

# Annual Review and Impact Report 2017-18



**Children's  
Health Scotland**

Promoting the healthcare rights and needs of children and young people

**‘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.’**

# Chair's Introduction

The stories in this Annual Review attest to the wide range of work undertaken by Children's Health Scotland, and its impact, during 2017-18. My introduction this year covers activities not mentioned elsewhere in the Report.

## Name Change

Action for Sick Children Scotland changed its name to **Children's Health Scotland in June 2017**. The reasons for this change were to avoid confusion with other similarly named charities, and the fact that many of the children and young people we work with do not see themselves as 'sick'. **The transition has been surprisingly smooth, helped no doubt by our decision to keep our 'corporate' colours and a logo that, although redesigned, is recognisably similar to the old one.**

## Parental Access and Family Facilities Survey

Our Parental Access and Family Facilities Survey covers all hospital wards that admit children in Scotland. As of August 2018, we are currently at the preparation stage of what will be the 8<sup>th</sup> survey since 1985 but only the second to be completed on-line. For the first time we have introduced an additional questionnaire relating specifically to children and young people admitted to adult wards.

The aim of this survey, funded by the Scottish Government, is to assess the provision of care for children and their families against the basic principles of 'good' paediatric care. The findings will be used by CHS to share examples of good practice and to encourage Health Boards to improve services where problems are seen to exist. It will also provide the Scottish Government with evidence about the quality and standard of child health services in relation to NHS Scotland Quality Standards and inform its provision and planning.

## Campaigns

Activity focused on better mental health provision for children and young people and on the rights of children and young people with health issues to education and to healthcare support in schools. In the year ahead we will **also campaign around training for community children's nurses and the right to good transition to adult services.**

We have achieved much in the past year and I am confident that our work on behalf of children and young people over the next 12 months will be equally productive.



*Professor Richard Olver*

# During 2017-2018 Children's Health Scotland



Directly supported 823 children and young people



Gave 2,030 families information on: health rights; how to access child healthcare; preparing children for treatment; how to support those in care and those with long term conditions



Delivered 46 presentations and talks at events attended by 571 professionals



Directly supported 802 parents and carers



Delivered  
15 child health  
workshops to  
119 Foster and  
Kinship carers



Trained 82 oral  
health professionals  
throughout Scotland  
in child rights based  
dental play

## Executive Committee

Professor Richard Olver (Chair)  
Gwen Garner (Vice-Chair)  
Duncan McEachran (Treasurer) (until October 2017)  
Derek Quick (Treasurer) (from February 2018);  
Alison Closs; Dr Zoe Dunhill; Kay Fowlie;  
Jane Holmes; Dr Una MacFadyen; Sylvia Smith  
David Thompson; Laura Thorburn.

## Staff

Linda Alexander, Development Officer  
Deborah Brown, Area Officer Tayside (until May 2018)  
Dani Cochrane, Project Assistant, Self Management Project  
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  
Michelle Wilson, Area Officer Tayside (from May 2018)

## Advisers

Frances Barbour; Lady Caplan; Dr Alice Fitzgibbon;  
Gita Ingram; Juliet McCann; Dr Elaine Lockhart;  
Jacqueline Reilly; Professor George Youngson.

# Working with Children and Young People

**Self Management Project:** This supports children and young people with long term conditions. 17 year old Kieran describes his experience of taking part.

**'The Lothian Self-**Management group has played a huge role in building up my confidence and making me more able to accept and live with my condition. It has helped me develop the capabilities to talk about issues that affect me and has made me more aware of the circumstances faced by others. The workshops with the group have helped me gain an understanding of my rights, both in everyday life and in a medical setting as well as made me more confident with managing my condition and speaking out when I disagree with things.

A WhatsApp group was set up to allow the members of the group to communicate outside the workshops and form our own support network. This group message chat has allowed us all to be there for one another at times **when it wouldn't have been possible without that.** **Personally, I'd say the group feels more like a family than just friends.**

When I went along to the first session, I had a lot of anxieties about what other people would be like or if

**'The Lothian Self** Management group has played a huge role in building up my confidence and making me more able to accept and live with my **condition.'** *Kieran*



**I'd feel like I fit in with them but by the end of the session,** I knew we were going to end up being friends for a very long time.

**I wasn't sure what to expect at the workshops themselves** but they were all really enjoyable, informative and useful. For example, the workshop on anxiety coping techniques **has been something that I've been able to use many times** since and the knowledge from that session has really paid off in my day-to-day life.

By the second session, we were all smiling just from the **sight of each other and I'm sure I speak for all members of** the group when I say we felt comfortable being ourselves and felt relaxed when with each other.

I have nothing but positive comments to make about the self-management programme and would 100% recommend it to any person with a long term condition. Even if they feel like they have their condition under control, I feel that they would benefit and would still be able to learn things that they can use in their life. As well as being an important learning experience, it will provide the person with friends **that understand where they're coming from which is something that doesn't really happen in a standard school setting.** The group leaders are also really amazing people **who are very supportive and approachable.'**

## A Parent's Perspective

**'This group is amazing. My daughter Ellie lost a lot confidence in herself due to her illness. Simita and Dani were fantastic. They gave her loads of advice and tools to try help combat her anxieties and rebuild her confidence again.**

She loved every workshop she went to, I am so thrilled she was a part it. She made great friends through the programme. Thank **you guys x.'**

*Alison, Parent of Ellie*



*Photo: istock*

## Highlights

- The project was one of 6 short listed for the Alliance 2017 Self Management Project of the Year.
- It supported 51 children and young people from 8-17 years with a range of long term conditions.
- It delivered 22 workshops and held 4 social events.
- Four young people met with Maureen Watt MSP former Minister for Mental Health to talk about their conditions.
- Project Officer Simita Kumar presented at the 2018 Royal College of Paediatrics and Child Health Conference on how young people contribute to the **project's development. Four young people from the project** took part in the question and answer session.



*Simita (centre) and young people at the RCPCH conference*

# Working with Families

**Hard to Reach Families Project:** This aims to ensure that we are easier to reach and know more about barriers facing families, children and young people.

Development Officer, Linda Alexander, has delivered child health rights information sessions to families from Syria, Vietnam, Pakistan, Turkey, Russia, Poland and Zimbabwe as well as other African and Middle Eastern countries.

Topics featured in sessions to the refugees and asylum seekers included: appointments; GP access; understanding **information; asking for an interpreter; children's rights** and the role of the parent; circumcision; rare conditions; using accident and emergency; worries about toddlers and babies; visiting; access to health monitoring equipment; waiting times; and sickle cell pain management.



Linda (right) with families at a Hope Project Scotland event

We used our play resources with asylum seeker/refugee children.

**'The hospital playbox is very useful, it helped calm down the child and also parents (as they worry about child). It helped them to be more happy after medical treatment.'**  
Refugee Parent



**Children in and Leaving Care Project:** This works with foster and kinship carers and agencies supporting carers. Carrie-Ann Logan, Kinship and Support Worker at Family Addiction Support Services in Glasgow, told us that their carers identified the need for more information on accessing healthcare for children. She said that working with Development Officer, Anne Wilson, to deliver sessions had been invaluable in helping their kinship carers understand and overcome some barriers faced.

**'The information has helped me to ask more questions when I attend appointments with my grandson.'**

**'The children's rights charter made it easier to understand how children should be helped.'**



# A Parent's Experience

Tayside Area Officer, Deborah Brown, supported a family whose daughter underwent heart surgery at Great Ormond Street Hospital (GOSH). Here, in order to help others, the parent has shared her experience.

**'If a parent is not happy with what they have been told about their child's treatment, they can obtain a second opinion from another centre and seek help from a charity like Children's Health Scotland. If they're going through a particularly stressful time a coping mechanism could be time away from home doing something they enjoy, or yoga or meditation for relaxation. Joining support groups can be useful. I joined the Heart Mummies for Scotland Facebook Group and got in touch with two mothers whose children had undergone heart surgery at GOSH. They gave me lots of useful information.**

Find out about transport costs and if your Health Board will pay for these. Make contact with the liaison nurses as they can give you advice and support. Find out about the canteens. Ask staff if you are entitled to food vouchers. Ask about Family Support services and activities for siblings.

Think about how you will share information and update **family and friends about your child's progress, as this can**

be overwhelming. Have a main contact that will disseminate information on your behalf. I created a closed Facebook group and gave updates.



Children in the Intensive Therapy Unit are sensitively **cared for and sedated. Whilst it's important for the parent to be there, if possible, this can be an opportunity to rest for short periods, for when your child is on the ward it's difficult to get a break. It's ideal if another parent can be there to share the care.**

Really my main piece of advice is to get in touch with the **excellent staff at Children's Health Scotland!**  
**Thanks so much again for all you have done for us.'**

*'My main piece of advice is to get in touch with the excellent staff at Children's Health Scotland!'*

# Supporting Professionals



## Our Conference

**'Child Healthcare in Scotland: Overcoming the Challenges to Equality'** took place in November. The event, chaired by Dr Steve Turner, RCPCH Officer for Scotland, provided insight into the diversity of developments undertaken and challenges faced in delivering healthcare which caters for all our children and young people. It was an opportunity for over 90 delegates to learn from a range of speakers including Dr Catherine Calderwood, Scotland's Chief Medical Officer, and to reflect on practice. 94% of delegates reported significantly increased understanding of health issues and challenges facing different groups of children and young people.

***'I need to take a step back and look at some of the wider issues and consider how to make a difference in challenging times.'***

***'I felt I learnt a lot, particularly about the developmental origins of adult disease and about refugees and asylum seekers.'***

## Learning Resources and Information

Our DVD, 'Health Matters for Children and Young People in Kinship Care' is used by local authority kinship care officers in training. *'It stimulates good discussion and helps kinship carers to identify their own issues.'*

Several hundred practitioners completed our e-learning resource developed for those working with looked after children and young people. The Learn Pro modules cover healthcare needs and rights and the mental health and emotional wellbeing of children and young people in care.

Our new e-learning resource, Children and Young People's Healthcare Rights, was launched at the 2018 NHS Health Scotland conference. It helps practitioners reflect on children's healthcare rights in their workplace. [www.enetlearn.com/childhealthscot](http://www.enetlearn.com/childhealthscot)



In June 2017 we launched our new, improved website [www.childrenshealthscotland.org](http://www.childrenshealthscotland.org)

Arabic and Romanian versions of our 'GP Service for Children and Young People' guide have been well received. <http://www.childrenshealthscotland.org/how-we-help/families/>

## Sharing Good Practice

Through membership of 19 committees and groups, we have raised awareness of the healthcare needs and rights of children, young people and their families and shared good practice with 301 professionals. Fiona Wylie, Senior Nurse at the Prince and Princess of Wales Hospice in Glasgow explains how our Area Co-ordinator helped:

**‘Dagmar was able to articulate why inter-professional and agency working is so important. She continuously brought the voice of the young person and their family into the room to ensure they were heard and that any potential working had the young adult and their family at its heart. She was able to give a policy overview and highlight the role of different managed clinical networks and where we could feed in any outputs from work taken forward. When looking at developing a community of practice around transition for young adults with life limiting illness, she shared work about pathways used elsewhere that will hopefully influence the work we do now and in the future.’**

## Training

Our Special Smiles Dental Play™ boxes have been placed in all NHS Boards. To assist staff to use this



resource most effectively, we worked with NHS Education Scotland (NES) and in the last year trained 82 oral health professionals from all parts of Scotland in a rights based approach to dental play. Feedback from those attending has been hugely positive.

***‘I came away full of inspiration and hope. I have so many ideas now. Thank you!’***

***‘Great course ... so much learning has been gained by all our staff in Orkney.’***



We have represented the interests of sick children, young people and families with:

**Angus Third Sector Children's Services Forum**

**Barnardo's**

CELCIS

**Children's Hospices Across Scotland**

Childsmile

CLAN Child Law

Contact

Drumchapel Early Years Forum

Edinburgh Napier University

Enquire

Family Fund

Family Addiction Support Service, Glasgow

**for Scotland's Disabled Children**

Govan Community Project

Grandparents Parenting Again & Kinship Carer (Midlothian)

Health and Social Care Alliance, GIRFEC Project Advisory Group

Human Development Scotland

Maryhill Integration Network

MECOPP

Mental Health Foundation, UCAN Steering Group

NHS Education Scotland

NHS Greater Glasgow & Clyde – *Patient Experience & Public Involvement, Health Improvement Team; Transition for Cerebral Palsy Group*

Prince and Princess of Wales Hospice

Royal Hospital for Children Glasgow - *FILES Committee; The Rights of the Child Group; Family Support Service;*

**Glasgow Children's Hospital Charity**

Royal Hospital for Children Edinburgh

**Scottish Children and Young People's Palliative Care Network**

National Managed Clinical Network for Children with Exceptional Healthcare Needs (CEN) – *Steering Group & Education Group; Exceptional Families Project Steering Group*

NHS Tayside: *Transforming Health Visiting & School Nursing Tayside Improvement Group; Early Years Pathway Group; Leaflet Group*

Royal College of Paediatrics and Child Health  
Scottish Attachment in Action

**Scottish Government Children and Young People's Health Support Group**

**Scottish Government Children's Rights Team**

Scottish Transition Forum; ARC

Scottish Epilepsy Centre

Strategic Litigation Steering Group

Tayside Storyworlds Life Group

Tayside Third Sector Interface Group

The Fostering Network

The Yard

**West of Scotland Deaf Children's Society**

*We worked closely with Angus, Fife, East Lothian, Dundee City, Edinburgh City, Falkirk, Perth & Kinross Local Authorities; NHS Fife; Forth Valley; Lothian Paediatric Psychology & Liaison Service.*

# Financial Overview 2017-18

## Total Income 2017-18 (£193,911)



1  
2  
3

## Total Expenditure 2017-18 (£186,736)



1  
2

## Sources of Income 2017-18



1  
2  
3  
4

Income	2018 £	2017 £
1. Voluntary Income	176,090	173,545
2. Charitable Activities	17,724	27,748
3. Investments	<u>97</u>	<u>912</u>
	<u>193,911</u>	<u>202,205</u>

Expenditure	2018 £	2017 £
1. Raising Funds	9,216	8,454
2. Charitable Activities	<u>177,520</u>	<u>191,952</u>
	<u>186,736</u>	<u>200,406</u>

## Summary Balance Sheet as at 31 March 2018

	2018 £	2017 £
1. Scottish Government Children, Young People and Families Early Intervention Fund	57%	
2. Trusts	31%	
3. Other Donations	3%	
4. Other Income	9%	
Fixed Assets	565	753
Current Assets	<u>169,331</u>	<u>163,118</u>
	169,896	163,871
Current Liabilities creditors/accruals)	8,557	9,707
Deferred Income	-	-
Net Assets	<u>161,339</u>	<u>154,164</u>

The full 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

# Thanks to our funders and supporters

We are very grateful for support from the Scottish Government Children, Young People and Families Early Intervention Fund and from:

Aberbrothock Skea Trust

Alexander Moncur Trust

BBC Children in Need

**Edinburgh Children's Hospital Charity**

G Rooney (in memory of Mary Boyle)

The Leng Charitable Trust

Moston Care Foundation

Nancie Massey Charitable Trust

NHS Glasgow & Clyde Endowment Funds

Ponton House Trust

Robertson Trust

Snowball Trust

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# Children's Health Scotland

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## Children's Health Scotland

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