

Their Health Matters

Annual Review
and Impact Report 2015-16



Promoting the Healthcare Rights and
Needs of Children and Young People

Chair's Report - Our Year in Focus



Professor Richard Olver

2015 -16 has been a busy year for Action for Sick Children Scotland - campaigning, delivering effective projects, being involved with Scottish Government policy development and working groups, and giving practical support to families and children.

Highlights include awards to the Special Smiles Dental Project and our successful funding applications:

- Special Smiles was awarded the 2015 **Patron's Prize at the National Oral Health Promotion Group Conference** and a runner up prize in the Bright Smiles-Bright Futures category at the International Association of Paediatric Dentistry Conference.
- The success of our funding application to the new Children, Young People and Families Early Intervention Fund for 2016-17 enables us to support our core activity, our Children and Young People in and Leaving Care workstream and the appointment of a Development Officer.

The Holyrood election gave us the opportunity to highlight our campaigning priorities in our Manifesto for the Scottish Government, MSPs and those responsible for the formulation of healthcare policy. These included the need for the mental health of children and young people to receive the same priority as their physical health; facilities for young people in hospital; the administration of medicines in schools; paediatric training for GPs.

During the year ASCS carried out a survey of 242 parents/carers about whether they were able to be present with their child during induction of anaesthesia and at recovery and their views on the care they received. An initial analysis of results, which showed that many parents were unable to be present as their child woke up, was published in our Summer 2016

newsletter and detailed results will be fed back to Area Health Boards.

Representation on Scottish Government Working Groups

ASCS contributed as a member of a number of Scottish Government Working Groups. The Stakeholder Group reviewing the Guidance on Education of Children Absent from School through Ill-health (2001) was set up as a result of our campaign some years ago and the revised Guidance was published in 2015.

The Administration of Medicines and Healthcare Procedures in Schools working group is currently reviewing the 2001 Guidance which is due to be published later this year. At a policy level, ASCS is a member of the Ministerial Advisory Committee of the Scottish Government for Children and **Young People's health**.

We also contributed as a member of the Scottish Government Reference Group **to the Review of the 'Food in Hospitals (Scotland) 2008' Guidance which will be published in 2016**. For the first time there are stand alone sections on **children's food**.

Projects and Workshops

- Our Lothian Self-Management Project started in August and, as you can read on page 5, it has got off to a good start - delivering two programmes of workshops to young people aged 12-17.
- The Special Smiles Dental Project (see page 6) was extended to schools in Stirling, Clackmannanshire, Edinburgh City, West and East Lothian, and supported schools in Falkirk, East and West Dunbartonshire. Evaluation feedback from teachers, children, parents and carers was very positive.
- Our Area Co-ordinator in Greater Glasgow & Clyde and Area Officer in Tayside have represented the needs and rights of sick children, young people and their families on a range of committees and working groups and provided practical support, information and advice to families caring for a sick child.
- As well as delivering workshops to kinship and foster carers (see page 5), the Children and Young People in and Leaving Care Project has started development of an e-learning resource for professionals working with looked after children and young people.

In the year ahead:

- A major task in the year to come will be to develop the next in our series of surveys of Parental Access and Family Facilities provided by Scottish Hospitals admitting children. These surveys, of which this is the 8th, have been hugely influential in shaping Health Board policy and practice.
- Our campaigning activity will focus on **young people's services in hospital: parental access on the day of their child's operation: and mental health services for children and young people**.
- We hope to carry out a pilot working in selected dental health settings to help families to use our dental play resources to support their children cope better with the dental environment. The pilot will also train dental health professionals in the use of play to support their child patients.
- Subject to funding, we plan to continue working in close collaboration with the Royal Hospital for Sick Children (Edinburgh) supporting children and young people with long term conditions to self-manage their illness.
- The Children and Young People in and Leaving Care Project will roll out its e-learning resource as it continues to work on behalf of vulnerable groups, helping them and their carers to access healthcare at times of illness.

Welcome

We welcome Shona Agnew to the staff as our newly appointed Development Officer, new Executive Committee member Mike Keohane and Dr Elaine Lockhart, who joins our team of Professional Advisors.

Thanks

We are grateful for the generous support of our funders and fund raisers and also to our office volunteer, Jenny Lowe. Thanks also to Dr Michael Morton who steps down from his role as a Professional Advisor. Lastly, I record our debt to Catherine Nelson and Amy Joss who left ASCS after 12 years, during which time they contributed to our work with commitment and distinction.

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

Richard Olver, Chair

Our Financial Year

Executive Committee 2015-16

Professor Richard Olver (Chair)
 Jim Robinson (Vice-Chair)
 Duncan McEachran (Treasurer)
 Mary Boyle
 Alison Closs
 Dr Zoe Dunhill
 Gwen Garner
 Mike Keohane (*from Dec 15*)
 Jane Holmes
 Dr Una MacFadyen
 Sylvia Smith (*from Oct 15*)

Staff

Shona Agnew, Development Officer (*from July 16*)
 Deborah Brown, Area Officer Tayside
 Dani Cochrane, Project Assistant, Self Management Project (*from Oct 15*)
 Mary-Flora Ferris, Dental Project Officer
 Amy L Joss, Dental Project Officer (*until June 16*)
 Dagmar Kerr, Area Co-ordinator Greater Glasgow & Clyde
 Simita Kumar Project Officer, Self Management Project (*from Aug 15*)
 Elizabeth May, Company Secretary/National Co-ordinator
 Catherine Nelson, Dental Project Co-ordinator (*until Sept 15*)
 Anne Wilson, Development Officer

ASCS Advisers

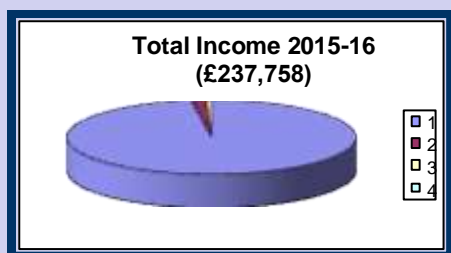
Frances Barbour
 Melanie Brown
 Lady Caplan
 Gita Ingram
 Juliet McCann
 Dr Elaine Lockhart (*from June 2016*)
 Dr Michael Morton (*until April 2016*)
 Jacqueline Reilly
 Professor George Youngson

Grateful thanks to our funders and supporters

We are very grateful for support from the Scottish Government Third Sector Early Intervention Fund; NHS Greater Glasgow & Clyde Endowment Funds; The Sick Kids Friends Foundation and from the following:

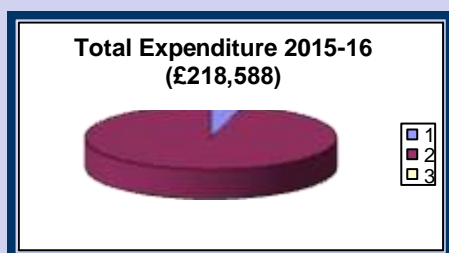
The Binks Trust
 David & Claudia Harding Foundation
 Hugh Fraser Foundation
 The Leng Trust
 Lloyds TSB Foundation for Scotland: Henry Duncan Award
 Nancie Massey Charitable Trust
 Ponton House Trust
 Snowball Trust
 Soroptimist International Glasgow City Club
 Woodward Trust.

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



Income April 2015- March 2016

	2016	2015
	£	£
1. Donations and Legacies	232,461	216,883
2. Charitable Activities	3,942	8,861
3. Investments	1,355	1,323
4. Other	-	-
	<u>237,758</u>	<u>227,067</u>

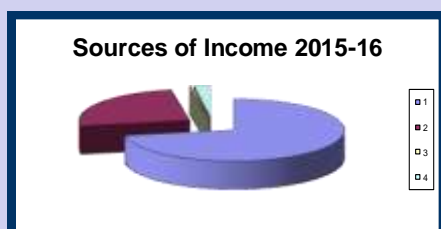


Expenditure April 2015 - March 2016

	2016	2015
	£	£
1. Raising Funds	9,254	8,943
2. Charitable Activities	209,334	195,652
3. Other	-	-
	<u>218,588</u>	<u>204,595</u>

Summary Balance Sheet as at 31 March 2016

	2016	2015
	£	£
Fixed Assets	-	375
Current Assets	162,505	141,123
	<u>162,505</u>	<u>141,498</u>
Current Liabilities (creditors/accruals)	7,642	5,805
Deferred Income	-	-
Net Assets	<u>154,863</u>	<u>135,693</u>



1. Scottish Government Third Sector Early Intervention Fund	72.1%
2. Trusts	25.2%
3. Other Donations	0.3%
4. Other Income	2.4%

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

Finance Officer Alison Glass FCCA

Auditor Jeffrey Crawford & Co

Bankers The Royal Bank of Scotland Plc

Getting it Right for Children & Families

511 families and 1,003 children were directly supported by our projects in the year to 31 March 2016.

Karen and Sophie

ASCS helped Karen and her adolescent daughter Sophie who **was about to be admitted to a dedicated children's hospital** outside their health board area. Sophie has a long term health condition and is on the autistic spectrum. Her mother was **very worried about the forthcoming admission given Sophie's** previous experiences at hospital when it had been difficult to access appropriate equipment and facilities for her. Karen told us, **'Hospital bed spaces, toilet and shower facilities do not accommodate or meet the needs of people with physical disabilities and wheelchairs users very well.'**

The planned procedure was for Sophie to have a bi-pap machine fitted. This type of procedure requires a great deal of commitment from the patient while in hospital and afterwards at home; support from the family is also very important.

With permission from the family we contacted the **Charge Nurse on the ward to discuss arrangements for Sophie's** admission and the medical equipment she would need, such as the type of hoist and compatible slings, mattress, commode and disabled toileting facilities. This sharing of ideas and information also covered the impact of autistic spectrum disorder on Sophie, such as her need for routine and consistency of carers. Parent facilities were considered and it was agreed to provide a separate room for Karen. Most procedures were going to be carried out in the evening and so the option of having a day pass to enable the family to leave the hospital was explored, and access to offsite family support and provision was arranged.

ASCS contacted the local Paediatric Complex Needs/Palliative **Care Nurse for additional information about Sophie's** needs and shared information about plans being put in place. The Charge Nurse agreed to arrange for a local disability nurse to visit the family on the ward to offer support.

In essence ASCS took on a co-ordinating role to ensure that **Sophie's health rights were met. We kept in contact with the** family regularly to ensure they were fully aware of any discussions taking place and arrangements being made and updated other professionals involved as appropriate. After her **daughter's discharge Karen told us:**

'Everything was put in place for us before we arrived at the hospital and the experience was so different to the previous one. From the minute we arrived we felt welcomed and all the necessary equipment was ready. A smaller, more consistent number of staff cared for my daughter and this was helpful as she was able to get used to them. She was so comfortable I even managed to sleep in my own room, with the exception of the first night. Getting some sleep meant I coped better and I was more supportive to my daughter

when she needed me. On a couple of occasions the hospital was able to arrange a day pass and we had shopping trips to town - it actually felt a wee bit like a holiday! Sophie fully committed to the procedure in hospital and continues to at home too. Now that I know what can and should be provided for my daughter during a hospital stay I will feel able to speak up to ensure her **healthcare rights are met in future.'**

Names of child and parent changed to protect their identity



5,767 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.

'Your workshops were really successful in making parents aware of their children's rights in respect of visiting both their GP and hospital. There was a wide range of ability in our group and the structure of the workshops and your patient, respectful and non threatening approach meant that parents were relaxed and able to take information on board.'

*It was really good for parents to be given time to relate this information to their own situations and experiences and have the opportunity to discuss this with you and the rest of the group. One of our aims in adult learning is to empower parents and I think this workshop did just that. I look forward to **working together in the future.'***

Alison Low, Community Learning and Development Worker, Douglas Community Centre, Dundee

Helping to Make a Difference

Supporting Carers

Our Children in and Leaving Care Project delivered training workshops to 128 foster and kinship carers helping them to improve their knowledge and understanding of the health care needs and rights of those they look after.

The workshops aim to improve health and wellbeing outcomes for looked after children and young people by supporting carers to access primary medical care and specialist health services on behalf of those in their care. Workshops covered child health rights; consent and confidentiality; mental health and emotional wellbeing; dental and hospital play; disability. Feedback from carers showed that 88% felt more able to access healthcare services after the workshops.

'I am now more aware of children's health rights and how important it is when looking after a young person or child's needs and healthcare.'

'I would make sure I have the correct papers when our foster children need treatment and ask more questions from authorities before and on behalf of the children receiving treatment.'

Jacqui Doyle, Supervising Social Worker at Quarriers Family Placement Services told us that one foster carer had used the



information he had received on dental and hospital play to get support for a child with disabilities who had previously not complied with dental intervention.

The project also developed e-learning modules for professionals working with looked after children and young people, available from summer 2016.

Supporting Children and Young People with Long term Conditions

Between August 2015 and March 2016 our [Lothian Self Management Project](#) delivered two programmes of 12 workshops to 14 young people aged 12 - 17 years who presented with a range of long term conditions. During the workshop programme, participants learned new skills such as breathing techniques, pacing, problem solving and they had an opportunity to speak about their feelings and emotions.

Each programme involved fun and social activities such as drumming, going to a panto, pottery, going for a pizza and bowling. Feedback has been hugely positive.

Young people said: **'I liked meeting other people who had been through a similar thing.'**

'Once we all had finished the sessions we all kind of miss each other'.



Having fun decorating pottery

'The leaders were very supportive and really easy to talk to. It was quite fun the whole time, not boring. I got involved in everything we did.'

'I started to do stuff with my friends - I get involved with others, I used not to.'

Parents said: **'See it's really positive, it's not about curing an illness, but about learning how to positively manage it in your life.'**

'It all comes under confidence that I could never have asked for, it's amazing!'

'Loved the fact he was with people that understood him and that he felt comfortable in the group.'

'Going out and meeting people of all different ages. Hear their stories - a problem shared is a problem halved. Feel a sense of belonging, non-judgemental. She looked forward to it, was very motivated to go.'

Clinicians said: **'... somewhere that they can build their confidence and their self-esteem.'**

'It's filling a gap in the care of kids with chronic illness, giving them a good experience of hearing what it's like having a chronic illness. They get a lot from talking to each other, we can't offer a group experience.'

'It's very different to talking to a doctor or a professional and reduces their isolation.'

Early Intervention for better outcomes

Children with support needs

Our Special Smiles Dental Project trained 212 teachers to use our Special Smiles Dental Play™ resources in 16 additional support for learning schools in 8 local authority areas.

319 children with additional support needs and 129 parents were supported. Evaluation showed increased child understanding of oral health practices and reduced dental anxiety. Teachers and parents were better able to support their children.

Carly's Story

We worked with the 'Time Zone' which supports children with severe and complex needs in Maddiston Primary, Falkirk. Project Officer Mary-Flora Ferris, Carly's mother and Carly's class teacher, Celia Snowden, felt that more intensive support would enable Carly, a P1 pupil, to become more aware and confident when toothbrushing and help her to co-operate with treatment when visiting the dentist.

Early in term 3, Carly's mother attended our workshop to support play at home and she borrowed our Dental Playpack for 4-6 weeks. This gave Carly and family the opportunity in the familiar surroundings of home to learn about healthy snacks, tooth brushing and preparing to visit the dentist. Carly's mother said:

'I was really impressed. The pack made me look at the sugar content in foods, especially the hidden sugars that I didn't expect. It also helped me with Carly's tooth brushing and I learned more about what is difficult for her when attending a dentist. Carly dresses up and the whole family join in. She lies back and I definitely don't feel as stressed. She's opening her mouth and I can brush all her back teeth too. It used to be only her front teeth I could do and I'm more positive. While her understanding has not improved, she has a great routine for her brushing. She has reduced her sugary snacks and now eats plain, ready salted crisps, rather than flavoured ones. She absolutely loved the pack - took it everywhere and she is comfortable going to the dentist.'

Her favourite items were books, CDs, puppet, large mouth, dressing up mask, gloves, mirror. She lies back on the couch, we look at her teeth and she looks at ours.

She took care of the puppet and now plays with her dolls'.

At school, Carly continued to learn through planned curricular activities. Support started during the second term and continued throughout the third from January until March 2016. Depute Head Teacher, Hazel Swanston, reported:

'Carly is a P1 pupil with significant communication, learning and autistic spectrum disorder needs. She did not engage with the concept or process of brushing her teeth and had a very limited diet.'

On previous visits to the dentist her mother reported that Carly had not allowed any staff to look at the health of her teeth and gums and she had been distressed by the visit. School staff implemented a programme of support:

During term two staff from Forth Valley Childsmile team visited Carly and her family to share information about the supportive service offered through the hospital dental service.

Then in term three our topic work focused on 'people who help us.' We had a carousel of different agencies who were involved in our lives over the weeks and we continued to revisit and focus on dental support.

During Carly's work with the ASCS Dental teaching resources she demonstrated an increasing confidence and familiarisation with the equipment and also the purpose of the dentist. Early in this term her mum also received training from Special Smiles staff and a playpack was taken home to reinforce familiarisation and confidence through play at home.

Carly enjoys observation and investigation and the role play and modelling allowed her to deepen her knowledge about the dentist and develop a routine for visiting the dentist through using the dress up clothes, chair, backdrop and instruments. Throughout this topic she demonstrated progression in her acceptance and understanding of the role of a dentist to support her through:

- Observing others including peers, staff and family members
- Briefly touching and de-sensitising herself with all the unfamiliar instruments that a dentist uses
- Exploring the resources in more detail and enjoying trying these out through role play on others. Eventually she enjoyed using the large apparatus and puppets and found this less invasive and a safe way for her to explore action and consequence.



Carly continued: **The final stage of Carly's journey will be to allow dental staff to use these instruments during visits to the dentist and to improve her brushing technique and enable some 'hand over hand' guidance. Celia has identified that a social story would support this final stage as she enjoys and finds reassurance with this resource.**

During her time in the Time Zone Carly has been involved at a **very early stage of 'noticing' when our children try out new foods and tastes once a week associated with a special occasion, time of the year or topic. Over the term we have focused on 'people who help us' and with the support of her mum who includes healthy options in her bag, Carly is showing more tolerance to these foods. Very recently she expressed interest in some of the lunch options available and now chooses, on occasion, a school meal and not her sandwiches.'**

As a result of identifying her specific needs, some creative play ideas and home support, Carly and her family now enjoy a more positive experience, both in terms of tooth brushing and **visiting the dentist.'**

In 2015 Special Smiles won the Patron's Prize at the National Oral Health Promotion Group Conference and was runner up in the Bright Smiles-Bright Futures category at the International Association of Paediatric Dentistry Conference.

Promoting Children and Young People's Rights

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

2,587 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 48 rights based presentations and talks at events attended by 1,451 professionals. These have been well received. A member of staff at Scottish Epilepsy Centre who attended the children's rights training provided by Dagmar Kerr said:

'Thank you, deeply useful and interesting, provocative and challenging and good impact on my practice.'

Partnership Working - Influencing Policy

ASCS contributed to policy development through our representation on 27 national and regional working groups and committees.

Scottish Government groups included the Administration of Medicines and Healthcare Procedures in Schools Working Group; the Working Group reviewing the 'Food in Hospitals (Scotland) 2008 Guidance'; the Scottish Children and Young People Palliative Care Executive; and the Ministerial Advisory Committee for Children and Young People's Health. NHS Scotland groups included the Scottish Paediatric Patient Safety Programme, Clinical Reference Group; and the National Managed Clinical Network for Children with Exceptional Care Needs. We worked on various NHS Board committees and **were invited as a 'critical friend' to advise on the planned Children's and Young People's Centre at the Borders District General Hospital.**

With the support of Malcolm Chisholm MSP we raised questions in the Scottish Parliament on the Education Bill and the Administration of Medicines in Schools and met with the Cabinet Secretary for Education & Lifelong Learning. As a **member of the Scottish Children's Services Coalition we raised issues around children's and adolescents' mental health provision. Our concerns about oral health provision in additional support for learning schools instigated a review by the Chief Dental Officer and a welcome change in policy.**

Our projects worked closely with local authority education and social work departments. We collaborated with third sector partners including for Scotland's Disabled Children; the Mental Health Foundation's project - 'Mental Health of Young People with Long Term Condition' and the Alliance GIRFEC Project.

Christina Kiddie from NHS Tayside's Child Health Physiotherapy Service writes about work Tayside Allied Health Professionals and ASCS carried out with the Angus Early Years Collaborative:

'We have been fortunate to work in close partnership with ASCS's Deborah Brown delivering on a new pathway for young children with complex needs who access Allied Health Professionals (AHPs). This relationship has proved valuable. As part of the Early Years Collaborative, we have learned together, attending workshops to increase our knowledge of improvement methodology, taking forward tests of change to improve our services. It has been interesting to have the views and experience of a non NHS colleague to stimulate our thinking. It has also been an opportunity for us to learn about the work of ASCS.

The most important part of this work has been the link with the families to gain a true understanding of their experiences of our services. We know that families will often respond to individual therapists in a positive manner sometimes not reflecting any concerns they may have, and having Debbie offer to take on that role on our behalf has been hugely useful. We have had honest feedback, not always what we would best like to hear, but this has then informed the changes that require to be made across our methods of service delivery.

Debbie has been enthusiastic and willing to help out and will continue to be an active partner, building on our relationships and joining our Tayside Complex Needs network which will lead on activities across the spectrum of **complex needs.'**

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.



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

Alliance– Getting to Know GIRFEC Project
Angus Early Years Collaborative

Angus Third Sector Children's Services Forum

Association of Paediatric Anaesthetists
Centre for Excellence for Looked After Children in Scotland

Children and Young People's Commissioner Scotland

Childsmile
Dundee Young Parents Pathway Group
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
End of Life Care for Children and Young People in Scotland Group
Enquire Scotland

for Scotland's Disabled Children

Lochee Pathfinder Project Dundee
Mental Health Foundation, Mental Health of Young People with Long Term Conditions Steering Group
National Association of Health Play Staff

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
Royal Hospital for 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

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 Guidance on Education of Children Absent from School due to Ill Health Review 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

UK Committee for Children and Young People's Nursing

We also worked closely with Angus, Fife, Dumfries and Galloway, East Lothian and Perth and Kinross Social Work Departments; Angus, Dundee City, Edinburgh City, Falkirk, Clackmannanshire, Stirling, East and West Dunbartonshire, East and West Lothian, Glasgow City, North and South Lanarkshire Education Departments; NHS Forth Valley, NHS Lothian and Lanarkshire Dental Services; NHS Lothian Paediatric Psychology & Liaison Service.



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