

# Their Health Matters

Annual Review and  
Impact Report 2012-13



Helping sick children and young  
people meet their healthcare needs

# Chair's Report - Our Year in Focus



Professor Richard Olver

2012-2013 has been a year of substantial achievement for Action for Sick Children Scotland in its work to improve standards of healthcare for children and young people in Scotland.

## **Our 'EACH Child and Young Person's Health Matters' Campaign', focusing on**

the right to education in hospital, prompted the Scottish Government to set up a group to review the Guidance on Education of Children Absent from School Through Illness, in which ASCS is an active member. The campaign was given a boost by Alison McInnes, MSP, tabling a motion in the Scottish Parliament and sponsoring an ASCS exhibition in the Parliament Building which attracted interest from many MSPs.

## **'A major feature of our work to improve standards is the latest Parental Access and Family Facilities survey of Scottish NHS hospitals.'**

A major feature of our work to improve standards is the latest Parental Access and Family Facilities survey of Scottish NHS hospitals. By the end of March we had gathered responses from 66 wards admitting children and, as I write, we are finalising the report to be published in the autumn.

## **Projects**

We have several projects providing direct support to children and families:

The Special Smiles Dental Project, funded by **Inspiring Scotland's Early Years Early Action Fund**, supported nearly 400 children in 29 special needs schools in Glasgow and South Lanarkshire and,

significantly, evaluation showed that this **play-based project reduced children's anxiety and improved their oral health.**

By its conclusion in May 2012, the Stay Well Lanarkshire Self Management Project had helped 55 young people with chronic illness, making them more self-confident, more socially included and better able to be open about their condition. This work moved into a new phase at the beginning of this year when we started our West Lothian Child Self Management pilot which aims to support younger children with long term conditions.

We continue to work with other vulnerable groups. Our Children and Young people in and leaving Care Project delivered workshops to more than 150 foster and kinship carers, assisting them to better support the health needs of children and young people in their care. The Tayside Child Health Project supported young mothers caring for their children at times of illness until its completion in December 2012. We hope to resume work in Tayside in due course.

In NHS Greater Glasgow & Clyde we have worked with a range of NHS committees and working groups and provided practical support, information and advice to families in the area caring for a sick child. Our Family Participation Group has influenced child health policies and delivery.

## **Plans for the Future**

ASCS will continue to inform, promote and campaign on behalf of all sick children and young people.

We expect our 2013 Parental Access and Family Facilities Survey findings to highlight areas where improvements need to be made and this will inform our new campaigning activity. Preliminary analysis shows the need for much better facilities for young people, many of whom are still admitted to adult wards.

**'We will continue our involvement with the Scottish Government review group to ensure that children and young people get appropriate and equitable education when absent from school due to illness.'**

We will continue our involvement with the Scottish Government review group to ensure that children and young people get appropriate and equitable education when absent from school due to illness.

Confirmation of funding for the next **two financial years from BIG's Third Sector Early Intervention Fund** was great news. It will support important core activities and allow the Special Smiles Dental Project to work until March 2014 in schools in North and South Lanarkshire. It will also enable the Children and Young People in and Leaving Care Project to continue its work with foster and kinship carers.

Continuing our work to assist children with long term conditions to self-manage their illness, the West Lothian Self Management pilot will develop and test activities for children aged 8 - 12 years and evaluate supporting information for their parents/carers.

As in previous years, we will continue to provide practical support, advice and information to families with a sick child.

## **Thanks**

We are grateful for the generous support of our funders and fund raisers and also to our office volunteer Jenny Lowe. Our thanks also go to Executive Committee member Liam Campbell who stepped down and we welcome new member Alison Closs and also Gwen Garner, who returned to the Executive Committee.

Last but certainly not least, I end this report with a sincere thank you to members of our Executive Committee and staff who have worked hard to ensure that sick children, young people and their families get access to the support and care they need. Special thanks should go to our National Coordinator, Liz May, who has worked tirelessly on behalf of our organisation and was instrumental in securing our future with the funding from BIG.

Richard Olver, Chair

# Helping to make a difference to children,

## Special Smiles



Role Play at Glasgow school

Our Special Smiles Dental Project funded by Inspiring Scotland's Early Years Early Action Fund continued to work with 17 special schools in Glasgow whilst rolling out to 11 more in Lanarkshire. It has been enthusiastically received by all 29 schools. As one teacher said, **'It really works!'**

In the year under review, we trained 105 teachers and supported 131 parents/carers. 397 children accessed the resources, enabling them, through play, to learn about good oral health and deal with their fears about going to the dentist.

An Evaluation Report in November 2012 showed a marked improvement (88%) in oral health practices amongst participating children and a significant reduction in anxiety. The following statements are some of many received which show how we helped.

**'This Special Smiles Project brings parents, children and staff together to tackle the ongoing issue of poor oral health and is a fantastic way of working together. The Playbox and home Parent Packs are extremely well resourced and allow children with varying additional support needs to access equipment to meet their individual needs.'** Depute Head Teacher

A Parent of twin boys with Autism said, **'The Play-pack was amazing, the boys loved it, had a fantastic time! I was involved in Role Play. I was the patient and they dressed up as dentists, with their gloves, masks and mirrors. Mark,**

**who would not let me do his teeth is now doing it! Donald was fantastic when he went to the dentist. Before he went, the school did the story 'Donald goes to the Dentist'. In the waiting room Donald looked at the 'Big Kangaroo Puppet', and was excited. Off he went, sat in the dentist's chair and opened his mouth, it was amazing. I can't believe how play has helped Donald go to the dentist. Both my sons are now brushing their teeth and allowing me to help them. I am taking Mark to the Dentist tomorrow. He wants to go to be the same as Donald.'**

A parent whose child has sensory issues said, **'The Play-pack has been so helpful to Jack. I dressed up as a Dentist and we played with his sister. Jack wasn't brushing his teeth before and now he is letting me help him, asking me to help. I can't believe how play has made such a difference. It's so good there are people like you to help children like Jack.'**

Children also gave excellent feedback and said that they really enjoyed the play resources. One boy said **'I liked practicing with the giant mouth'**. While another child summed up his feeling by saying, **'It's wonderful'**.

## Stay Well Lanarkshire

In May 2012 our Stay Well Project for young people with long term health conditions concluded, with a family event at Hamilton Town Hall and the launch of a DVD and toolkit at the Royal College of Paediatrics and Child Health (RCPCH) meeting in Glasgow. The latter event was attended by paediatricians and others with an interest in child and adolescent medicine.



Stay Well young people making the DVD

The DVD was made with young people who wanted to describe their experiences of living with a condition and how the project helped them. An RCPCH Youth Advisory Panel member described the impact of watching the DVD as follows:

**'ASCS has spotted a clear gap in the market and do a fantastic job in providing emotional support for children and young people who are really ill. There are plenty of support groups out there for adults, or parents of affected children in particular, but it is incredibly rare to see something for the children themselves. The video clearly shows how their work helps the children form a support network between themselves, providing new friends for some children who have very few, and giving them an emotional bedrock and increase in confidence that will aid their day-to-day lives long after their sessions with ASCS.'**



'Dealing with Change' workshop activity

Over three years 51 young people were helped to self manage by taking part in the self management programmes. Nine programmes were delivered.

## West Lothian Child Self Management

In February 2013, Project Officer Amy Joss began making contacts with health, education and voluntary sector partners in the initial stage of a self management project pilot for children aged 8-12 years with long term health conditions living in West Lothian.

This project hopes to work directly with at least 32 children and 20 parents/carers up until March 2014.

The main aim is to develop and pilot an age-appropriate self management programme with children who are living with long term health conditions such as asthma, diabetes, epilepsy, inflammatory bowel disease, and others.

It is anticipated that a programme increasing self-esteem and confidence will support their health and wellbeing into the teenage years. The project will also develop information and support for parents/carers.

# young people, families and professionals

## Children and Young People In and Leaving care

Over the year, we continued to work for the healthcare needs of children and young people in care, delivering 16 workshops to 153 Foster and Kinship Carers through Independent Fostering Agencies, including Kibble, JMT and via Local Authority Social Work Departments. Workshops were delivered to carers in Paisley, Dundee, Livingston, Ayr and in East Lothian, City of Edinburgh, Fife and Clackmannanshire.



The sessions covered a range of topics including *Managing the Healthcare Needs and Rights of Children and Young people in Foster and Kinship Care; Mental Health and Wellbeing; Dental Healthcare; and Consent and Confidentiality*. These allowed carers to explore issues and challenges particularly relevant to them such as:

- Higher level of need
- GP issues: registration, second opinions
- Being listened to by healthcare practitioners
- Hidden illnesses: Hepatitis C/HIV support
- Lack of history of care
- Fear of medical/dental intervention
- Surgery: delays due to consent issues

A Care Inspectorate Care Inspection Report on Intensive Fostering Services at Kibble **commented on ASCS's input, 'The feedback from recent external training attended by several carers about the health care needs of looked after children in foster care was very positive.'**

Looked after children in general are likely to have poorer health outcomes than children not in care for a range of reasons, including early trauma and neglect; missing health records; gaps in treatment; missed medical appointments. These can all affect children in kinship care but such children, and their kinship carers, often have to deal with the impact of:

- The mental health of the birth parents
- Fear of inherited conditions
- Challenges around consent and confidentiality
- Interfamilial tensions relating to why the child came into care.

The project also delivered a Seasons for Growth Programme for Kinship Carers [http://www.educationscotland.gov.uk/resources/s/genericresource\\_tcm4207544.asp](http://www.educationscotland.gov.uk/resources/s/genericresource_tcm4207544.asp) to help them address the adverse impact arising from their situation on their physical and mental health. This was very well received by carers.

**'I would tell others how much it would help them to get through difficulties life brings us'** and

**'It should be mandatory for all carers.'**

## Tayside Child Health

In August 2012, we bade farewell to Fiona Bartley-Jones, who in recent years had developed our DVD *'Child Health Rights, What do you know? Young Parents Speak Out'*, in conjunction with young parents in Tayside, and delivered workshops to support them to look after their children at times of illness. ASCS staff member Amy Joss took over the delivery of the workshop programme until its completion in December. Both Officers worked hard over the period to raise awareness of **young parents' specific child health needs** and to encourage the NHS to deliver specialist services aimed at young parents.

Between April and December 2012, we delivered 7 workshop sessions to 66 parents/carers of 69 young children and provided individual support for 5 parents. 61 NHS and 50 Education and Voluntary Sector professionals received information and had direct links with the Project, and 16 attended the Child Health workshops. One playgroup organiser said, **'We had a workshop recently run by Amy, we wanted to let her know that the mums found it interesting especially talking about diet and dental hygiene. We feel that this has gone some way to alleviate a lot of concerns we all have regarding the health and welfare of our children in the healthcare system...'**

## Greater Glasgow & Clyde

Our Area Co-ordinator, Dagmar Kerr, continued to support families with children experiencing illness or hospital admission. These are anxious times for families who naturally worry about their child or young **person's health. One mother got in touch** because she was anxious about her three **year old daughter's forthcoming operation.**

Dagmar provided the family with a customised Hospital Playbag with toys, books, uniforms and real hospital equipment which the child might see in hospital and encouraged the parents to use these to play with their child. She

talked to them about the pre-admission visit to the hospital, what questions they might ask, how best to talk to their child and also about the importance of playing with their child after the operation. After the operation the mother wrote,

**'Getting the information from you was extremely useful for before and after surgery. It helped me to realise this was her way of processing what had happened. She also used the toys (which were a wonderful resource) to re-enact some of her experiences. She will require another operation in roughly a year and I would be very grateful for advice/support again. I feel the impact of surgery on children can be underestimated and it is crucial that there are independent organisations which provide support to families.'**

Our Campaign for the right for education for children and young people absent from school due to ill health has resulted in more families seeking support about this issue. Dagmar supported several of these parents providing information about how to find help. One parent of an anxious child who was unable to attend school was grateful for useful suggestions and signposting information and said: **'Your listening alone has already helped so much. Thank you.'**

Other activities included raising awareness of **children's and young people's health** rights through presentations to junior and senior classes at a **'Rights Respecting School'**. Pupils said that they found the talks **'useful', 'reassuring, informative', 'fantastic,'** and teachers reported that, **'the children are very excited to find out more'.**



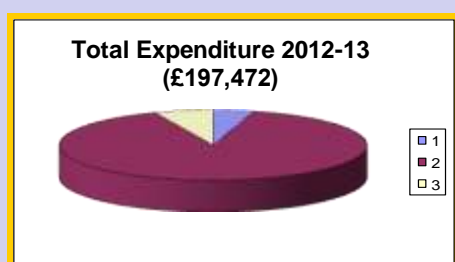
During the year to 31 March 2013, our projects had 5,708 contacts with children, young people, families, voluntary groups and healthcare providers.

# Our Financial Year



Income April 2012- March 2013

	2013	2012
	£	£
1. Voluntary Income	222,111	169,549
2. Activities for Generating Funds	2,455	3,867
3. Investment Income	1,407	1,291
4. Income from Charitable Activities	259	128
	<u>226,232</u>	<u>174,835</u>

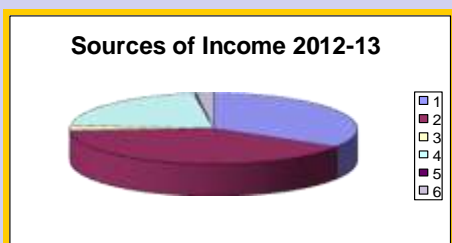


Expenditure April 2012 - March 2013

	2013	2012
	£	£
1. Cost of Generating Voluntary Income	8,526	8,831
2. Charitable Activities	176,712	168,896
3. Governance	12,234	12,203
	<u>197,472</u>	<u>189,930</u>

Summary Balance Sheet as at 31 March 2013

	2013	2012
	£	£
Fixed Assets	1,243	2,212
Current Assets	<u>166,333</u>	<u>137,954</u>
	167,576	140,166
Current Liabilities (creditors/accruals)	3,839	5,189
Deferred Income	-	-
Net Assets	<u>163,737</u>	<u>134,977</u>



1. Scottish Government	33.7%
2. Inspiring Scotland	40.4%
3. BBC Children in Need	2.3%
4. Other Trusts	21.4%
5. Other Donations	0.2%
6. Other Income	2.0%

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

Finance Officer Alison Glass FCCA

Auditor Barstow & Millar

Bankers The Royal Bank of Scotland Plc

## Executive Committee 2012-13

Professor Richard Olver (Chair)  
 Margaret Rooney (Vice-Chair)  
 Duncan McEachran (Treasurer)  
 Frances Barbour  
 Liam Campbell (until Sept 2012)  
 Deborah Catty (until June 2012)  
 Dr Zoe Dunhill  
 Gwen Garner (from Oct 2012)  
 Marjorie Gillies  
 Dr Una MacFadyen  
 Robert McFarlane (until June 2012)  
 Jim Robinson (from June 2012)  
 Simon Robinson (from June 2012)

## Staff

Fiona Bartley-Jones, *Project Officer Tayside (until August 2012)*  
 Mary Cox, *Dental Project Officer*  
 Amy L Joss, *Project Officer Stay Well Lanarkshire then West Lothian Child Self Management Project (from Feb 2013)*  
 Dagmar Kerr, *Area Co-ordinator Greater Glasgow & Clyde*  
 Grace Lacey, *Dental Project Officer*  
 Elizabeth May, *Company Secretary/National Co-ordinator*  
 Catherine Nelson, *Dental Project Co-ordinator*  
 Anne Wilson, *Development Officer*

## ASCS Advisers

Professor Jane Aldgate  
 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*  
 Liz Nicol, *Volunteer Manager, NHS Fife*  
 Jacqueline Reilly, *Discharge Co-ordinator, Royal Hospital for Sick Children Glasgow*  
 Professor George Youngson

## Grateful thanks to our funders and supporters

BBC Children in Need, The Binks Trust, Forteviot Trust, Harold Merton Adams Trust, Jenny Lowe, Margaret Gilbride School of Dancing, **Miss Agnes H Hunter's Trust, Moffat Charitable Trust, NHS Greater Glasgow & Clyde Endowment Funds, R J Larg Family Trust, The Robertson Trust, R S Macdonald Charitable Trust, Scottish Community Foundation, Scottish Government Early Years Early Action Funding from Inspiring Scotland, Scottish Government Healthcare Policy & Strategy Directorate, Snowball Trust, Waitrose, Widowers' Children's Home Trust, Yorkshire Building Society Charitable Foundation.**

Action for Sick Children Scotland (ASCS) 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 IN PARTNERSHIP with the following to represent the views and needs of sick children, young people and families

Association of Paediatric Anaesthetists of Great Britain & Ireland  
**for Scotland's Disabled Children** - Interim Co-ordination Group  
Centre for Excellence for Looked After Children in Scotland (CELCIS) - *Scottish Universities Insight Institute - Series of Knowledge Exchange Seminars on Looked After Disabled Children and Young People*  
City of Edinburgh Council Multi-Agency Advisory Group Kinship Care  
Health Information Services at NHS 24 (formerly 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 (completed October 2012); HRIS consent leaflet for young people*  
National Association of Health Play Staff  
NHS Greater Glasgow and Clyde - *Better Together Quality & Monitoring Steering Group; Community Engagement Team - Youth Panel and Family Panel, Patients' Panel; 'Fit for the Future' Clinical Services Review – Child and Maternal Health Steering Group and Patient Reference Group; Stakeholder Group for Transition for Children and Young People with cerebral palsy*  
NHS Lanarkshire - *Child Health Services Executive Group (until August 2012)*  
NHS Lothian – *RHSC + DCN – Little France: Project Stakeholder Board (formerly Royal Hospital for Sick Children Edinburgh Hospital Patient Focus Public Involvement Task Group; Charities Forum Group)*

NHS Tayside - *Family Nurse Partnership Operational Group; Sexual Health Strategy Group; Ninewells Hospital Leaflet Group (until December 2012)*

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)

National Managed Clinical Network for Congenital Cardiac Disease  
**Scottish Government Children and Young People's Health Support Group**

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

Scottish Government Specialist Services for Children and Young People Monitoring Group

Scottish Paediatric Anaesthetists Network (SPAN)  
Scottish Patient Safety Paediatric Programme Action Group

**St Andrew's Family Support Group** (up to June 2012)

Strategic Paediatric Educationalists and Nurses in Scotland (SPENS)

**UK Committee for Children and Young People's Nursing**

In addition we worked closely with Glasgow City Council Education Department; South Lanarkshire Education Department; NHS Greater Glasgow and Clyde Oral Health Directorate.



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