle contacted Dagmar who put the family in touch with the hospital play service at Yorkhill. A play specialist then visited Bob and explained to him about what to expect. The family said, **'This was a big help to him as no one had explained the procedure and it certainly reassured Bob of what would happen.'**

Dagmar also advised the family about their right to stay with Bob and his right to receive education during his illness and so they felt able to make sure that he received the care he needed. ASCS also informed senior NHS staff about the situation which has now helped staff in the adult hospital to address gaps in their knowledge of age appropriate care and

helped inform the Board's age appropriate care policy.

Our playboxes continue to help not only children attending hospital but also their siblings. We gave the parents of a baby undergoing major surgery a hospital playbag for their older children. They told **us: 'The contents helped the boys to understand better what was happening to their sister. One book was particularly helpful (the one where one sibling goes to hospital and the other one feels a bit left out). They enjoyed playing with the fuzzy felts, equipment and uniforms. The bag helped them a lot. Thank you very much.'**

Tayside Child Health

The project has delivered workshops to young mothers supporting them to look after their children at times of illness. A Perth Midwife reports: **'Young girls have benefited enormously from the workshops, not only do they benefit from peer education, but the audio visual tools are an excellent resource for girls with limited literacy skills. Young girls have limited knowledge and experience of using healthcare services and it is important that as new parents they are aware of and confident to use services. They often lack confidence to ask questions, but the workshops aim to give them knowledge and support to maximise use of any services.'**



Photo: Scottish Youth Health Photography Project

The project has also helped healthcare professionals. Feedback from the Midwifery Programme at the University of Dundee, included: **'The students have access to the perspective of the young people rather than only the perspective of specialist midwifery approaches to the care of pregnant teenagers. Capturing the service user perspective is something we are challenged with and Fiona has given us an invaluable opportunity in relation to this group of young women who do not always have the opportunity to express themselves.'**

to families and professionals we work with

Children and Young People In and Leaving Care

The project continued working for the healthcare needs of children and young people in the care system.

Feedback from our 2010-11 foster carer training programmes had indicated a need to include more specialist topics and sessions to support carers to address their sense of loss and its impact on their own health and wellbeing. Such sessions would enable them to become more resilient in their caring role.

Accordingly the 2011-12 training programme was developed to include an extended range of topics which covered: **Children and young people's healthcare rights**; Dental healthcare for children with complex healthcare needs; The emotional impact of tube-feeding; Consent and confidentiality; Mental health and wellbeing (of children and young people in care); Specialist health needs; Communication with children and young people with complex healthcare needs.

We also delivered training for the first time to kinship carer groups.

Over the year we delivered 13 sessions to 109 carers in Edinburgh, Ayr, Dundee, Stirling, West and East Lothian, Paisley, Livingston, Clackmannanshire and Falkirk. These helped carers to support their children at times of illness, in particular those whose health has been adversely affected by early experiences, or those with a long term condition or complex healthcare needs. Feedback has been very positive:

'Very interesting day – will help me take more time to understand the child. I need to think not, What's wrong with you? but What's happened to you?'

'Good insight into mental health and trauma – the case studies especially helpful.'

Mirroring last year's Seasons for Growth Programmes for children and young people in care, we delivered two separate Seasons For Growth programmes to foster and kinship carers to address their emotional and psychological needs.

One carer said, **'This programme should be mandatory for all carers.'**

Another carer told us, **'I wasn't going to come back after the first session because I got so upset, but I made myself and I am so glad I did as it has helped me cope.'**

Stay Well Lanarkshire



Young People who took part in Stay Well

At the end of March 2012 the Stay Well Self Management Project was two months from completion after three years operating in Lanarkshire. With funding from BBC Children in Need, Lloyds TSB Foundation, The Robertson Trust and The Self Management Fund for Scotland, the project delivered nine self management programmes, each with six workshop sessions. Six programmes were completed in 2011-12. Fifty-one young people between 11–17 years with long term conditions benefited from the programmes held in local centres and schools.

Eighteen of the Stay Well young people also attended peer support training during the year and many returned to assist the project in delivering workshops. They helped create a DVD and a new leaflet, **'Talking About My Health Condition'** which is included in the USB wristband toolkit.

The young participants enjoyed the workshops, learned new skills, gained in confidence and developed an increased awareness of the impact of long term conditions on their and on other people's lives. Here are some of their comments:

'I liked it all and it was good how you could get someone to come in and do stuff like drums.'

'The Stay Well Project has helped me as I have found that I am more confident and relaxed.'

'The fact that you know that there are other people out there with it, not just you. It just makes you feel a bit better.'

James*, age 13, gave a talk to his English class about living with asthma, raising awareness about his condition and providing factual information. He told his 24 classmates,

'I hope this gives you a better understanding of asthma. Thanks to the Stay Well Project I have learned that it's not so bad to have an illness, and also I have made lots of friends with different problems who have to all cope differently, but we all get there, with help from people like Amy and Lysia (project team) they help us along our road and don't make us feel different from other kids.'
(* name changed)

Parents and carers expressed the same hopes for their young people as the project had for them: increased confidence; improved ability to communicate and express feelings; increased awareness of having a long term condition; more social interaction and an increase in their emotional wellbeing. One parent of a 14 year old described the impact on her son of coming to workshops:

'After coming to the workshops, [my son] has not been as moody; he's been a bit happier. He can be quite shy so he enjoyed being behind the camera when they made a DVD. He is more confident about going to the workshops now and he likes the small groups.'



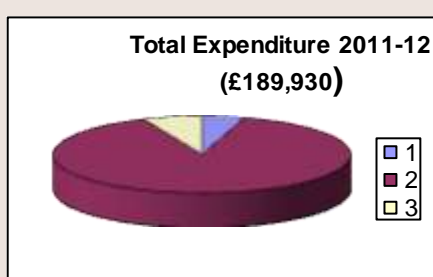
Finance and Funding

Our People



Income April 2011- March 2012

| | 2012 | 2011 |
|--------------------------------------|----------------|----------------|
| | £ | £ |
| 1. Voluntary Income | 169,549 | 147,284 |
| 2. Activities for Generating Funds | 3,867 | 8,070 |
| 3. Investment Income | 1,291 | 1,404 |
| 4. Income from Charitable Activities | 128 | 22 |
| | <u>174,835</u> | <u>156,780</u> |



Expenditure April 2011 - March 2012

| | 2012 | 2011 |
|--|----------------|----------------|
| | £ | £ |
| 1. Cost of Generating Voluntary Income | 8,831 | 12,614 |
| 2. Charitable Activities | 168,896 | 133,104 |
| 3. Governance | 12,203 | 12,568 |
| | <u>189,930</u> | <u>158,286</u> |

Summary Balance Sheet
as at 31 March 2012

| | 2012 | 2011 |
|--|----------------|----------------|
| | £ | £ |
| Fixed Assets | 2,212 | 1,304 |
| Current Assets | 137,954 | 152,655 |
| | 140,166 | 153,959 |
| Current Liabilities (creditors/accruals) | 5,189 | 3,887 |
| Deferred Income | - | - |
| Net Assets | <u>134,977</u> | <u>150,072</u> |



| | |
|-------------------------|-------|
| 1. Scottish Government | 32.2% |
| 2. Inspiring Scotland | 24.2% |
| 3. BBC Children in Need | 16.0% |
| 4. Other Trusts | 24.2% |
| 5. Other Donations | 0.2% |
| 6. Other Income | 3.2% |

Executive Committee 2011-12
 Gwen Garner (Chair) (*until Sept 2011*)
 Professor Richard Olver (*from Sept 2011*)
 Robert McFarlane (Vice-Chair) (*until Sept 2011*)
 Margaret Rooney (Vice-Chair) (*from Sept 2011*)
 Liam Campbell (*from Sept 2011*)
 Duncan McEachran (Treasurer)
 Frances Barbour
 Deborah Catty
 Dr Zoe Dunhill
 Marjorie Gillies
 Dr Una MacFadyen
 Patrisha Summers (*until March 2012*)

Company Secretary/National Co-ordinator
 Elizabeth May

Staff

Lysia Abercrombie, *Project Assistant Stay Well Lanarkshire* (*until March 2012*)
 Fiona Bartley-Jones, *Project Officer Tayside*
 Mary Cox *Dental Project Officer* (*from Dec 2011*)
 Amy L Joss, *Project Officer Stay Well Lanarkshire*
 Dagmar Kerr, *Area Co-ordinator Greater Glasgow & Clyde*
 Grace Lacey *Dental Project Officer* (*from Nov 2011*)
 Catherine Nelson, *Dental Project Co-ordinator*
 Anne Wilson, *Development Officer*

ASCS Advisers

Melanie Brown
 Jonathan Bryden, *Head of Finance, Clyde Community Health Partnerships*
 Gwendoline Cowan

Lady Caplan

Rory Farrelly, *Director of Nursing, NHS Greater Glasgow & Clyde Acute Operating Division*

Gwen Garner (*from Sept 2011*)

Liz Nicol, *Play Co-ordinator/Volunteer Manager, NHS Fife*

Jacqueline Reilly, *Discharge Co-ordinator, Royal Hospital for Sick Children Glasgow*

Professor George Youngson

Finance Officer Alison Glass FCCA

Auditor Barstow & Millar

Bankers The Royal Bank of Scotland Plc

The full audited accounts are available from the Company Secretary at the Registered Office at 22 Laurie Street, Edinburgh EH6 7AB

Thanks to all those who funded and supported us during 2011-12

Alexander Moncur Trust, Appletree Trust, BBC Children in Need, Binks Trust, Hugh Fraser Foundation, J Sainsbury Plc, Jenny Lowe, Jim Woodward, Leeds Building Society Charitable Foundation, Lloyds TSB Foundation for Scotland, Margaret Gilbride School of Dancing, Moffat Charitable Trust, Mugdock Children's Trust, NHS Greater Glasgow & Clyde Endowment Funds, The Robertson Trust, Scottish Government Early Years Early Action Funding from Inspiring Scotland, Scottish Government Healthcare Policy & Strategy Directorate, Snowball Trust, Widowers' Children's Home Trust, W M Sword Charitable Trust

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 and young people within our healthcare system

Our Vision is for the best quality healthcare for children and young people in Scotland. Our Mission is to enable children and young people to meet their individual healthcare needs, in partnership with parents, carers and professionals.



We work with the following to represent sick children, young people and their families ...

Association of Paediatric Anaesthetists of Great Britain & Ireland
for Scotland's Disabled Children - Coalition Group; Transition Task Group; Education Task Group
Community Child Health for the 21st Century Steering Group
Health Rights Information Scotland and Scottish Government
Development of the Charter of Patient Rights and Responsibilities - focus group on user testing of information for adults and stakeholder group for development of information for children
Long Term Conditions Self Management Engage a Generation Project, Scottish Government

National Delivery Plan for Children & Young People's Specialist Services in Scotland Implementation Group (known as Specialist Services for Children and Young People Monitoring Group from January 2012)

National Association of Hospital Play Staff
National Services Division - Short life Working Group: Reimbursement Travel for Specialist Services
National Services Division - Transition Event: Make It Happen, National Standards Planning Group (ended November 2011)

NHS Greater Glasgow and Clyde - **New Sick Children's Hospital** Stakeholder Reference Group; Better Together Quality & Monitoring Steering Group; Community Engagement Team - Youth Panel and Family Panel, **Community Engagement Advisory Panel (CEAP); Patients' Panel; Partners in Advocacy**

NHS Lanarkshire - **Child Health Services Executive Group**
NHS Lothian - **Royal Hospital for Sick Children Edinburgh Hospital Patient Focus Public Involvement Task Group (formerly Children, Young People & Families Advisory Board)**
NHS Tayside - **Family Nurse Partnership Operational Group; Sexual Health Strategy Group; Ninewells Hospital Leaflet Group**
Paediatric Scottish Patient Safety Programme Steering Group
Royal Hospital for Sick Children Glasgow - **FILES Committee; The Rights of the Child Group; Family Support Service, Chaplaincy team; Play Service Re-design Group**

Scottish Children and Young People's Palliative Care Network

National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN)

Scottish Healthy Care Network

Scottish Government Children and Young People's Health Support Group

Scottish Government, Modernising Nursing in the Community - Complex Care Subgroup

Scottish Government Guidance on Education of Children Absent from School due to Ill Health Review Group

Scottish Paediatric Anaesthetists Network (SPAN)

St Andrew's Family Support Group

UK Committee for Children and Young People's Nursing



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