



**Children's
Health Scotland**



**Promoting the healthcare rights and needs
of children and young people**

**Annual Review
2016-17**

Chair's Report



Professor Richard Olver

After more than 50 years of campaigning for the healthcare rights of children and young people, and their families, Action for Sick Children Scotland has **changed its name to Children's Health Scotland (CHS)** in order to better reflect its current focus and range of activities.

We may have changed our name but **what we stand for hasn't changed.** CHS is the only charity in Scotland dedicated to representing, promoting and safeguarding the interests and healthcare rights and needs of all children and young people within our healthcare system. And we do this through campaigning, delivering effective projects, being involved with Scottish Government policy development and working groups, and giving practical support to families and children. What follows are examples of our work over the past year.

Campaigning

- As a result of our campaign to highlight inequities in oral health provision for children in additional support for learning schools, the Chief Dental Officer instructed Boards to ensure that ASL schools are now offered Childsmile tooth brushing, fluoride varnish application and inclusion in the Basic National Dental Inspection Programme.
- In our survey of children undergoing anaesthesia in hospital, one in ten parents told us that they, and their child, were upset because they were not present at the time of waking. We used this data to engage with the Scottish paediatric anaesthetist community to

jointly develop information for families about the induction of anaesthesia and the recovery process, with a stated principle of parental presence in recovery (ward or recovery room) as soon as it is safe.

- As a member of the **Scottish Children's Services Coalition**, we campaigned for improvements in mental health provision for children and young people. Although appropriate Government policies are in place, inadequate resources and recruitment of clinical staff continue to limit provision.

Projects

- The Lothian Self Management project completed four programmes over the year. It has also introduced volunteering possibilities to the young people and extra social activities to help everyone keep in touch. The first programme for 8-11 year olds has now taken place with parents and carers joining the workshops.
- As well as delivering workshops to 161 kinship and foster carers, the Children and Young People in and Leaving Care project launched its **new DVD 'Health Matters for Children and Young People in Kinship Care'**. The film includes interviews with kinship carers and advice and guidance from professionals and experts.
- Our Special Smiles dental project concluded in June 2016 when funding ended. Now, what we learnt from the project is being taken forward through collaboration with NHS Education Scotland to deliver Dental Play training to oral health professionals throughout Scotland.

Representation on Working Groups and Committees

- We contributed to a number of groups and committees which are listed on the back page of this report.
- At a policy level, CHS remains a member of the Ministerial Advisory Committee of the Scottish Government for Children and Young People's Health.
- **The 'Food in Hospitals (Scotland) 2008' Guidance, to which we contributed as part of the Scottish Government Reference Group, was**

published in 2016.

- Our Area staff in NHS Greater Glasgow & Clyde and in NHS Tayside have represented the needs and rights of sick children, young people and families on a range of committees and working groups and provided support, and advice to families caring for a sick child.

In the year ahead

- Child Healthcare in Scotland: Overcoming the Challenges to Equality, is the theme of our conference which takes place on November 10th in Edinburgh. Speakers include Mark McDonald MSP, Minister for Childcare and Early Years, Dr Catherine Calderwood, Chief Medical Officer, and leading child health professionals.
- Our 8th survey in the series '**Parental Access and Family Facilities Provided by Scottish Hospitals Admitting Children**', which has been hugely influential in shaping Health Board policy and practice, should now go ahead during 2017-18.

Welcome

We welcome Linda Alexander as Development Officer with a remit to **meet 'harder to reach' families**, children and young people.

Thanks

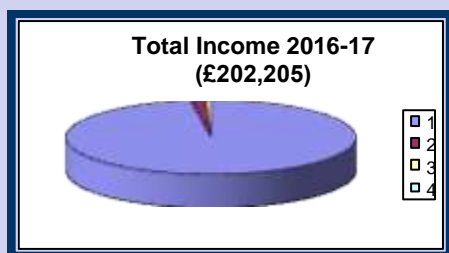
It is with great sadness that I report the untimely death of our Vice Chair Mary Boyle. Mary worked tirelessly for **children and young people's health** rights and will be greatly missed. Thank-you Mary.

We are grateful for the generous support of our funders and also to our office volunteer, Jenny Lowe. Thanks also to Shona Agnew and Mike Keohane who stepped down as Development Officer and Executive Committee Member respectively.

As always, I end my 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.

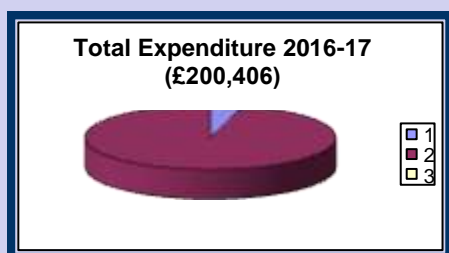
Richard Olver, Chair

Our Financial Year



Income April 2016 - March 2017

	2017	2016
	£	£
1. Voluntary Income	173,545	232,461
2. Charitable Activities	27,748	3,942
3. Investments	912	1,355
4. Other	-	-
	<u>202,205</u>	<u>237,758</u>

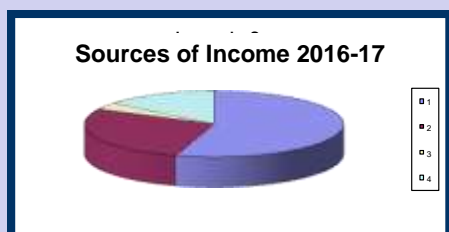


Expenditure April 2016 - March 2017

	2017	2016
	£	£
1. Raising Funds	8,454	9,254
2. Charitable Activities	191,952	208,646
3. Other	-	-
	<u>200,406</u>	<u>217,900</u>

Summary Balance Sheet as at 31 March 2017

	2017	2016
	£	£
Fixed Assets	753	-
Current Assets	<u>163,118</u>	<u>162,505</u>
	163,871	162,505
Current Liabilities (creditors/accruals)	9,707	10,140
Deferred Income	-	-
Net Assets	<u>154,164</u>	<u>152,365</u>



1. Scottish Government Children, Young People and Families Early Intervention Fund	55%
2. Trusts	28%
3. Other Donations	3%
4. Other Income	14%

The full examined 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

Executive Committee 2016-17

Professor Richard Olver (Chair)
 Jim Robinson (Vice-Chair) (until September 2016)
 Mary Boyle (Vice-Chair) (September 2016 - March 2017)
 Duncan McEachran (Treasurer)
 Alison Closs
 Dr Zoe Dunhill
 Gwen Garner
 Mike Keohane (until March 2017)
 Jane Holmes
 Dr Una MacFadyen
 Sylvia Smith

Staff

Shona Agnew, Development Officer (until January 2017)
 Linda Alexander, Development Officer (from March 2017)
 Deborah Brown, Area Officer Tayside
 Dani Cochrane, Project Assistant, Self Management Project
 Mary-Flora Ferris, Dental Project Officer (until December 2016)
 Amy L Joss, Dental Project Officer (until June 2016)
 Dagmar Kerr, Area Co-ordinator Greater Glasgow & Clyde
 Simita Kumar Project Officer, Self Management Project
 Elizabeth May, Company Secretary/National Co-ordinator
 Anne Wilson, Development Officer

Advisers

Frances Barbour
 Melanie Brown (until October 2016)
 Lady Caplan
 Gita Ingram
 Juliet McCann
 Dr Elaine Lockhart (from June 2016)
 Dr Michael Morton (until April 2016)
 Jacqueline Reilly
 Professor George Youngson

Grateful thanks to our funders and supporters

We are very grateful for support from the Scottish Government Children, Young People and Families Early Intervention Fund; NHS Greater Glasgow & Clyde Endowment Funds; The Edinburgh Children's Hospital Charity and from the following:

Aberbrothock Skea Trust
 Alexander Moncur Trust
 M & T Ferris
 The Forteviot Charitable Trust
 Grant Charitable Trust
 Harold Merton Adams Trust
 Hugh Fraser Foundation
 J K Young Endowment Fund
 John Lewis plc
 The Leng Charitable Trust
 Lloyds TSB Foundation for Scotland: Henry Duncan Award
 R J Larg Family Trust
 Snowball Trust
 Waitrose plc
Widowers' Children's Home Trust.

Thanks also to Jenny Lowe and the Margaret Gilbride School of Dancing for their support.

Getting it Right for Children & Families

Greg and Amy



Our Tayside Area Officer Deborah Brown shares the story of a family she has helped:

‘Over the last year I have supported a local family Pat, Michael and their children Greg and Amy. Shortly after Amy’s birth, she was diagnosed with a congenital heart condition. This required surgery at a national children’s hospital when she was only a few days old and Amy was in hospital for over two months. The impact of her health condition, as well as a lengthy stay in hospital away from support networks, had a huge impact - not only on her Mum and Dad, but also on her four year old brother Greg. The little boy had been looking forward to becoming a big brother, but he was completely unprepared for the trauma he experienced. His Mum spent most of her time at the hospital, while he stayed with Dad in nearby accommodation. This meant Greg was unable to attend his local nursery and he no longer had the security of a consistent routine.

I was introduced to the family by their Health Visitor **when they returned home after their baby’s operation.** Understandably, they were finding it difficult to come to **terms with their daughter’s health condition. They were** also finding it difficult to get their son back into a routine. I was able to offer some support for Greg, using our Hospital Play Box resources which helped him to process his experiences and feelings about the time when his baby sister had been so unwell in hospital. As I got to know the family I was also able to offer support and advice in relation to Amy and her health condition. This included **sharing information about children’s health rights and** signposting to other appropriate services including to a local authority welfare rights adviser. When Greg was

struggling with separation anxieties I was able to support the family to share information with his nursery to ensure that he received appropriate support.

Amy’s health was monitored closely at the local hospital and at the national children’s hospital where surgery had taken place. Before Amy’s next operation, I again provided play support to Greg to prepare him for going **back to the hospital where his sister’s surgery had taken place.** I made sure the family were aware of support **services available at the dedicated children’s hospital. I** also provided information about claiming travel costs for families who have to travel outside their home health board for treatment for their child.

When the family received very difficult news about their **baby’s health they were faced with the prospect of** agreeing to an operation that would follow a palliative route. At that point I was able to support them to explore the option of seeking further medical opinions. This resulted in the family travelling to Great Ormond Street Hospital (GOSH) where very complex surgery, which would potentially provide a better overall quality of life, was offered. Once they had made the decision to go ahead with this surgery, I supported the family to organise and prepare to travel to GOSH. This involved the family staying away from home on several occasions, at a much bigger hospital this time and with many more scary and traumatic experiences for all of them.

Thankfully Amy’s surgery was successful and she has recovered extremely well. Her health has improved greatly and she continues to surprise everyone on a daily basis with her progress. Family life now has a much more settled routine and Greg now feels less anxious and more confident. He loves having a healthy sister he **can play with and is a very protective big brother.’**

861 families and 1,013 children were directly supported by our projects in the year to 31 March 2017.

4,474 families were given information about child health rights; how to access healthcare; how to prepare children for medical, hospital or dental treatment; how to support the health of children and young people in care and those with long term conditions.

Early Intervention for better outcomes

Abbie

The Family Worker from a Dundee Nursery School contacted our Area Officer Deborah Brown, to see if she could support the family of Abbie, a 4 year old due to have **ear, nose and throat surgery at Tayside Children's Hospital**. **The family were very anxious and didn't know what to expect** when their daughter went into hospital. Deborah met the family and was able to answer lots of their questions. **She shared helpful information about children's health rights** and gave them leaflets to read at their leisure. She also arranged to deliver two Hospital Play Box sessions at **Abbie's nursery**. **Later on the family told us:**

*'The initial meeting was so helpful and the support given at such an early stage of the process was what we needed. **I wasn't aware until then that there was help available to parents in our situation**. My husband and I were so grateful for the help and it gave us the tools to prepare our daughter for the operation (and calm me down a bit). The information leaflets were great as it gave us a chance to look through everything after speaking to Deborah. Abbie just loved the interaction and came home buzzing from the play sessions. She was able to share with her friends what she was going **through and about to go through.**'*



Role play helped Abbie prepare for hospital

Helping to Make a Difference

During the year our Lothian Self Management Project delivered 4 self management workshop programmes to children and young people with a range of long term conditions. Project Officer Simita Kumar spoke to 12 year old Ben and his Mum Sarah.

What did you like best about the Self Management Programme?

B: 'Simita and Dani have been very supportive.'

S: 'Ben is enjoying it and is happy. He has managed to open up about his condition which he has never done before. I've also seen an increase in his confidence.'

What did you like least?

B: 'Nothing really!'

S: 'That it's finished!'

What effect, if any, has the programme had on you, your family and your (or your child's) condition?

B: 'Well, I think it's been great and has made me

happy. It's good to know that there are other children with conditions and it has helped me to not feel sad and lonely.'

S: 'It has been good for Ben to get out and when he is happy, I am happy. It's had a positive knock on effect. Just a massive thank you for all your help!'



Ben enjoyed the programme

Would you recommend the programme to others?

B: 'Yes I would!'

S: 'Most definitely, any parent who has a child with a condition should be offered this as their children can feel very isolated and sometimes children are unable to disclose to parents.'

Supporting Foster and Kinship Carers

Our Children and Young People in and Leaving Care Project delivered workshops to 161 foster and kinship carers helping them to improve their knowledge and understanding of the health care needs and rights of those they look after. 97% of carers surveyed, reported increased knowledge and ability to access care for their child at times of illness. Feedback included:

'I learned about legal rights of the child and the difficulties faced by foster carers. I have more confidence to seek out the correct information and to stand up for what is right.'

'Exceeded expectations. Very relevant to the children being cared for in kinship care.'

'Anne delivered a very good course which gave lots of information and food for thought.'

The Project also produced a DVD, 'Health Matters for Children and Young People in Kinship Care' in collaboration with Grandparents Parenting Again & Kinship Carers (Midlothian).



Carers attend the launch of our Kinship Care DVD

Supporting Professionals

Our Special Smiles work in additional support for learning schools may have finished for the time being, but we have been collaborating with NHS Education Scotland (NES) to ensure learning from this work is sustained.

Special Smiles Dental Play™ boxes have been loaned to each NHS Board courtesy of NES. Mary-Flora Ferris and Amy Joss delivered six training sessions to over 120 oral health professionals throughout Scotland with a further three sessions to be delivered in the autumn/winter. This rights based approach to dental play aims to help dental professionals better support the children in their care. Delegates told us that they had learned a great deal such as:

'Lots of new techniques to interact with children who are apprehensive of the dentist, some great ideas.'

'Children have the right to play - I am going to request more toys for the waiting room and in surgery as motivators.'



Having fun at Glasgow training



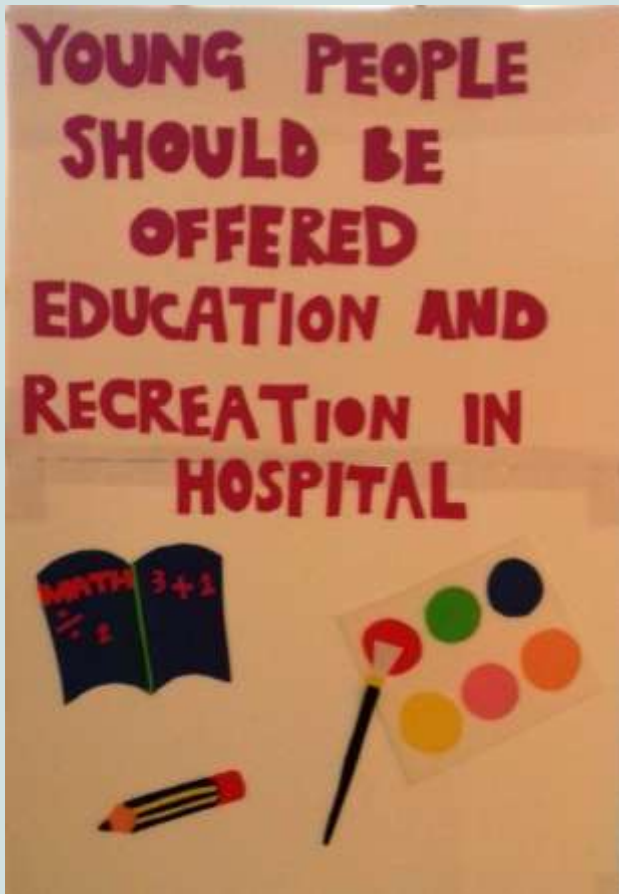
Deep in discussion at Perth training

Promoting Children and Young People's Health Rights

During the year we promoted the healthcare rights and needs of children, young people and their families.

2,520 health, education, social work and voluntary sector professionals received our resources and information. This helped to increase their awareness of the rights and needs of sick children, young people and families.

We delivered 63 rights based presentations and talks at events attended by 844 professionals.



Partnership Working - Influencing Policy

We contributed to policy development through our work on various national and regional working groups and committees. One example was our work with the Scottish Dental Clinical Effectiveness Programme (SDCEP). Our Area Co-ordinator Dagmar Kerr contributed to the revision of the guideline on conscious sedation in dentistry. Dr Douglas Stirling, SDCEP Programme Development Manager told us that it was hugely beneficial to have an advocate for a wider patient group present at discussions because a more diverse range of views and experiences could be represented.

'Dagmar made important contributions by challenging members of the group on clinical aspects of the guidance from the patients perspective. She was keen that adaptations to the environment for sedation to make it more suitable for children were described within the guidance, and this has been done.'

'She also provided her expert input on children's rights around consent which informed revisions made to this section of the guidance. She also commented on patient information on conscious sedation for dental care, which has impacted on how it has been referred to in the guidance.'

Another Committee we worked with was the NHS Tayside Transforming Health Visiting and School Nursing Board.

Joan Wilson, Associate Nurse Director, Children, Young People, Families, Primary Care, Protection, NHS Tayside told us,

'Your Area Officer made a positive contribution to the Transforming Health Visiting and School Nursing Board by:

- Promoting the health care rights and needs of children and young people
- Raising awareness to key health partners and stakeholders of the impact of hospital admission, long term conditions for children and families and the need for co-ordinated care to get it right for every child.'

Children's Health Scotland is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of all sick children and young people within our healthcare system.

Our Vision is for the best quality healthcare for children and young people in Scotland.



Our Mission is to enable 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.

Over the year we have worked with the following to represent the views and needs of sick children, young people and families

Angus Third Sector Children's Services Forum

Barnardo's

Centre for Excellence for Looked After Children in Scotland
Childsmile
Dundee Young Parents Pathway Group
European Association for Children in Hospital
Health and Social Care Alliance, GIRFEC Project Advisory Group
End of Life Care for Children and Young People in Scotland Group
Drumchapel Early Years Forum
Family Fund

for Scotland's Disabled Children

Prince and Princess of Wales Hospice
Mental Health Foundation, Mental Health of Young People with Long Term Conditions Steering Group
National Association of Health Play Staff
NHS Education Scotland
NHS Greater Glasgow and Clyde – *Patient Experience & Public Involvement, Health Improvement Team*
Royal Hospital for Children Glasgow - *FILES Committee: The Rights of the Child Group; Family Support Service, Glasgow Children's Charity*
Scottish Children and Young People's Palliative Care Executive
Scottish Children and Young People's Palliative Care Network
National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN) – Steering Group and Education Group
NHS Tayside: *Transforming Health Visiting & School Nursing Tayside Improvement Group; AHP Complex Needs Network*

Royal College of Paediatrics and Child Health
Scottish Attachment in Action

Scottish Children's Services Coalition members

Scottish Government Children and Young People's Health Support Group

Scottish Government Administration of Medicines and Healthcare
Support in Schools Guidance Review Group
Scottish Government Paediatric Short Life Working Group into the
Review of the 'Food in Hospitals (Scotland) 2008

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)
Tayside GIRFEC Practitioners Forum
The Fostering Network

We also worked closely with Angus, Clackmannanshire Fife, East Lothian, Dundee City, Edinburgh City, Falkirk, Midlothian, Perth and Kinross, Stirling, West Lothian, Local Authorities; NHS Lothian and NHS Greater Glasgow & Clyde Dental Services; NHS Lothian Paediatric Psychology & Liaison Service.



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