

Annual Review  
and Impact Report  
2013-14



# Their Health Matters



**Action for Sick Children Scotland**  
helping sick children and young people meet their healthcare needs

# Chair's Report - A Busy and Productive Year



Professor Richard Olver

2013-14 has been a busy and productive year for Action for Sick Children Scotland, the highlight of which was the publication of our 2012-13 Parental Access and Family Facilities Survey of Scottish hospitals admitting children and young people. This was the latest in a series carried out since 1985 with the aim of reporting on current provision of care and facilities for children and their families.

Work on the survey concluded during the year and the findings were presented at a well attended ASCS event held at the Scottish Parliament in October hosted by Alison McInnes MSP. The findings **informed our new 'EACH Child and Young Person's Health Matters'** campaigning priorities which focus on:

- facilities in hospital for young people – particularly those admitted to adult wards
- the right for children to have a parent or carer with them in the anaesthetic room before surgery and afterwards during recovery from the anaesthetic
- the right of children and young people to nutritious and appetising food in hospital.

## Representation on Working Groups

ASCS continued to work as a member of the Scottish Government Stakeholder Group reviewing the Guidance on Education of Children Absent from School through Ill-health (2001). Set up as a result of our campaign on the right to appropriate, equitable education at times of illness for all sick children and young people, the Group will publish the new Guidance during 2014. A closely linked

issue is the Administration of Medicines in Schools. ASCS was pleased to contribute as a member of the working **group set up by Scotland's** Commissioner for Children and Young People to produce recommendations on this issue for submission to Scottish Government. At a policy level ASCS is a member of the Scottish Government **Children & Young People's Health** Support Group and continued to represent the voluntary sector on the **Scottish Government's Specialist** Services for Children and Young People Monitoring Group.

Throughout the year staff have highlighted the importance of children **and young people's healthcare rights** in various NHS committees and working groups. Our Area Co-ordinator in NHS Greater Glasgow & Clyde represented the needs of sick children, young people and their families on a range of committees and working groups and provided practical support, information and advice to families in the area caring for a sick child.

## Projects

Work continued from previous years included:

- The Special Smiles dental project which works in additional support for learning schools, using dental play resources developed for children and young people with complex and additional support needs. Its work in South Lanarkshire was extended into North Lanarkshire and feedback from teachers, children, parents and carers **shows that children's oral health** understanding and practices are improved and dental anxiety is reduced.
- The Children and Young people In and Leaving Care project delivered workshops to foster and kinship carers **on the healthcare needs of 'looked after'** children and young people, assisting carers to better support the health needs of children and young people in their care. The impact of the workshops was evaluated externally **with evidence that carers' knowledge** and confidence are increased.
- ASCS assisted children with chronic health conditions to learn to self manage their illness. A pilot project working in West Lothian developed and piloted self management workshops for children aged 8 -12 years.

The organisation continued to offer families opportunities to influence child health policies and delivery through its Family Participation Group.

## Future Plans

As in previous years, ASCS will work for improved standards of healthcare for all sick children and young people in Scotland, to highlight gaps in child health services and to raise awareness of the healthcare rights of children and young people. We have already made a start on our campaigning issues:

- working with SPENS (Strategic Paediatric Educationalists and Nurses Scotland) to develop guidance and a suite of documents that can be adapted locally for adult wards admitting young people
- engaging in a dialogue with the Scottish Paediatric Anaesthetists Network over the presence of parent/carers during induction of anaesthesia and at recovery
- forming a focus group to develop a questionnaire for hospital catering and dietetic staff in order to identify best practice and
- carrying out an online survey of **parents' experience of their children's** food in hospital.

As I write this, ASCS is looking ahead with anticipation to its Conference in November, the central theme of which is **'Person Centred Health Care for Children and Young People, Myth or Reality?'**

## Thanks

We are grateful for the generous support of our funders and fundraisers and also to our office volunteer Jenny Lowe. Our thanks also go to Executive Committee Vice-Chair, Margaret Rooney and members Marjorie Gillies and Simon Robinson who stepped down and we welcome new members Mary Boyle and Jane Holmes.

As before, I end this report with a sincere thank-you to members of our Executive Committee and staff who have worked tirelessly on behalf of children and young people.

Richard Olver, Chair

# Helping to make a difference to children,

## Greater Glasgow & Clyde

Some of the most valuable work we do is to provide support to families. Dagmar Kerr our Co-ordinator in the area regularly speaks to parents and carers worried about their child's forthcoming hospital admission. Families often approach her with general questions about their child's health care or about specific issues such as education during illness. Such families often get back to let us know how their child is doing. One parent who used a Hospital Playbag to prepare her child for surgery wrote: *'Thank you so much for all your help over the last few weeks which, for us, turned out to be quite traumatic. The children were delighted with the 'bag of goodies'. They were well used!'*

**At a Children's Rights Conference in a Greenock High School,** Dagmar met some carers who contacted her later to ask about specific rights of the young people in their care. **One said:** *'Thank you for your time and for listening. You have helped me a lot and I'll be able to take action on some of these points.'*

**A key aspect of Dagmar's work is to** ensure the needs of sick children, young people and their families are taken into account by those responsible for child health policy and delivery. During the year she worked with a group of doctors, nurses and physiotherapists in Glasgow to develop a transition pathway for young people with cerebral palsy who are moving from paediatric to adult services. Transition is an important issue and not only for health boards; it is being looked at with interest at a national level and in March the Scottish Parliament Health and Sports Committee heard evidence from ASCS and others on the issue of transition from paediatric to adult healthcare.

Following its Clinical Services Review, NHS Greater Glasgow & Clyde is in the process of setting up paediatric community outreach clinics for certain conditions. **Dagmar's input ensures that support** services like play provision, and a child friendly environment are considered alongside governance and clinical work in the provision of excellent care closer to home for young patients and their families.

Dagmar has continued to work on the Scottish Government Stakeholder Group reviewing the Guidance on Education of Children Absent from School through Illness. The Guidance is due for publication in 2014.



Learning through play

## Special Smiles

Our Dental Project, funded by the Third Sector Early Intervention Fund, worked in 24 additional support for learning schools in Lanarkshire. Teachers have been very enthusiastic and one said, **'It's fantastic to see resources that are designed with our children's needs in mind - a rare occurrence to not have to adapt resources to fit their needs!'** Over the year we trained 106 teachers to use our dental play resources.

We also supported 225 parents, 62 of whom borrowed a dental play pack to use at home. This helped prepare their children for dental treatment and oral health practices such as tooth brushing.

724 children used the resources, learning through play about good oral health and how to deal with worries about the dentist. Our project team actively supported 266 children; 97 completed before and after quizzes which showed increased oral health understanding and practices; increased confidence about the dental environment; and reduced anxiety.

Feedback from teachers and parents demonstrates the hugely beneficial impact. **'I have had fantastic feedback from the parents you have been working with. It is brilliant that you can help us to deal with something that many of us take for granted but has such a huge impact on a family if there are problems. The resources have already benefited the children in many ways.'** Principal Teacher, Crosshouse School.

One parent said, *'My son has autism. We struggle on a massive level with him and his oral health. He doesn't allow me to help him but he can't always help himself. I wish I had had this box years ago to start us off with tooth brushing and the dentist - can't wait to borrow the pack!'*

Another parent told us, *'The playpack made a huge difference to my twin sons*

*who are autistic. They have been twice to the dentist since using it. They have had their teeth cleaned by the dentist. They were really good at the dentist as they knew what to expect, had used the playpack before going. They were terrified before! It was a worry!'*

Another said, **'Thanks - my daughter has been able to complete a course of treatment using the multi-sensory story mainly. She walked through the steps with me right through to making another appointment at reception. It gave her a sense of security knowing what to expect.'**

**And another...** **'Jamie thoroughly enjoyed playing with the pack and loved the role play of being a dentist along with his sister. This pack has helped Jamie as he is more enthusiastic when brushing his teeth and more confident in going to the dentist. I had a really hard time with Jamie before this, with getting him to brush his teeth and also to get him to behave at the dentist. Since using the playpack he has improved in his behaviour and is much better. Two adults are no longer needed to take Jamie to the dentist and he no longer displays stress. I have seen a huge improvement in Jamie and it is down to the dental playpack - it has really helped.'**



In the year to 31 March 2014, our projects directly supported 342 families caring for 673 children.

We provided information to 2,344 families on child health rights; how to access healthcare; how to prepare children and young people for medical or hospital treatment and how to cope with painful procedures and needles.

We worked with 504 health, education, social work and voluntary sector professionals in various working groups and committees.

# young people, families and professionals

## West Lothian Child Self Management

Our 'Managing Me' pilot project for children aged 8-12 years in West Lothian, represented a continuation of our work supporting children living with long term conditions and their families. The Project developed and tested age-appropriate activities with children and information for their parents/carers. This was well received, found to be helpful and informed the content of the joint pilot sessions for children and parents. These sessions covered communication; developing friendships; coping with emotions and worries; and increasing confidence. The adults also had separate sessions on GIRFEC and the named person; how to help their child to cope with pain; and understanding and coping with bullying.



Communication Workshop

One very positive aspect was that parents and children were able to discuss concerns and successes in a peer environment.

Two families had a child with type 1 diabetes. Anna was diagnosed at 2 years and at 10, she struggled with food choices, with injections, and awareness of potential low and high blood sugar episodes. Her attempts to inject insulin had been unsuccessful, and her parents and carers had to do this for her. The preferred treatment option was for Anna to have an insulin pump, but the family resisted this because they were worried about the changes and learning this would involve.

Leanne, age 11, was diagnosed at 8 years. This had been emotionally very difficult, but she and her parents had quickly learned to control her diabetes with dietary changes and insulin injections. Leanne had eventually been fitted with an insulin pump which improved her quality of life and overall health. She had an active sporting and social life and coped very well with her pump at school and on outings.

When the two families met, they discussed the positive impact a pump could have.

**As a result Anna's family decided to move from four daily injections to a diabetes pump.** This shows how providing an opportunity for parents and children to discuss concerns with one another can **result in an improvement to a child's health and quality of life.** (Note: names of children in our report have been changed)

## Children and Young People In and Leaving Care

The National Foster Care Review, launched in January 2014, recommends that Foster Carers have access to continuous learning and development, training and if appropriate, qualifications opportunities and support to provide the best possible care for their children.

We are therefore delighted to have delivered training to 140 participants (Foster Carers, Kinship Carers and a small number of staff working with looked after children with complex health needs) via 17 sessions in the following areas: Midlothian, Edinburgh, Glasgow, Falkirk, Dundee, Livingstone, Ayr, Fife, Forth Valley and Dumfries and Galloway.

The sessions aim to help Carers understand the healthcare rights of children and young people and give them greater ability to manage children and **young people's overall healthcare needs.** Carers have an opportunity to raise questions in the course of sessions and as necessary, we provide them with further information after the session and extra resources on request.

Feedback has been excellent. 88% of Carers rated an increased knowledge about how to access health services and 77% rated increased confidence in



Photo: NHS Health Scotland

supporting their child. One Foster Carer said, **'Following the session, I was empowered to have the confidence to ask for a referral for my child and this resulted in them getting much needed help.'**

The sessions also provided excellent opportunities for peer support and learning. For example, a participant in a session on Mental Health and Well-Being raised the issue of children hoarding food and keeping food under their beds. Another carer spoke about how she had successfully dealt with a similar problem by providing the child with their own box of food stuffs to keep, so that the child could feel more secure and in control of their fear of having nothing to eat. She described this technique in great detail to the other Carer.

Outputs for the year included session descriptors for each workshop, a podcast with a Foster Carer and a resource covering questions asked by Carers. Feedback from organisers and agencies gathered through the external Evaluation process has also been positive and included the following:

**'We appreciated the interactive nature of the training and discussions – the trainer was good at allowing discussion while keeping the training on track.'** and

**'The trainer was very good at adapting the training to the audience.'**

## Family Participation

Our Family Participation Group enables families, parents and carers to have their voices heard on issues concerning their **child's health and in so doing to influence child health policy and practice.**

**Many organisations ask us for families' views on a range of issues.** Our Parent and Carer views were presented to the **Scottish Government and to Scotland's Commissioner for Children and Young People on the Administration of Medicines and Health Care Procedures in Schools and on Toilet Provision in schools.** The Group also provided helpful user perspectives as we reviewed our Information Guides on Helping children cope with pain and needles. One member presented an eloquent account of her experiences of visiting and staying with her children in hospital to an audience of 50 at an ASCS event held in the Scottish Parliament to discuss the findings of our 2012-13 Parental Access and Family Facilities Survey.

Another highlight was a Participation Learning event held with the Royal College of Paediatrics and Child Health in March, at which 16 participants shared ideas on Participation, explored the challenges and shared examples of best practice.

# Finance and Funding

## Executive Committee 2013-14

Professor Richard Olver (Chair)  
 Margaret Rooney (Vice-Chair) (*until August 2013*)  
 Jim Robinson (Vice-Chair) (*from November 2013*)  
 Duncan McEachran (Treasurer)  
 Frances Barbour  
 Alison Closs (*from August 2013*)  
 Dr Zoe Dunhill  
 Gwen Garner  
 Marjorie Gillies (*until November 2013*)  
 Dr Una MacFadyen  
 Simon Robinson (*until November 2013*)

## Staff

Mary Cox, *Dental Project Officer*  
 Amy L Joss, *West Lothian Child Self Management Project Officer*  
 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  
 Lady Caplan  
 Rory Farrelly, *Director of Nursing, NHS Greater Glasgow & Clyde Acute Operating Division*  
 Jacqueline Reilly, *Discharge Co-ordinator, Royal Hospital for Sick Children Glasgow*  
 Professor George Youngson

## Grateful thanks to our funders and supporters

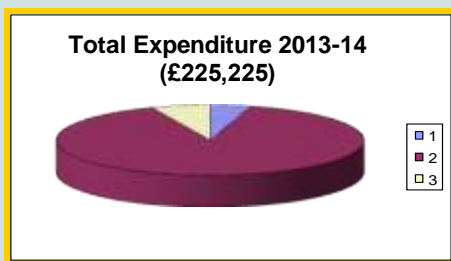
Third Sector Early Intervention Fund, BBC Children in Need, The Binks Trust,  
 Jenny Lowe, Margaret Gilbride School of Dancing, NHS Greater Glasgow & Clyde Endowment Funds, Scottish Government Early Years Early Action Funding from Inspiring Scotland, Scottish Government Healthcare Policy & Strategy Directorate, Snowball Trust.



The Margaret Gilbride School of Dancing has raised more than £10,000 over the years for ASCS in programme sales.

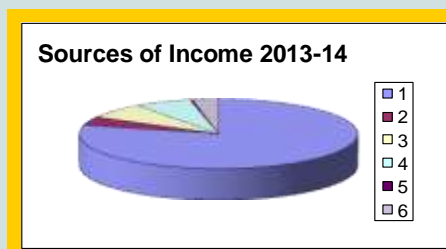


Income April 2013- March 2014	2014 £	2013 £
1. Voluntary Income	169,742	222,111
2. Activities for Generating Funds	3,676	2,455
3. Investment Income	1,291	1,407
4. Income from Charitable Activities	-	259
	<u>174,709</u>	<u>226,232</u>



Expenditure April 2013 - March 2014	2014 £	2013 £
1. Cost of Generating Voluntary Income	8,817	8,526
2. Charitable Activities	204,687	176,712
3. Governance	<u>11,721</u>	<u>12,234</u>
	<u>225,225</u>	<u>197,472</u>

Summary Balance Sheet as at 31 March 2014	2014 £	2013 £
Fixed Assets	750	1,243
Current Assets	<u>117,054</u>	<u>166,333</u>
	117,804	167,576
Current Liabilities (creditors/accruals)	4,583	3,839
Deferred Income	-	-
Net Assets	<u>113,221</u>	<u>163,737</u>



1. Third Sector Early Intervention Fund	78.9%
2. Scottish Government	4.1%
3. BBC Children in Need	7.2%
4. Other Trusts	6.6%
5. Other Donations	0.2%
6. Other Income	3.0%

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 Jeffrey Crawford & Co

Bankers The Royal Bank of Scotland Plc

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

Centre for Excellence for Looked After Children in Scotland (CELCIS)  
City of Edinburgh Council Multi-Agency Advisory Group  
Kinship Care

**for Scotland's Disabled Children**

Health and Social Care Alliance, GIRFEC Project Advisory Group  
Healthcare Improvement Scotland: Scottish Paediatric Patient Safety Programme, Clinical Reference Group  
Health Information Services at NHS 24 (formerly Health Rights Information Scotland)  
Mental Health Foundation, Mental Health of Young People with Long Term Conditions Steering Group  
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; Steering group for pilot of paediatric community outreach clinics*  
NHS Lothian – *RHSC + DCN – Little France: Project Stakeholder Board*  
Royal Hospital for Sick Children Glasgow - *FILES Committee; The Rights of the Child Group; Family Support Service, Chaplaincy team*

**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  
Royal College of Paediatrics and Child Health  
Scottish Commissioner for Children and Young People (SCCYP) - *Administration of Medicines in Schools working group and SCCYP Toilet Campaign – Flushed with Success*

**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 Health Council  
Scottish Health Play Specialist Network Group  
Strategic Paediatric Educationalists and Nurses in Scotland (SPENS)

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

We have also worked with Fife, Dumfries & Galloway and Falkirk Social Work Departments; Glasgow City Council, South Lanarkshire and North Lanarkshire Education Departments; NHS Fife; NHS Greater Glasgow and Clyde Oral Health Directorate; NHS Lanarkshire Dental Services.



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