



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 within our healthcare system. Our work includes:

Working with the Scottish Government, NHS and voluntary sector to ensure that health services are planned for sick children and young people in child centred environments with appropriate ratios of trained staff

Informing children, parents and carers of their rights and responsibilities; empowering them to participate in decisions about treatment and care

Raising awareness, representing **children's needs and concerns** within government, healthcare committees and other non-governmental organisations

Promoting high quality of health care services at home and in hospital, while working to obtain equality of services and access across Scotland

Action for Sick Children Scotland

Newsletter

Summer 2016

A Child's Anaesthetic Experience? Not All That it Should Be

Action for Sick Children Scotland's ward based Parental Access and Family Facilities Survey 2012-2013 <http://www.ascscotland.org.uk/default.asp?page=19> revealed a mixed experience amongst parents and carers whose children were undergoing surgery.

Wards reported that the parents/carers could:

- Visit on operating day (83%)
- Accompany their child to and from theatre (81%)
- Stay with their child until they were under anaesthetic (76%)
- Be in the recovery room with their child (67%)
- Be with the child when they return to the ward (81%).

These figures appeared to show that up to a third of children were without parental/carer support at some point in their anaesthetic journey, in clear breach of Article 2 of the EACH Charter <http://www.ascscotland.org.uk/default.asp?page=66> which states that, 'Children in hospital shall have the right to have their parents or parent substitutes with them at **all times**'.

We were surprised to find that the practice of allowing a parent to stay with their child until anaesthetised was not universal and were particularly concerned that there had been an apparent drop in the number of wards reporting that parents/carers could be in the Recovery Room with their child since the previous survey. Nevertheless, we were conscious of the fact that interpretation of the figures might not be straightforward since in some units children are sent straight back to the ward for recovery or might go direct to PICU (paediatric intensive care unit). What was important, we thought, was that a parent or other carer should be present when their child woke up from the anaesthetic.



Children have the right to have their parents or parent substitutes with them at all times (EACH)

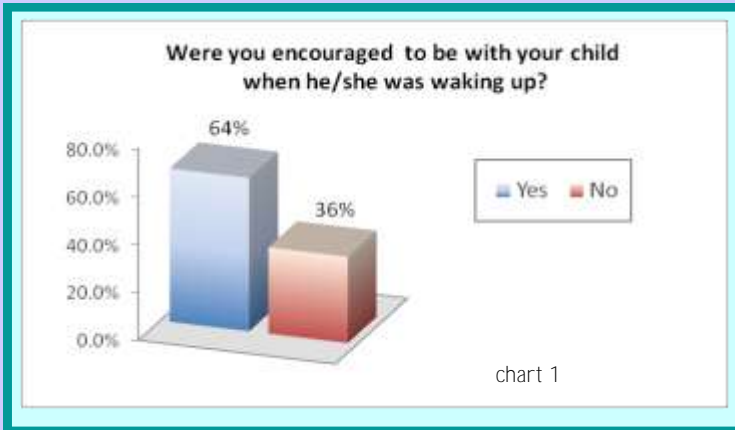
We decided to undertake a survey of the anaesthetic experience of children and young people as reported by their parent/carers rather than health professionals. In all, we received 242 complete responses from parents/carers whose children (0-18 years) had been given an anaesthetic in a variety of hospital settings within the last three years: Edinburgh, **Glasgow, Aberdeen and Tayside children's** hospitals and all the large district general hospitals (DGHS) across Scotland.

Across all hospital settings, satisfaction with the way children were looked after in the Anaesthetic Room was high, with 93% of respondents reporting that they were able to be with their child and 96% satisfied with the way their child was looked after. However, when it came to recovery, a different picture emerged, with only 73% saying that they were happy with the way their child was looked after. Less than 2/3 of parents/carers said they were encouraged be present while their child was

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Promoting the Healthcare Rights and Needs of
Children and Young People

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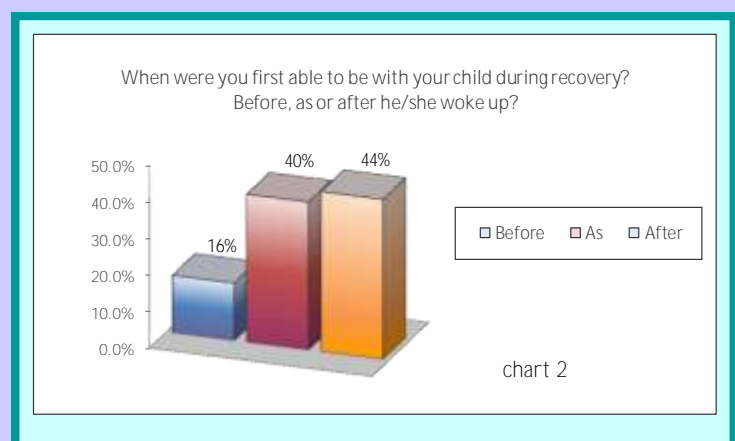


waking up (chart 1) with 44% reporting that they were first able to be with their child only after he/she had woken up (chart 2). A typical comment from such a parent was, 'I would have preferred to have been with my daughter when she woke as she was very scared and disorientated when I first saw her in the recovery room' and another wrote, 'I regret not insisting on being with her as it was too upsetting for both of us'.

'I would have preferred to have been with my daughter when she woke as she was very scared and disorientated when I first saw her in the recovery room'

There were no significant differences in responses to survey questions according to type of hospital (large or small children's or DGH) and it does appear that there is a significant problem across Scotland with procedures governing recovery. As psychoanalyst James Robertson found in his ground breaking research (see article in ASCS Autumn 2015 newsletter) the most distressing part of hospitalisation for children is not pain or illness but 'separation from mother' and it is clear from our survey that all too many children are being denied the right to have a parent or other carer with them and as a consequence are left distressed and upset, and possibly damaged. As a result of these findings, we intend to engage with anaesthetic departments across Scotland to improve on current practice and, if necessary, call on the Scottish Government to issue appropriate guidance.

Professor Richard Olver, ASCS Chair



Chief Dental Officer Reviews Oral Health Provision to ASL Schools

In the course of our work in additional support for learning (ASL) schools, ASCS became aware of inequities in dental health provision for children with additional support needs. Unlike mainstream schools, ASL schools are not included in the Basic National Dental Inspection Programme (BNDIP) inspections and so parents of ASN children do not receive information on their child's dental health and no data is gathered on children in ASL schools to inform future care planning and services. We found that pupils in ASL schools do not routinely receive Childsmile toothbrushing and fluoride varnish application unless the school is situated in an area of high deprivation. This is despite ASN children being at higher risk of dental caries and tooth extraction under general anaesthesia.

As a result of ASCS raising these concerns, Margie Taylor the Chief Dental Officer for Scotland, instigated a review of provision to ASL schools in all NHS Boards. We are delighted that the Chief Dental Officer has now issued guidance to Boards to ensure that from August 2016, ASL schools, including annexes, units and enhanced provision settings, will be offered Childsmile tooth brushing and fluoride varnish application and will be included in BNDIP inspections.

The Importance of Play

We've been busy spreading the message about the value of play preparation. In March, our Special Smiles team piloted a half day workshop for Dental Health Support Workers, hosted by NHS Education Scotland in Glasgow. The session focused on the importance of communicating with children through play; understanding and supporting children's play; and exploring the Special Smiles Dental Play™ resources to support children and families with dental visits and treatment. Participants assessed the course as relevant and enjoyable, and they felt it could have been longer with 'More playing please!'

We also presented to 75 dental health nurses from Lothian on how to improve children's dental experience through play at their Study Day in May. Last but not least, in November, Amy Joss, Project Officer and Health Play Specialist, delivered the 2015 Hugh Jolly Memorial Lecture in London, focussing on Special Smiles and how play can reduce dental anxiety and improve oral health. This is particularly relevant across the UK as tooth extraction remains the most common reason for children requiring general anaesthesia in our hospitals.

In partnership with Angus Early Years Collaborative

Deborah Brown, ASCS Area Officer (Tayside) writes: ASCS was delighted to take part in a recent test of change project seeking to improve the support provided to young children and their families who receive services from Allied Health Professionals (AHPs). This project was facilitated by the Early Years Collaborative, a multi-agency quality improvement programme to support the transformation of early years in Scotland, focusing on strengthening services by utilising improvement methodology to test, measure and introduce new ways of working in order to improve outcomes for young children and their families.

Through the Angus Early Years Collaborative and TcEO (Tayside Centre for Organisational Effectiveness) ASCS was invited in August 2015 to join the Child Health Allied Health Professionals 0 – 3 Years **Children's Pathway** Project. The project team attended monthly Action Learning Sets supported by NHS Teaching Lead Jackie McCallum who guided them through the development of a Project Charter, Project Aim and Mission Statement, as well as providing guidance on how to use the Model for Improvement and PDSAs (Plan Do Study Act).

Special Smiles in Action

Castlevue School in Stirling and the Special Smiles team were delighted to host a visit by Margie Taylor, Chief Dental Officer (CDO) in March. The CDO took part in oral-health focussed activities with **Mrs Blakemore's pupils, the youngest in the school** for children with additional support for learning needs. **Head Teacher Janet Stirling, said it was 'a pleasure to be able to showcase the work of the school and the impact of the project.'**



Margie Taylor,
Chief Dental Officer
meets Castlevue
School pupil

Child Health Allied Health Professionals 0 – 3 Years **Children's Pathway**

An earlier audit gathering feedback from families of young children who see more than one therapist had identified that: children attend multiple appointments with multiple therapists, families feel overwhelmed, expectations between families and therapists are not always clear, they lack confidence to manage the needs of their child and AHPs do not always listen and respect their views in term of priorities for their child. Further investigation tracking the journey of a sample of children indicated a variation in the management across Tayside with therapists often working independently within their own specialism.

In light of this information from families, the team led by Christina Kiddie, NHS Tayside Physiotherapy Manager and supported by representatives from Occupational Therapy, Physiotherapy, Speech and Language Therapy and the voluntary sector agreed the case for change. The aim of the Child Health Allied Health Professionals 0 – 3 Years **Children's Pathway Project was agreed as being:**

To reduce multiple therapy appointments for families and improve parent confidence by ensuring that by 30th June 2016, 100% of families referred to more than one AHP service in Angus who require a joint goal setting session will receive this within 8 weeks of the second referral and a review within 6 months.

Using the Model for Improvement/PDSAs the project progressed the following change ideas:

- Developed a mission statement with input from staff, parents and families
- Developed and implemented a protocol for the identification of families
- Developed a database to support data collection
- Tested new ways of working to support Joint/Shared Goal Setting Session within identified timescales
- Tested role blurring between AHP services when giving advice and information to families
- Developed and tested a parent satisfaction questionnaire based on the mission statement
- Developed and tested a questionnaire for AHP staff to share their experience of the new way of working

Early feedback from a parent survey carried out by Action for Sick Children Scotland and Parent to Parent indicates improved satisfaction accessing a more joined up approach from AHPs. Feedback from AHPs also reflects an increased **confidence in each other's role. Whilst this qualitative feedback is extremely positive, there is a requirement to develop a more robust database to collect more reliable and accurate quantitative data and this is currently being addressed.**



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The Child Health Allied Health Professionals 0 – 3 Years **Children’s Pathway Project** is aligned to the **Early Years Collaborative Stretch Aim 2** and in line with the GIRFEC (Getting it Right for Every Child) agenda the project provides opportunities for professionals to use common tools and processes working closely with children, their families and other professionals supporting them. We are also pleased to report that the work has been assessed and published by IHI (Institute for Healthcare Improvement).

An Early Years Collaborative Celebrating Success event was hosted in Angus in April to showcase the work of this and other projects and to provide an opportunity for information sharing. Guests from local authority, health and the voluntary sector were invited to hear about the projects and to discuss how they can support sustainability and development. Project teams received certificates of achievement in recognition of their hard work.

ASCS is grateful for the opportunity to be involved in the Angus Early Years Collaborative and the Child Health Allied Health Professionals 0 – 3 Years **Children’s Pathway Project** and hopes to have the opportunity for future involvement.



Deborah (3rd from left) and some of the AHP team members

ASCS News on Children in Care

E-learning resource for Professionals on Children and Young People in Care

ASCS delivers workshops for foster and kinship carers on different health related topics and this learning will soon be available as an e-learning resource for professionals working with looked after children and young people. The e-learning modules developed by ASCS with the University of Stirling and Learn Pro, use materials from our workshop programme and include interactive activities and a personal reflective journal.

- Module 1 looks at managing the healthcare needs and rights of children and young people in care in the context of the Children & Young People (Scotland) Act 2014.
- Module 2 examines issues around the mental health and emotional wellbeing of looked after children and the impact on carers.

New Kinship DVD Resource Planned

Over recent years ASCS has delivered workshops to kinship carers across central Scotland through kinship care support groups and local authority kinship care groups. This has enabled ASCS to collect case studies and questions from carers on healthcare experiences with their children to use in this new resource, which will include FAQs and a DVD. To find out more or to take part in this work contact Anne Wilson: a.wilson@ascscotland.org.uk or call 0131 553 6553

ASCS Self Management Programme



Having fun and making friends - a collage of workshop activities

Workshops are going well with the 3rd programme for young people with long term conditions rolling out over May and June. Children and young people in the 2nd programme had a fantastic time getting to know one another. We attended a panto by Circus Star before learning ways to self-manage health conditions including learning about children’s rights at hospital, relaxation techniques, discussing issues that matter like schools and friendships. The programme ended with our **Healthy Living competition for the ‘Best Looking Fruit Sushi’** and a visit to **Ceramics Doodle** to choose and paint a piece of pottery. If you would like to take part or to find out more, contact Simita Kumar (s.kumar@ascscotland.org.uk)

ASCS is grateful to the Scottish Government which provides Children, Young People and Families Early Intervention Funding.



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