



Annual Review 2007-2008



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

Chairs' Report - Our Year in Focus



Gwen Garner (left) and Melanie Brown

Action for Sick Children (Scotland) is the only charity in Scotland which represents, promotes and safeguards the interests of all sick children and young people. Whilst our core purpose remains that of influencing and collaborating to secure best health care outcomes for sick children and young people, our activities also reflect the dynamic developments in the planning and delivery of health care in Scotland today.

Since 2006 the Scottish Government's National Steering Group for Specialist Children's Services has led the most comprehensive review ever undertaken in Scotland and drawn up the National Delivery Plan. We welcome this piece of work and are pleased to have been involved in the whole process of its development, from being the only voluntary organisation represented on the National Steering Group, to have contributed, alongside other user organisations, on individual working groups such as Age Appropriate Care and Children's Cancer Services.

During the year our Project Officer in Tayside and Angus completed a project which surveyed the impact on families when they have a sick child. The resulting report has highlighted the need for families to have better knowledge of their rights and sources of help from health professionals and voluntary organisations. Her new project focuses on supporting vulnerable families including teenage mothers and their children, by raising their awareness of their healthcare rights and

responsibilities. For the past two years our Big Lottery funded project officers, based in Central Scotland, North of Scotland and in Ayrshire, Lanarkshire and Renfrewshire have worked to ensure that a total of 2,448 children, young people, families and carers understand their health care rights and responsibilities when accessing health services. An outcome has been the development of a Children and Young People's Healthcare Rights Resource Pack, which can be used by anyone working with children and young people on health issues. The pack includes DVDs, which interpret the EACH (European Association for Children in Hospital) charter points, as understood by the children and young people who helped to make the films.

In Greater Glasgow & Clyde our Area Co-ordinator continues to represent the views of children, young people and their families on various committees, including the planning group for the new children's hospital for Glasgow.

In February we published our 2005-07 Family Facilities Report which surveyed Scottish hospitals admitting children to their wards.

Our Boots Plc funded Dental Project concluded in July with the development of an innovative dental play resource for use by children and young people with a range of complex and additional support needs. The project also reported on the current preparation and support available for children requiring surgical dental treatment at hospital and encouraged the NHS Dental Services to adopt standards of care for the provision of appropriate preparation. A new leaflet 'Preparing your Child for Dental Treatment' was also produced and distributed widely. Following on from this we were delighted in November to start work on our new Special Smiles Dental Project, funded

for two years by the Scottish Government. This project will pilot our 'special needs' dental play resources in up to 30 'special needs' schools in Tayside. Our Special Smiles Dental Project Officer and Project Co-ordinator have been making good progress and the project has been well received.

Our Development Officer has been active in forging links with vulnerable, hard to reach groups, particularly focusing on 'looked after children and young people' and has been in contact with health professionals working in this field to discuss how we can help.

Our National Co-ordinator, who is pivotal to the running of the organisation, has undertaken many tasks, including working with the staff and Executive committee and on funding, publications, policy, etc.

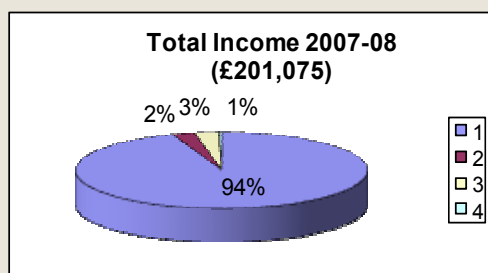
During the year under review we were delighted to welcome four new Executive Members: Richard Olver Emeritus Professor of Child Health, University of Dundee, Frances Barbour who is an Early Years Lecturer and Play Specialist and Jan Maxwell, Transition Co-ordinator for NHS Lothian. We also welcomed back Dr Una MacFadyen, Consultant Paediatrician, Stirling Royal Infirmary. In the months ahead we look forward to working with two new members, Robert Macfarlane who has an extensive business background, and Dr Zoe Dunhill who has recently retired as Clinical Director for Children's Services, Royal Hospital for Sick Children, Edinburgh.

We would like to thank the Executive Committee, staff and volunteers for all their hard work and dedication which has enabled us to work towards our vision for gold standard healthcare to be provided for all sick children and young people in Scotland.

Melanie Brown, Gwen Garner, Co-Chairs

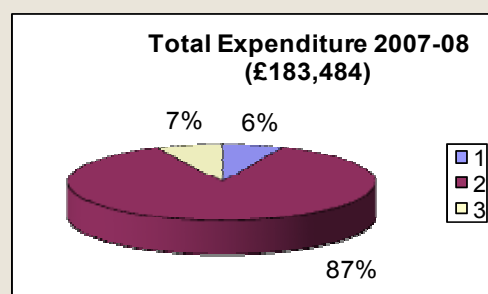
'Our vision is for gold standard healthcare to be provided for sick children and young people in Scotland'

Finance and Funding



Income April 2007 - March 2008

	2008	2007
	£	£
1. Voluntary Income	190,209	157,245
2. Activities for Generating Funds	4,919	5,322
3. Investment Income	5,271	2,560
4. Income from Charitable Activities	<u>676</u>	<u>476</u>
	<u>201,075</u>	<u>165,603</u>

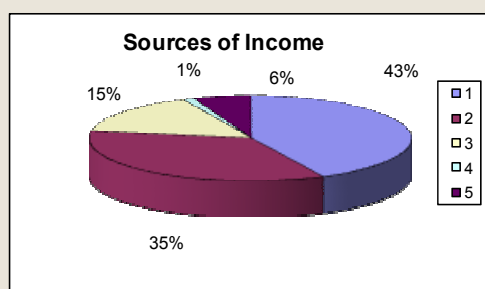


Expenditure April 2007 - March 2008

	2008	2007
	£	£
1. Cost of Generating Voluntary Income	11,734	7,134
2. Charitable Activities	158,966	118,441
3. Governance	<u>12,784</u>	<u>13,872</u>
	<u>183,484</u>	<u>139,447</u>

Summary Balance Sheet as at 31 March 2008

	2008	2007
	£	£
Fixed Assets	1,939	1,475
Current Assets	<u>213,035</u>	<u>81,449</u>
	214,974	82,924
Current Liabilities (creditors/accruals)	3,934	2,151
Deferred Income	<u>112,676</u>	-
Net Assets	<u>98,364</u>	<u>80,773</u>



1. Scottish Government	43%
2. Big Lottery Fund	35%
3. Trusts	15%
4. Other Donations	1%
5. Other Income	6%

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

We are grateful to the following who supported our work during 2007-08

Big Lottery Fund, Binks Trust, Gannochy Trust, Lord Provost's Fund (Dundee), Jenny Lowe, Lloyds TSB Foundation for Scotland, Stuart McMonagle, Moffatt Trust, NHS Greater Glasgow & Clyde, Order of St Lazarus, R J Larg Family Trust, Scottish Government Department of Health & Wellbeing, Snowball Trust, Widowers' Children's Home Trust, St Katherine's Fund

Executive Committee 2007-08

Melanie Brown (Co-Chair)
 Gwen Garner (Co-Chair)
 Gael Murchison (Vice-Chair)
 Duncan McEachran (Treasurer)
 Lady Caplan (until September 2007)
 Deborah Catty
 Dr Una MacFadyen (from October 2007)
 Jan Maxwell (from March 2008)
 Liz Nicol (until September 2007)
 Professor Richard Olver (from December 2007)
 Jean Swaffield (until August 2007)

Company Secretary/National

Co-ordinator Elizabeth May

Staff

Fiona Bartley-Jones, Project Officer Tayside
 Amy L Joss, Project Officer Central Scotland
 Dagmar Kerr, Area Co-ordinator Greater Glasgow/Clyde
 Sheila Lawtie, Project Officer North of Scotland
 Karen Martin, Project Officer Lanarkshire, Renfrewshire & Ayrshire
 Catherine Nelson, Dental Project Co-ordinator
 Gill Sutherland, Dental Project Officer (from Jan 2008)
 Anne Wilson, Development Officer (from July 2007)

ASC(S) Advisers 2007-08

Jonathan Bryden, Head of Finance, Clyde Community Health Partnerships

Dr Zoe Dunhill, Clinical Director for Children's Services, Royal Hospital for Sick Children Edinburgh (until March 2008)

Rory Farrelly, Director of Nursing, Southern General Hospital, Greater Glasgow and Clyde Health Board

Jacqueline Reilly, Health Visitor, Royal Hospital for Sick Children Glasgow

Finance Officer

Alison Glass FCCA

Auditor

Barstow & Miller

Bankers

The Royal Bank of Scotland Plc

Our Activities - How We Help



In the year ending March 2008 we worked with 7,714 children, young people, families, voluntary groups and health care providers

We provide direct support, resources and information

'Our son was very much helped to talk about issues that were troubling him from his visits to professionals. The play box eased his frustrations and anxieties by giving him a way to talk to us about what was really troubling him. There needs to be more widely available resources such as this. I am so pleased that I met with Amy, it really helped our boy to regain some control over his situation.' *Father of 5 year old boy needing several specialist surgical procedures*

'The information given was very good and presented in a way we were able to understand, take time to digest and then ask questions. We felt the Project Officer acted as an interpreter between us and the health care staff. She was able to explain what the staff were telling us and she helped us ask questions of the staff.' *Mother of girl (9) admitted to hospital with mental health problem*

'I feel that your intervention was tremendous. Without it I was fighting a losing battle. I was glad that someone else stepped in and talked to the hospital for me and achieved a result. Thank you so much.' *Mother in Dumfriesshire told by the hospital that they could not provide transport at the weekend to take her young child home after surgery. The hospital had also advised she could not travel by bus for fear of infection and she did not have access to a car.*

'ASC(S)' literature was great. It helped me explain to Angus what he should expect. It also encouraged him to ask questions. You also pointed me in the right direction so that I could make good use of the excellent play specialist at Yorkhill Hospital who gave us a lot of support. Angus felt empowered because he was allowed to make choices.' *Mother of 8 year old boy terrified of going to hospital for surgery*

'Fiona always keeps in contact to make sure we are all okay especially my son as he has heart problems. She's always trying to find ways of making my life easier but I don't make it easy for her. She never gives up on me. She has been a great help to me.' *Mother of 8 year old boy, Dundee*

We work to ensure the best standard of child health services

'By providing access to resources, ideas and advice ASC(S) has really helped us to engage children and families in the plans for the new children's hospital in Glasgow. Your willingness to share your experience and expertise has helped us to deliver on our promise to give children, young people and families a voice in the plans for their new hospital. We appreciate the support and encouragement we have received and look forward to continuing to work closely with you.' *Kate Munro Community Engagement Manager, NHS Greater Glasgow & Clyde*

We empower young people to make decisions about their healthcare

'Thank you for coming along to visit the group ... they enjoyed the workshop and it was interesting. It is important that the programme has a mixture of theory and interactive activities, and I think that this was managed extremely well. I particularly liked the traffic lights activity, and the kids seemed to enjoy it also. I thought it was really good how you asked the group questions relating to music and teenage issues to get the kids interested and motivated before asking them questions on health rights and bringing it back to the workshop.' *Young Carers Officer, Central Scotland*

We raise awareness of and represent children's needs

'The Project Officer's insight into the needs of young mums and their babies has made a considerable difference to the development of this new service. Her involvement has been invaluable in helping us think outside the needs of the service and in keeping women at the heart of this development.' *Fiona Greig, Consultant Midwife, NHS Tayside*

We develop innovative solutions to healthcare problems

'I was inspired and excited to see the work you are doing. The dental play boxes are great and fit very well with the idea I outline in my books of playing out the experience in advance. Avril Webster, Author of 'Going to the Dentist'



'Special Smiles' Dental play bag for children and young people with complex and additional support needs

Health Rights of Children and Young People



As a member of the European Association for the Welfare of Children in Hospital (EACH) a key focus for ASC(S) is to promote the EACH Charter. This outlines the rights of children in hospital in the form of 10 Articles and all 19 members are working to have the principles of the Charter incorporated into their countries' health laws, regulations and guidelines. During the past year several Scottish Health Boards have ordered quantities of the EACH charter booklets to disseminate to their staff. This is encouraging since the Charter is recommended by the Scottish Government in *Delivering a Healthy Future: An Action Framework for Children and Young People in Scotland* as a standard against which NHS Boards can assess their Child Health services.

To accompany the EACH Charter booklet we have also produced a new poster which illustrates the 10 Charter points. Both Charters and Posters can be ordered from our national office. We also gave talks on children's health rights to nursing students, hospital play specialists, nursery nurses and as part of the staff induction course at Yorkhill Hospital.



Aside from this, our most successful workshop sessions from our Big Lottery Project have been included in our new Children and Young People's Healthcare Rights Resource Pack. This pack, with accompanying DVDs, can be used by anyone working with children and young people to help them increase their understanding of their rights at times of illness.

'The Children and Young People's Healthcare Rights Resource Pack is so practical and well laid out. The sessions are very interactive and encourage children and young people to discuss health services, experiences and their hopes for future health services. Could have done with this a few years ago but it is very much welcome now and I congratulate Action for Sick Children (Scotland) on their work. Can't wait to use it.' Julie, Health Advisor
NHS Ayrshire & Arran



Volunteer Stories

People get involved as volunteers for lots of reasons. They may have experience of caring for a sick child or know someone who has. Some people may volunteer because they want to be part of a charity which works for sick children and young people regardless of their illness or condition. Our volunteers fulfil many roles, as committee members, advisers, patient representatives, office helpers, fundraisers, and through staffing our stalls at public events. Without volunteers we would not exist. If the following stories from two of our volunteers inspire you, do get in touch to discuss how you could help.

Trisha 'As the mother of a young deaf person with health problems, volunteering has allowed me to have a say in the welfare of children, before and during a stay in hospital. I have spoken at a Community Paediatricians conference allowing me to put forward the parent perspective. I also am the parent representative on the 'Asthma Services for Children and Young People Board Wide Multidisciplinary Group'. It is important to me to put something back and raise the profile of deaf awareness. After all, I have received encouragement and help from so many professionals over the years.'

Lynda 'As a young child I was admitted to hospital on a few occasions, which was a traumatic experience. Also as a parent I had to endure time spent in hospital with my own ill children. As a trained nurse I was able to help alleviate their fears and worries, by giving them all the information and knowledge that they needed. This is why I volunteered with Action for Sick Children (Scotland), so that I can help children and parents deal with issues that may arise in the health service, by giving information about services available and using hospital play boxes and making hospitals a less scary place to be.'

Action for Sick Children Milestones

1900 In the early 1900's James Nicol, who pioneered day surgery, rented a house near the children's dispensary in Glasgow where out patients and their mothers could be accommodated after an operation

1927 Professor James Spence began to admit mothers and babies together in Newcastle

1948 Scot James Robertson joined the Tavistock Clinic in London to study further the effect of early separation from the mother in early childhood. He observed many young children before, during and after a stay in hospital which led to his classic description of a child's response to separation: protest, despair and detachment. He showed 'the greatest single cause of distress is not illness or pain but separation from mother'

1952 Robertson released his films *A Two year Old Goes to Hospital* and later *Going to Hospital with Mother*

1958 Robertson published *Young Children in Hospital* the definitive text for all who care for the emotional well being of sick children. [He later lectured world wide providing inspiration for organisations like ACCH (America) AWCH (Australia), Kind im Ziekenhuis (Holland), Kind in Krankenhaus (Germany)]

1959 The Ministry of Health report *The Welfare of Children in Hospital* published and was strongly influenced by Robertson's work. It made 55 recommendations on the care of children in hospital

1961 Robertson's films shown and discussed on TV. He wrote a series of Observer articles urging community pressure to bring about change. Young Battersea mother Jane Thomas accepted his challenge and under his guidance 'Mother Care for Children in Hospital' was launched. The Association for the Welfare of Children in Hospital Wales began

England

1962 First hospital visiting survey reveals disparities and very limited access for parents

1963 Thirty one member groups formed into one national organisation and first national conference organised

1965 'Mother Care for Children in Hospital' changed to 'The National Association for the Welfare of Children in Hospital' (NAWCH)

1973 *National Survey of Visiting Arrangements, Accommodation and Play Provision* report published - inadequacies reported to Regional Hospital Boards

Scotland

1977 Due to increasing workload NAWCH (Scotland) set up as a separate charity

1980s Two members appointed to Local Health Councils

England

1983 *Survey of Hospital Facilities for Parents* highlights continued restriction on visiting, especially on operation day, and lack of parental accommodation

Scotland

1984 *Working together Parents and Professionals in Special Care Baby Units* joint conference with NCT supported by Twins Club and Neonatal Nurses Group in Irvine

England

1985 The NAWCH Charter itemising standards of care for children in hospital is adopted by the Department of Health and endorsed by over fifty professional and voluntary healthcare organisations. It is later used as a basis for the European Charter for Children in Hospital.

Children in Hospital Action Guide is published by the Consumers Association and NAWCH

Scotland

1985 *Survey on Parental Access and Family Facilities in Wards admitting Children in Scotland*

Joint study day with Play in Scottish Hospitals *Practical Activities and Support for Adolescents in Hospital*

1987 Minister for Education and Health at the Scottish Office welcomes NAWCH Charter
10th Anniversary Conference *Hospital Care and the Adolescent*

1988 *Update of Parental Access and Family Facilities in Wards admitting Children in Scotland*

Europe

1988 The European Association for Children in Hospital (EACH) Charter is agreed in Leiden at the first European Conference on Children in Hospital

England

1989 Publication of *Setting Standards for Children in Health Care*, the first in a series of Quality Reviews aimed at health professionals

1990 Publication of *Setting Standards for Adolescents in Hospital and Quality Management for Children Play in Hospital* (Play in Hospital Liaison Committee)

England and Scotland

1991 NAWCH in England and Scotland adopt campaigning name of Action for Sick Children to reflect the growing number of children nursed in the community

England

1992 Publication of *With Health in Mind*, a review of mental health services for children and adolescents

England and Scotland

1993 Launch of the *Too Dear to Visit* campaign with Contact a Family, to establish a fund for hospital visiting costs

England

1993 Published *Health for all our Children* a guide to the provision of healthcare for ethnic minority children; *Just for the Day* on day surgery and *Bridging the Gaps* on the interface of health services on behalf of the *Caring for Children in the Health Services Consortium*; *When Your Child is Sick* a guide for parents; *Teenagers in Hospital* a young person's guide to staying in hospital

Scotland

1993 NHS Trusts created; Member appointed to Board of Yorkhill NHS Trust Glasgow

England

1994 Parent Advice Line set up. Publication of *Setting Standards for Children Undergoing Surgery* and Parents' booklet, *Helping Children Cope with Needles*
1995 Comments on the Department of Health's draft *Children's Charter*

Scotland

1995 Update of *Parental Access and Family Facilities in Wards admitting Children in Scotland*

England

1996 *Health Services for Children and Young People - A Guide for Commissioners and Providers* is published; oral evidence given to the House of Commons Select Committee on the care of sick children in hospital and in the community
1997 Publication of *Emergency Framework for Children and Young People*
1998 Publication of *Child Friendly Primary Health Care: Youth Matters* (as part of the *Caring for Children in the Health Services Consortium*) focusing on provision for teenagers in hospital; *Pictures of Healthcare: A Child's Eye View* illustrating children's views of hospital

Scotland

1998 21st Birthday Conference, *Empowering the Child and the Family*

England

1999 Millenium Charter for Children's Health written, establishing ten targets for child health in the 21st Century

Evidence provided to the Bristol Royal Heart Surgery Inquiry

Scotland

2000 Member appointed to the Scottish Executive Child Health Support Group. Campaign to have Child Health Commissioners in all Health Board areas is achieved. Published *Update on Family Facilities and Access Survey*
2001 Conference *It all Matters* held jointly with the Scottish Executive Child Health Support Group at which the Minister for Health and Community Care launched the *Child Health Template*

England, Scotland and Wales

2002 As UK member of EACH, contributions are made to work on annotations to the EACH Charter which give detailed explanations of the articles

Scotland

2003 New project set up to pilot dental play box, following the success of hospital play boxes
2004 Conference *Looking after Me: from Policy into Practice*. New Scottish Commissioner for Children and Young People gives keynote speech
Child Friendly Health Check Survey
Campaign to keep the link between maternal and child health with the retention of the Queen Mother Maternity and Royal Hospital for Sick Children Glasgow; new children's hospital announced by Minister for Health and Community Care
2006 Scottish Executive's *Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland* recommends the EACH Charter as a benchmark for all NHS Boards when reviewing their paediatric services
Evaluation of Dental play box Report published
Conference in Dundee *When Doctor doesn't Know Best*
2007 *Family Facilities Survey 2005-07* produced, funded by the Scottish Executive Child and Maternal Health Unit; *Caring for a Sick Child in Tayside* report; *Child Dental Surgical Services in Scotland* report written. Dental play box for children with complex and additional support needs developed. *Preparing your child for dental treatment* and *Questions parents often ask when their child is going to hospital* leaflets produced.
2008 Represented the healthcare needs of all sick children on the Scottish Government *National Steering Group for Specialist Children's Services in Scotland* since 2006. *Children and Young People's Healthcare Rights Resource Pack* produced



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 work includes:

- Working with others to ensure that health services are planned for sick children and young people in child-centred environments with appropriate ratios of trained staff
- Informing young people, parents and carers of their rights and responsibilities and empowering them to participate in decisions about the treatment and care of their child
- Raising awareness and representing children's needs and concerns within Government, healthcare committees and other Non-Governmental organisations
- Promoting high quality healthcare services at home and in hospital, while working to obtain equality of services and access across Scotland



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We Represent Sick Children, Young People and their Carers on

Aberdeen City Reading Bus (Tillydrone Network)
Aberdeen Children's Services Network
Children & Young People's Health Support Group
National Steering Group for Specialist Children's Services in Scotland
Age Appropriate Care Working Group;
Paediatric Surgery Project Group;
Children's Cancer Services Review
Forth Valley NHS - Acute Operating Division Patient Public Panel; Child Health Forum; Maternity Services Liaison Committee; New Hospital Build Subgroup
National Association of Hospital Play Staff
NHS Ayrshire and Arran - North Ayrshire, East Ayrshire and South Ayrshire PPFs; Review of Adolescent Mental Health Services Group; North Ayrshire Public Participation Forum
NHS Grampian - Asthma Standards Steering Group; Child Health Strategic Management Group; Community Health Forum; Paediatric Pain Group; Royal Aberdeen Children's Hospital Adolescent Users' Group
NHS Greater Glasgow and Clyde - Car Parking Steering Group; Renfrewshire Public Participation Forum; New Sick Children's Hospital Steering group; Emergency Care Framework for Children & Young People Group; QIS Asthma Services for Children & Young People Implementation Group
NHS Highland - Highland Child Health Network
NHS Lanarkshire - Child Health Group; Children and Young People's Mental Health Group; Integrated Children's Services Group; Paediatric Surgical Sub Group
NHS Lothian - Royal Hospital for Sick Children Edinburgh Hospital Reprovisioning Group
NHS Tayside - Ninewells Hospital Leaflet Group; Community Maternity Unit (CMU) Planning Group; CMU Development Group; Zone 2 Meetings Health Visitors Group; Senior Paediatric Nurses Group
North Ayrshire Youth Council; North Ayrshire PPF
North of Scotland Clinical Planning Group
Play Scotland
Renfrewshire Community Health Partnership
Royal Hospital for Sick Children Glasgow
FILES Committee; the Family Council; Surgical Short Stay Group; The Rights of the Child Group; Young People's Services Development Group, Managed Clinical Network for Children with Complex Needs
Scottish Ambulance Service Involving People Group and Continued Improvement Group
Scottish Colleges Committee for Children's Surgical Services
Scottish Complex Health Needs Group
Scottish Healthy Care Network
Scottish Managed Clinical Network for Children with Complex Mental Health Needs
Scottish Patient/Carers' Advisory Group (RCPCH)
Stirling Youth Partnership
South Lanarkshire Public Participation Forum,
Tayside Community Health Partnership – Engagement & Involvement of Young People Subgroup