



Their Health Matters

**Annual Review
and Impact Report 2014-15**



Action for Sick Children Scotland

**Promoting the Healthcare Rights and Needs of
Children and Young People**



Who We Are and What We Do

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 every child and young person to exercise their rights to healthcare and to have these rights upheld, and their healthcare needs met, in partnership with their parents, carers and professionals. We do this through direct support and advice, influencing policy and campaigning for service improvement.

Executive Committee 2014-15

Professor Richard Olver (Chair)
Jim Robinson (Vice-Chair)
Duncan McEachran (Treasurer)
Frances Barbour (*until August 2014*)
Mary Boyle
Alison Closs
Dr Zoe Dunhill
Gwen Garner
Jane Holmes (*from December 2014*)
Dr Una MacFadyen

Staff

Deborah Brown, Area Officer (*Tayside*)
Mary Cox, Dental Project Officer (*until June 2014*)
Mary-Flora Ferris, Dental Project Officer
Amy L Joss, Project Officer Lothian/Central (*until January 15*)
Locum Dental Project Officer (*from January 2015*)
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 (*until February 2015*)
Frances Barbour
Melanie Brown
Lady Caplan
Rory Farrelly, Director of Nursing, NHS Greater Glasgow & Clyde Acute Operating Division (*until April 2014*)
Gita Ingram (*from February 2015*)
Dr Michael Morton (*from December 2014*)
Jacqueline Reilly, Discharge Co-ordinator, Royal Hospital for Sick Children Glasgow
Professor George Youngson

Chair's Report - highlights of the year

2014-15 has been a year of substantial achievement for ASCS.

Major highlights include our November conference 'Person Centred Healthcare for Children and Young People - Myth or Reality?', our Parental and NHS Board Surveys of food provided for children in hospital, the award of a national prize to our Special Smiles Dental Project, the appointment of an Area Officer to work in NHS Tayside, and the publication of the revised Scottish Government Guidance on the Education of Children and Young People Unable to Attend School due to Ill-health.

- The ASCS conference was covered extensively in our Winter Newsletter (<http://www.ascscotland.org.uk/default.asp?page=16>) and I will not dwell on it here, suffice to say that it was generally agreed to be a great success – due in no small part to the contributions made by the young people themselves.

- Findings from our 2012-13 Parental Access and Family Facilities Survey prompted us to carry out surveys of parents/carers and Health Board Dietetic and Catering leads. The results, which demonstrated that there is much room for improvement in the quality, range and presentation of food provided for children in hospital, were sent to the Scottish Government group reviewing the 'Food in Hospitals (Scotland) 2008 Guidance' and as a result ASCS has become a member of the review's Paediatric Short Life Working Group.

- The Special Smiles Dental Project works with additional support for learning schools using dental play resources, developed for children and young people with complex and additional support needs. Over the past year it extended to schools in Falkirk, East and West Dunbartonshire and supported schools in South and North Lanarkshire. Evaluation feedback from teachers, children and parents/carers shows significant improvement in children's oral health understanding and practices and reduced dental anxiety. As a result of its work with NHS Lanarkshire, the Special Smiles Team won the Patron's Prize at the National Oral Health Promotion Group meeting in Manchester and was a runner up in the Bright Smiles-Bright Futures category at the International Association of Paediatric Dentistry conference in Glasgow earlier this year, both of which received national press coverage.

- The appointment of an Area Officer based in Tayside brings to an end a two year gap in the provision of support in the Tayside NHS area. As with our Area Co-ordinator in NHS Greater Glasgow & Clyde, the Tayside Officer represents the needs of sick children, young people and their families on a range of committees and working groups and has provided practical support, information and advice to families caring for a sick child.

- We have been a member of the Stakeholder Group reviewing Scottish Government Guidance on the Education of Children and Young People Unable to attend School due to Ill-health, set up as a result of our long running campaign. We hope that the revised document, although not mandatory, will result in appropriate, equitable education at times of illness for all sick children and young people.

Ongoing and Future Work

With the exception of the educational stakeholder review group, which has now been wound up, we will continue work in the areas highlighted. Additionally we will continue to promote the importance of children and young people's healthcare rights in various NHS committees and working groups including the national Children and Young People's Health Support Group, Scotland's Paediatric Patient Safety Programme (Clinical Reference Group), The Administration of Medicines and Healthcare Procedures in Schools Working Group, currently reviewing the 2001 Guidance. ASCS will continue to offer families opportunities to influence child health policies and delivery through its Family Participation Group.

Other important work to be continued from previous years includes the Children and Young People in and Leaving Care Project which delivers workshops to foster and kinship carers. Feedback shows that these help carers to better support the health needs of children and young people in their care. A DVD on health issues for looked after children and young people, aimed at foster carers and agencies involved in the care of the looked after child, was also produced.



Professor Richard Olver

During the past year ASCS has engaged in dialogue with the Scottish Paediatric Anaesthetics Network over the presence of parent/carers during induction of anaesthesia and at recovery and we plan to survey the experience of parents and carers in the current year.

An exciting new project on self managing chronic illnesses, to be undertaken in partnership with The Royal Hospital for Sick Children (Edinburgh), builds on our previous work in Lanarkshire and West Lothian and is due to begin in August 2015.

Last, but definitely not least, we will step up our campaign for better mental health services for children and young people, calling for parity with physical health.

Welcome

We welcome new Executive Committee member Sylvia Smith, Professional Advisors Michael Morton and Gita Ingram, Deborah Brown, Tayside Area Officer and Mary-Flora Ferris, Dental Project Officer.

Thanks

We are grateful for the generous support of our funders and fund raisers and also to our office volunteer, Jenny Lowe.

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

Richard Olver, Chair

Helping to make a difference

Supporting Carers

Our Children in and Leaving Care Project has continued to work directly with foster and kinship carers, supporting them with the challenges they face in their caring role. Over the year we delivered training workshops to 118 carers helping them to improve their knowledge and understanding of the health care needs and rights of the children and young people they look after.

The workshops aim to improve health and wellbeing outcomes for this vulnerable group by supporting their carers to access primary medical care and specialist health services on behalf of those in their care. The workshops cover child health rights; consent and confidentiality; mental health and well being and dental and hospital play. During the year we also developed a DVD resource specifically for foster carers and those working with them. It addresses some of the key issues raised by foster carers during workshops and includes interviews with carers, health and social work professionals.

Case Study - A Foster Carer's Story

Jane is a foster carer who attended our training. She contacted us some time later as she had been finding it difficult to access appropriate help for three children, all siblings, in her care. The children were all severely affected by their experience of abuse and related trauma while with their birth family. The eldest child in particular was extremely fragile and with behaviour so disturbed that the placement was at risk. The children had moved from their home local authority to be cared for in another receiving local authority through an independent fostering agency. There was a Permanence Order pending and so their case had either not yet been transferred to the new authority, or the transfer had not yet been concluded.

The children desperately needed help from the child and adolescent mental health service (CAMHS) but the Health Board in the new local authority had not progressed the referral to CAMHS. The family could have received support from the LAC (looked after children) CAMHS team in the originating Health Board area but this was impractical because of the huge travelling distances involved.

The foster carer was becoming increasingly desperate and did not understand why CAMHS in the receiving area had not picked up the referral. It appeared as if the Health Board where the children were now living were using the fact that the case had still not been transferred as a reason not to see the child (and that the implementing authority was still responsible.) It was also possible that CAMHS had taken the position not to see the child without first obtaining a formal psychiatric diagnosis.

We were able to advise the carer that a pending Permanence Order should not prevent children accessing the help they need. Health guidelines are very clear. The responsibility lies with the Health Board where the child currently resides to provide services in the same way as it would provide GP and dental services. We also advised Jane that when a child is showing such severe symptoms of trauma that CAMHS should provide other support, including consultation advice to the carer, pending a formal diagnosis.



Photo: NHS Health Scotland

As a result of our help, the carer was able to take this forward and access the appropriate service. She told us, ***'I think this is such an important subject. I will recommend to my Independent Fostering Agency they organise further ASCS workshops on mental health and emotional well-being for their carers.'***

Bernadette O' Beirne, Workforce Development Officer with Fife Council writes about the benefits the Project has had for those she works with.

'The training provided to our foster carers by ASCS has proved really useful for many foster carers, particularly when they are grappling with issues relating to consent and confidentiality and mental health issues. The session relating to supporting children with dental and hospital visits has also been very well received and the carers who attended have indicated that they feel more able to support children in these areas. As carers noted in the evaluation feedback:

'I am confident that I would be now able to identify strategies to help cope with any issues that arise'

'The facilitator was really good and sent the follow up information I requested quickly.'

The organisation of the training has also been excellent and communication always clear, making it easier to facilitate this training arrangement. There is a clear sense of enthusiasm to support foster carers through passing on relevant information which ultimately benefits the child. Many thanks to ASCS for providing this service.'

Early Intervention for better outcomes

Supporting Children

Our Special Smiles Dental Project went from strength to strength, training 221 teachers in additional support for learning schools throughout North and South Lanarkshire, East and West Dunbartonshire and Falkirk. This work, funded by the Scottish Government Third Sector Early Intervention Fund, helps children with additional support needs to look after their oral health and aims to reduce worries about visiting the dentist through the medium of play. 482 children and 72 parents used our dental play resources.

Evaluation showed increased child understanding of tooth brushing and healthy diet and less dental anxiety. Teachers and parents said that they felt much more able to support the children's oral health.

Case Study - A Parent's Story

Gina, whose son Lee attends Clydeview Nursery in North Lanarkshire, borrowed our dental playpack to play with her son at home. After four weeks she talked to us about how it was helping Lee learn about healthy eating, caring for his teeth and preparing for his next dental appointment. Her son has additional support needs and delayed speech and so communicating his needs can often be very difficult for him when looking after his diet, caring for his teeth and for his dental experience. Mum found all the materials useful and explained what she thinks has changed for the better.

'The resources helped Lee understand about healthy snacks and how to brush his teeth correctly and to follow a routine more often. He has dressed up and played with the mask, mirrors and uniforms every night. He wants to take the puppet to bed and has given it a name, Gogo!

The big mouth allowed him to practise brushing teeth and he loved the puppet very much as he learned to care for Gogo's teeth. This helped him take more responsibility for caring for his own teeth. He particularly enjoyed playing with the large toothbrush and became really attached to it.

The dressing up clothes have helped him to understand the dental instruments and given him more confidence to go to the dentist. On his next appointment he is going to dress up and go to the dentist in his dental uniform.

Lee can only concentrate for five minutes at a time, but he kept coming back to watch the DVD 'A Child's Eye View of the Dentist' and it helped him to be more confident in general. He played with the lunchbox game a lot and now

understands more about foods that are healthy for his teeth. We played with it after school and before bedtime when we read the stories to prepare for his visit to the dentist'.

Gina was so enthusiastic about the play resources that she kept the playpack for another six weeks. Lee visited the dentist after the summer break and his Mum told us, **'Lee was very anxious before going into the surgery but he had dressed up in the dental uniform from the playpack and once there he became very excited. He was so much better at sitting in the chair than before when he didn't like the noise or the lights and he would refuse to sit in the chair. As he had practised at home with the tools in the playpack, he understood what to expect at the dentist and he was much improved. The dentist was able to check his teeth and he co-operated really well. I am so happy that I have the playpack at home and my son is now less anxious about having dental treatment.'**

Supporting Teachers

One very enthusiastic and resourceful teacher found Special Smiles very helpful to the children in her class. Celia Snowden of Maddiston Primary in Falkirk described how she put her ideas into action in the classroom.

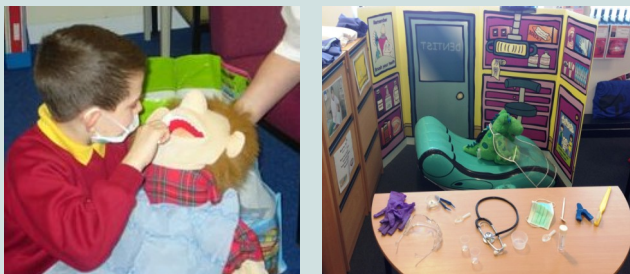
'Early sessions were based around the sensory story and allowing the children to explore the objects. Additional resources were introduced at each session afterwards, for example, the tweezers or cotton swabs were great for fine motor practice. Each session began with the sensory story and when children were comfortable using the items, the play doh pack and role play dentist scene were introduced. We looked at foods that made 'happy or sad teeth' sorting the play foods from the packs and additional unhealthy food samples. In the final two sessions we looked more closely at how some drinks affect teeth and why it is important to brush our teeth. We carried out an experiment using hard boiled eggs left in solutions of cola, coffee and milk and a raw egg in vinegar. Some of the children were able to identify which solution was better for teeth and could see how the brushing removed the staining from the egg shells. A few children were able to complete a pictorial record.

Using the sensory story and resources, along with 'Judy Bear Visits the Dentist' DVD, helped the children develop their role play skills during dentist role play where most were able to use the mirror, brush and other instruments appropriately. The playdoh pack tools, especially the drill, were popular too.

One of the children who used to play with his toothbrush during daily tooth brushing will now allow a little toothpaste on his brush and a short time in the mouth.

The sensory story objects, particularly the mirror, battery toothbrush, mask and glasses as well as the puppet allowed the children to play dentist without having to be patients. I found the playpack very useful particularly the real dental objects allowing children to become familiar with them in familiar surroundings at school and home.'

Names of child and parent have been changed to protect their identity



Schools benefit from a range of play resources

Getting it right for children & families

A most important aspect of our work is to support families caring for a sick child. We are contacted by families worried about issues around their children's health and also by agencies looking for support for families they work with. The following case shows how we helped one family. Mum Julie had initially contacted another charity which referred her to ASCS because of our expertise in children's health rights.

Julie and Andrew

When Julie spoke to our Area Co-ordinator she was beginning to doubt herself and wondered why there were so many things 'just not quite right' with her 10 year old son, Andrew. Mum felt that no-one took her concerns seriously. Andrew had experienced a complicated, premature birth and neonatal problems. He had undergone a difficult infancy and experienced various health problems throughout his childhood. His symptoms never seemed to be related to each other and usually were dealt with by different specialists. None of Andrew's problems were particularly remarkable on their own, but the combination of them all had become a burden of difficulties which had started to hold him back socially, physically and educationally. Andrew would be going to high school in a year's time and his mother was anxious to make sure he got all the support he needed to cope in the new school environment.

What was very clear to ASCS was that there was an apparent lack of co-ordination in Andrew's care. Many different specialists were involved and, while everyone was trying to do their best, no-one seemed to have the full picture. We discussed with Julie her rights in relation to accessing her son's medical information and raising concerns about the care he received. We advised her on the need for Andrew to have a co-ordinated support plan at school and the need for a multi disciplinary meeting to take place with all those involved with her son's care.

Julie acted on these suggestions and now feels that she is taken seriously and that her son's care and support is planned in a much more co-ordinated fashion. She contacted us to say, **'Thank you for listening and for pointing me in the right direction.'**

Prevention and early intervention helps



Dagmar Kerr with young doctor and teddy patient in Glasgow nursery

ASCS staff in Tayside and in Glasgow have worked with nurseries and playgroups to demonstrate how our hospital playboxes can prepare children for hospital or medical treatment or help them to cope after a difficult experience. Many children can benefit from health play and this is a great way for families to find out about how to support their child's health and wellbeing.

Scottish Government statistics show that over 70% of all hospital emergency admissions are for children up to age 4 years and over 50% of planned admissions are for those up to 9 years.

Source: ISD 2013-14 statistics

In the year to 31 March 2015

375 families and 653 children were directly supported through our projects.

5,546 families were provided with information on child health rights; how to access healthcare; how to support the health of children and young people in care; and how to prepare children and young people for dental, medical or hospital treatment.

Promoting Children and Young People's Rights

Through our work the rights and needs of sick children, young people and their families have been widely protected and promoted. During the year:

1,863 health, education, social work and voluntary sector professionals were provided with resources and information, thus increasing their awareness of the rights and needs of sick children, young people and families

We delivered 45 rights based presentations and talks at conferences and events attended by 559 professionals.

We delivered seminars on child health rights and children and young people with complex health needs to 1st and 2nd year child health nursing students at Napier University. One student said,

'It made me think of my role both as a student and a nurse in regards to children and patients' rights. There was a lot of emphasis on individualised thought and care.'

Names of child and parent have been changed to protect their identity

Partnership working - influencing policy

ASCS has contributed to national policy development through our representation on 22 national and regional working groups and committees.

Scottish Government multi-disciplinary working groups have included the Guidance on the Education of Children and Young People Unable to Attend School Due to Ill Health Stakeholder Group; the Administration of Medicines and Healthcare Procedures in Schools Working Group; and the Ministerial Advisory Committee for Children and Young People's Health. We input as a member of the National Foster Care Review Technical Expert Group to the development of a National Learning and Development Framework for Foster Carers. NHS Scotland groups included the Scottish Paediatric Patient Safety Programme, Clinical Reference Group.

We have continued to work closely with NHS Boards representing the needs and rights of sick children and families on various committees. In particular we provided the user perspective during a peer visit of anaesthetists at a hospital paediatric anaesthetic department; we commented on service redesign and patient pathways; input into child health strategy and advised on the incorporation of children and young people's rights in children's services. We share innovative practice across Scotland so that all Health Boards could benefit.

We contributed to Scottish Government consultations including the Draft Statutory Guidance on the Children and

Young People (Scotland) Act 2014. We have communicated with Scottish Government Ministers on transition from paediatric to adult health services and education at times of illness. We met with Scottish Government officials to discuss issues around, Getting it right for every child; GP training in child health; Education when ill. Our campaigning activity for nutritious food for children in hospital has informed the revision of the Scottish Government Food in Hospital (Scotland) 2008 Guidance. With the support of MSPs Alison McInnes and Dr Richard Simpson we have raised questions in the Scottish Parliament on issues around education, and child and adolescent mental health services.

Our projects have worked closely with local authority education and social work departments. We have also collaborated with a range of third sector partners, one example of which is our work with the Mental Health Foundation's project 'Mental Health of Young People with Long Term Conditions' where we have provided hands on support in the delivery of the project.



We WORK IN PARTNERSHIP with the following to represent the views and needs of sick children, young people and families

Association of Paediatric Anaesthetists
Borders District General Hospital – New Children & Young People's Centre Project Team
Centre for Excellence for Looked After Children in Scotland (CELCIS)
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)
Enquire Scotland
Nursing and Midwifery Council (NMC)
Mental Health Foundation, Mental Health of Young People with Long Term Conditions Steering Group
National Association of Health Play Specialists
NHS Forth Valley Child & Young People's Health Strategy Group
NHS Greater Glasgow and Clyde - Community Engagement Team - Youth Panel and Family Panel, Stakeholder Group for Transition for Children and Young People with cerebral palsy; Patient Panel Health Improvement Team

Paediatric Subgroup of the National Chronic Pain Steering Group
Palliative and End of Life Care for Children and Young People in Scotland Group
Royal Hospital for Sick Children Glasgow - FILES Committee; The Rights of the Child Group; Family Support Service
Scottish Children and Young People's Palliative Care Network
National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN) – Steering Group and Education and Service Users Group
Royal College of Paediatrics and Child Health
Scottish Commissioner for Children and Young People (SCCYP)
Scottish Government Children and Young People's Health Support Group
Scottish Government Guidance on the Education of Children and Young People Absent from School due to Ill Health Review Group
Scottish Government Administration of Medicines and Healthcare Procedures in Schools
Scottish Government Guidance on Food in Hospital Review Group
Scottish Health Play Specialist Network Group
Scottish Transition Forum, ARC – transition standards for young people
Scottish Epilepsy Centre
Strategic Litigation Steering Group
Strategic Paediatric Educationalists and Nurses in Scotland (SPENS)
The Fostering Network
UK Committee for Children and Young People's Nursing

In addition we have worked closely with Fife, Dumfries and Galloway, East Lothian and Perth and Kinross Social Work Departments; Glasgow City Council; North and South Lanarkshire Education Departments; East and West Dunbartonshire, Falkirk Council, NHS Forth Valley NHS Lanarkshire Dental Services.

Finance and Funding

Grateful thanks to our funders and supporters

We are very grateful for support from the Scottish Government Third Sector Early Intervention Fund, NHS Greater Glasgow & Clyde Endowment Funds and from the following Trusts:

Aberbrothock Skea Trust
Alexander Moncur Trust
The Binks Trust
Grant Charitable Trust
Harold Merton Adams Trust
Leng Trust
Moffat Charitable Trust
R J Larg Trust
Snowball Trust
Widowers' Children's Trust.

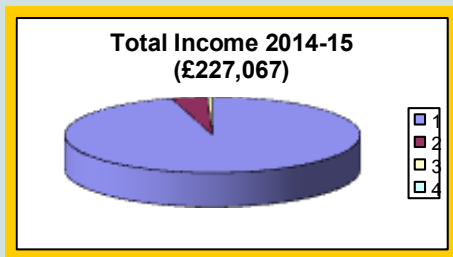
Thanks also to
Adopt an Intern
Jenny Lowe and
The Margaret Gilbride School of
Dancing
for their support during the year.

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

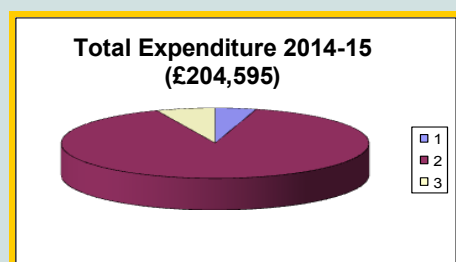
Independent Examiner Jeffrey Crawford & Co

Bankers The Royal Bank of Scotland Plc



Income April 2014- March 2015

	2015 £	2014 £
1. Voluntary Income	216,883	169,742
2. Activities for Generating Funds	8,861	3,676
3. Investment Income	1,323	1,291
4. Income from Charitable Activities	-	-
	<u>227,067</u>	<u>174,709</u>

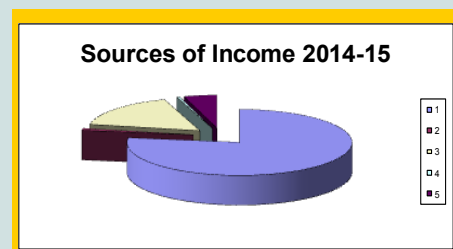


Expenditure April 2014 - March 2015

	2015 £	2014 £
1. Cost of Generating Voluntary Income	8,943	8,817
2. Charitable Activities	182,793	204,687
3. Governance	12,859	11,721
	<u>204,595</u>	<u>225,225</u>

Summary Balance Sheet as at 31 March 2015

	2015 £	2014 £
Fixed Assets	375	750
Current Assets	141,123	117,054
	<u>141,498</u>	<u>117,804</u>
Current Liabilities (creditors/accruals)	5,805	4,583
Deferred Income	-	-
Net Assets	<u>135,693</u>	<u>113,221</u>



1. Scottish Government Third Sector Early Intervention Fund	77.2%
2. Adopt an Intern	1.0%
3. Trusts	16.7%
4. Other Donations	0.4%
5. Other Income	4.7%



Action for Sick Children Scotland, 22 Laurie Street, Edinburgh EH6 7AB

Telephone: 0131 553 6553 **E-mail:** enquiries@ascscotland.org.uk

Website: www.ascscotland.org.uk

Facebook: Action for Sick Children Scotland

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