



## **Strategic Plan 2013 - 2016**

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## Executive Summary

This Strategic Plan describes the proposed future development of Action for Sick Children Scotland for the period April 2013 to March 2016. It has been prepared following discussion with Board members and staff.

### 1. Development of ASCS

The organisation began as Mother Care for Children in Hospital in the 1960s, becoming the National Association for the Welfare of Children in Hospital (NAWCH) in 1965. In 1977 NAWCH (Scotland) was constituted as a separate Scottish Charity. In 2008 the organisation registered with OSCR and Companies House as Action for Sick Children (Scotland) which had been its campaigning name since 1991. In 2012 its charity and company name was further amended to Action for Sick Children Scotland.

Over the years ASCS has worked for improvements in the standards of healthcare provision for children and young people and has campaigned for the greater involvement of children, young people and their families in decisions about the shape of future health services in Scotland. ASCS is a member of the European Association for the Welfare of Children in Hospital (EACH). The EACH Charter which sets out ten healthcare rights of children and young people is recommended in the Scottish Government's 'Delivering a Healthy Future: An Action Framework for Children and Young People in Scotland', as a benchmark against which NHS Boards should review their child health services.

Over the years ASCS has secured funding from various sources including the Scottish Government, Trusts, Area Health Boards and regional authorities. At the end of March 2012 ASCS had an annual gross income of circa £175,000 and seven staff.

### 2. Operating Principles

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

**Our Mission is to enable children and young people to understand their healthcare rights and to meet their individual healthcare needs in partnership with parents, carers and professionals. We do this through direct support and advice, influencing policy and campaigning for service improvement.**

**Our Organisational Values** are to:

- believe in the rights of children and young people
- listen to and meet the needs of children and young people
- empower children and young people
- keep children and young people safe
- be supportive
- work in partnership
- be challenging
- be independent
- be inclusive
- maintain confidentiality
- maintain integrity

**Our Strapline** summarising our whole approach is:

***Helping Sick Children and Young People Meet their Healthcare Needs***

**3. Services and Activities**

ASCS's work includes:

1. 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 equipped with appropriate ratios of trained staff.
2. Informing children and young people, parents and carers of their rights and responsibilities, where to access advice and support and what they should expect from health service providers - empowering them to participate in decisions about the treatment and care.
3. Raising awareness and representing children and young people's needs and concerns within government, healthcare committees and other non-governmental organisations.
4. Promoting the use of evidence based practice to provide high quality health care services at home and in hospital, while working to obtain equality of services and access across Scotland.

ASCS currently delivers or has recently completed the following major projects.

**Parental Access and Family Facilities Survey:** the 2013 survey of all NHS hospitals in Scotland admitting paediatric patients with the aim of assessing parental access and family facilities is the latest in a series conducted since 1985.

**Stay Well Self Management Project:** this assisted young people with long term conditions to stay well by enabling them to self manage their illness.

**Special Smiles Dental Project:** this trains teaching staff in Additional Support for Learning schools to use dental play resources developed for children with complex and additional support needs to help them understand and practice good oral health and to reduce child dental anxiety.

**Tayside Child Health Project:** this has focused on supporting families including young parents, to learn about their children's health rights and to be better able to look after their children at times of illness.

**NHS Greater Glasgow & Clyde:** this work supports sick children and their families, ensuring that their needs are heard by health care service providers and planners and reflected in service delivery.

**Children and Young People In and Leaving Care Health Project:** this project focuses on looked after children and young people. It delivers workshops to support foster and kinship carers to look after the health care needs of those children and young people in their care.

**Central Office Support Services:** co-ordinates all projects and encourages partnership working and collaboration with key partners.

#### **4. Governance and Management Structure**

The organisation is a Scottish Charity SCO006016 and company limited by guarantee No. 100114. It is managed by its voluntary Executive Committee, which delegates operational decision making to the National Coordinator, who in turn delegates authority to deliver individual projects to relevant staff members.

#### **5. Current Position**

##### **5.1 Our Client Group**

ASCS is the *only* Scottish charity which works for ALL sick children and young people (*irrespective of their illness and condition*), and their families.

##### **5.2 The Need for our Services**

Children and young people have a right to the highest attainable standards of physical and mental health, access to suitable healthcare, and support in learning to make healthy and safe choices.

There remain gaps in the full implementation of children and young people's healthcare rights as described in the EACH Charter and underpinned by the UNCRC. ASCS's EACH Child and Young Person's Health Matters campaign has recently focused on the right for all children and young people absent from school due to illness to have equitable and appropriate education provision, regardless of their illness, condition or where they live.

Most children admitted to hospital are in the 0-8 age group. Children can suffer psychological trauma through illness and/or poor hospital or healthcare experiences, resulting in lifelong aversion to /fear of hospitals and medical treatment.

Centralisation of hospital services may involve travelling outwith local areas to tertiary centres for specialist surgery. This means that increasingly children are unable to access specialist play support and may suffer as a result.

A child or young person with a chronic condition can suffer from social isolation; poor support during transition; poor mental well-being; poor communication with peers, healthcare and other professionals; poor educational outcomes.

During 2010-11 62,542 child patients in Scotland had teeth extracted, 12% in a hospital dental setting. Tooth extraction is the largest single reason for children receiving general anaesthesia in hospital.

Children and young people with complex additional support needs are at higher risk from dental disease and undergoing dental procedures and surgery.

There is a clear link between areas of deprivation, unequal access to healthcare, ill health and poor oral health. A child born into disadvantage is more likely to suffer from multiple health problems and more likely to experience physical and mental health problems in later life.

The number of children looked after by Local Authorities (July 2011) is at its highest level (16,711) since 1981. These children have much poorer physical and mental health than their peers and use health services much less. Mental health issues are recognised as both a cause and a potential result of being looked after.

Children in Scotland, aged 5-10, looked after at home or accommodated are six times more likely to have a mental *disorder* than those living with families in the community (52% compared with 8%).

Parents and carers especially those facing poverty, vulnerable families, or those dealing with additional challenges such as caring for looked after children and young people, sick children or those with long term conditions can find things challenging. They can benefit from support in what can, at times, be a difficult role. Supporting parents and carers will help their children achieve healthier outcomes.

### **5.3 The Demand for the Services**

There are over 1.1 million children and young people aged up to 18 years in Scotland representing over one fifth ( 20.9%) of the population of 5.25 million. (mid 2011 statistics) The trend of falling birth rates has reversed in recent years and the general fertility rate has also risen.

Detailed evidence of the demand for the work of ASCS is contained in the separate Statistical Appendix to this Strategic Plan.

#### **5.3.1 Hospital Admissions in Scotland**

Of the 1.43 million hospital admissions annually in Scotland (in-patients and day cases) just under 7 % (100,000) are for children aged 14 and under. This is a decrease on previous year (102,000 admissions).

During 2011-12, the emergency admission rate for children under 14 years was 55,000 (55,402 in 2010-11) while the elective admission rate was 38,000 (39,398 2010-11). This represents 38% of total child admissions.

Children under four years of age have the highest admission rate, largely due to emergency admissions (54,000 in 2011-12) and 54% of total children under 14 admission rate).

In 2011-12 around 34,000 planned procedures/operations were carried out for children under 14 years or age.

#### **5.3.2 Support Needs Services**

The Support Needs System (SNS) records information about children/young people with additional support needs, so as to monitor their progress and access to services/support. Currently, eleven NHS Boards use SNS and as at August 2010 14,445 children were being assessed.

#### **5.3.3 Dental Services in Scotland**

Dental services include the General Dental Service (High street dentists), the Community Dental Service and the NHS Hospital Dental Service (secondary care). The General Dental Service (GDS) constitutes the main provision for family dental services for people in Scotland.

The Community Dental Service mainly targets disadvantaged groups and those with special needs, learning difficulties and the elderly in residential care. They also

provide a 'safety net' for those who are unable to access GDS and play a significant part in service delivery in remote areas.

Childsmile, the Scottish Government oral health programme was introduced in 2006/07. It is designed to improve the oral health of children in Scotland and reduce inequalities in dental health and access to dental services.

86.1 % of Scottish children were registered with an NHS GDS dentist at 31 September 2011, an increase from 78.7% the previous year. The 6-12 age group had the highest percentage of population registered (97.9%) with a GDS dentist.

Children from the most deprived areas are nearly twice as likely to have already had dental decay at the age of 5 years than children from the least deprived area.

#### **5.4 The Benefits of the Work**

Children and young people taking part in our projects will benefit through: reduced anxiety associated with hospital admissions, medical or dental treatment, enhanced social inclusion, self confidence and self esteem; improved communication skills; a greater ability to access healthcare services; more positive contact with medical and dental services.

Parents and carers will benefit through: increased confidence in supporting their child during illness or hospitalisation; better awareness about health needs of children and young people including those with complex additional support needs or those who are looked after; improved parenting skills and abilities to communicate with healthcare professionals to access appropriate health care services; improved knowledge about child healthcare rights, parental responsibilities.

Healthcare professionals will benefit from a greater awareness of: the needs of sick children and young people including those with long term conditions; of the needs of young parents; of the need for improved facilities in hospital for children, young people and their families and a greater ability to provide a more appropriate service and response.

### **6. Monitoring and Evaluation**

ASCS monitors and evaluates its work through internal reporting systems and via qualitative and quantitative methods including statistical recording, questionnaires, referrals, case studies and user feedback. Funders are provided with regular progress reports.

### **7. Development Context**

#### **7.1 Key Influences on Development**

A PEST analysis has been completed. The principal political and legislative influences on ASCS's future development are:

- The European Association for the Welfare of Children in Hospital (EACH) Charter (1988)
- The Scottish Executive's 'National Framework for Service Change in the NHS in Scotland' (The Kerr Report) (2004), 'Delivering for Health' (2005);

'Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland' (2007)

- The Scottish Government's 'Better Health, Better Care Action Plan' (2007); 'Better Health, Better Care: National Delivery Plan for Children and Young People's Specialist Services in Scotland' (2009); Better Health, Better Care Hospital Services for Young People in Scotland (2009); Improving Health & Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan (2009); The Healthcare Quality Strategy for NHS Scotland (2010); The Scottish Patient Safety Paediatric Programme (2010)
- The Scottish Government's 'Looked After Children and Young People We Can And Must Do Better' (2007); These Are Our Bairns: A Guide for Community Planning Partnerships on being a good Corporate Parent: (2008).
- Early Years and Early Intervention Framework (2008)
- The Vision of Scotland's Ministers for all Scottish Children,' which outlines its hopes for children and young people to be fully supported as they grow and develop into successful learners, confident individuals, effective contributors and responsible citizens
- The Getting It Right for Every Child (GIRFEC) approach which puts the well being of children and young people at its heart and the eight areas of wellbeing, namely Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included (SHANARRI)
- Scottish Government's Children and Young People Bill (2012) which sets out a range of proposals to take forward ambitions for children's rights and services
- Royal College of Physicians of Edinburgh (RCPCE): Think Transition: Developing the essential link between paediatric and adult care (2007)
- National Parenting Strategy: making a positive difference to children and young people through parenting: Scottish Government 2012
- Referendum on Scottish Independence 2014: outcome of the referendum on independence may lead to changes in the Scottish Government's priorities.
- Election in 2015: any change of Government may lead to changes in Ministerial priorities with unpredictable outcomes
- Changes to and re-organisation of the NHS will impact on an NHS Board's ability to engage with ASCS.

The main economic considerations for the period of this Plan are:

- An economy which will continue to face a serious financial squeeze
- Instability of funding, with statutory and Trust sources coming under pressure
- Concern over move towards formal 'contracts' and competitive tendering
- Pressure on resources resulting in moves towards more 'partnership' working
- Increasing reporting requirements arising from a changed contractual arrangement in government funding from statutory bodies.

Social considerations include:

- Scotland is more multi-cultural and therefore needs to be more inclusive
- Children are becoming less physically active
- Developments in the way people communicate (web sites, facebook, blogs / twitter) may encourage social involvement but less personal interaction
- An expectation in economic times of greater reliance on the voluntary sector without the resources to deliver
- Increasing regulation of the voluntary sector and the heavy burdens of monitoring, assessment and evaluation.

## **7.2 SWOT Analysis**

A formal SWOT analysis has been carried out.

## **8. Strategic Development**

### **8.1 Long Term Aims**

Our overarching aims are to:

1. Ensure that children, young people and families have appropriate information and equitable access to best quality services at times of illness.
2. Promote universal recognition of the needs of and rights of sick children and their families.
3. Advise and work with parents/carers and professionals on the needs and rights of sick children in hospital and in the community, specifically to empower parents/carers, children and young people to identify their needs during illness and access appropriate services.
4. Ensure the best possible health services are provided for sick children and young people.
5. Influence the service specification of health care provision for sick children and their families.

### **8.2 Strategic Aims and Priority Areas for Development**

The strategic aims and priority areas for development are:

**Strategic Aim 1:** *Ensure that children, young people and families have appropriate information and equitable access to best quality services at times of illness*

#### **Priority - Awareness Raising**

ASCS will further develop its marketing strategy and communications plan to raise awareness of the needs and rights of children and young people eg:

Launch in 2013 of the Parental Access and Family Facilities Survey findings; the EACH Child and Young Person's Health Matters campaign; conferences; direct contact with opinion leaders/key groups; and raising awareness via ASCS's web site, communications materials, social media.

**Strategic Aim 2:** *Promote universal recognition of the needs of and rights of sick children and their families*

**Priority - Policy Development**

This will continue to focus mainly on the EACH Campaign which highlights gaps in children and young peoples' healthcare provision, taking into account the findings from the 2013 Parental Access & Family Facilities Survey of health services admitting children and young people. ASCS will also influence policy development via representation on various local and national policy forums; by responding to key policy consultations.

**Strategic Aim 3:** *Strengthen the infrastructure of the organisation to support staff and volunteers taking into account quality, efficiency and value for money*

**Priority - Development of the National Office**

The National Office will continue to be part of direct support to projects and to user groups and the need for further resources will be kept under constant review.

Other work will include: maintaining highest standards of governance; reviewing existing policies, procedures; increasing the level of volunteering; and developing and implementing strategy to build on core and project funding from various sources.

**Strategic Aim 4:** *Further develop existing and new pilot projects, as exemplars of best practice and as candidates for inclusion in main stream healthcare services*

**Priority 1 - Service Development**

ASCS has a track record in developing innovative child health related services and we will work to develop and pilot new approaches in response to local needs.

**Priority 2 - Further Development of Existing Projects**

Over the next three years, existing ASCS projects will have the following objectives:

*Parental Access and Family Facilities Survey*

- Develop plan to disseminate findings including launch in Spring 2013
- Review findings of survey to inform ASCS policy and campaigning work

*Special Smiles Dental Project*

- Seek further funding to extend into new local authority areas until March 2015
- Secure mainstreaming agreement for this activity during 2014 with a view to rolling out across Scotland by 2016

*Self Management Project*

- Undertake a review of the future resourcing and development of this work with young people
- Develop, pilot and roll out self management project for children aged 8-12 years

*Children and Young People In and Leaving Care*

- Deliver workshop programme during 2013 –14 to kinship and foster carers on issues relating to the health needs of children in their care
- Undertake planning work for and externally evaluate training programme

- Explore possibility of having programme included in mainstream training provided by foster carer agencies.

*Tayside Child Health Project*

- Undertake a review of the future resourcing and development of this work in Tayside or in another Health Board area

*Local Service Planning*

- Consider how funding can be secured to increase work activity in Greater Glasgow and Clyde NHS and in other health board areas
- Explore the potential for providing professional training

**Priority 3 - Development of New Service Initiatives**

*New Service Initiatives*

- Identify possible new service development areas taking into account findings of the 2013 Parental Access & Family Facilities Survey.
- Submit funding applications for new Service Initiatives during 2013
- Current candidates are in:
  - Project/service development around mental health and wellbeing.
  - Provision of facilities for young people and transition
  - Health Play project with parents and pre school children using playboxes
  - Pain Project

**9. Sources of Required Income**

We hope that funding will continue to come from established sources, such as the Scottish Government. Income will also be generated from a variety of sources, the main ones being Charitable Trusts and Foundations; NHS Boards and Donations.

## **Introduction**

This Strategic Plan describes the proposed future development of Action for Sick Children Scotland (ASCS) over the period 1st April 2013 to 31st March 2016. It has been prepared following a review of current and future projects, consideration of the healthcare needs of children and young people, and discussion with Board members and staff.

### **1. Development of ASCS**

#### **1.1 Origins**

The organisation has been in existence since the 1960s. It was originally called Mother Care for Children in Hospital, changing to the National Association for the Welfare of Children in Hospital (NAWCH) in 1965. NAWCH reached Scotland in the early 1960s when two groups started in Edinburgh and Glasgow and in 1977 NAWCH (Scotland) was constituted as a separate Scottish Charity. In 2008 the organisation registered with OSCR and Companies House as Action for Sick Children (Scotland) which had been its campaigning name since 1991. In 2012 its charity and company name was further amended to Action for Sick Children Scotland.

#### **1.2 Milestones in Development**

Since becoming a Scottish entity in 1977, ASCS has worked for improvements in the standard of healthcare provided for children and young people in hospital and community settings; and has campaigned for greater involvement of children, young people and their families in decisions about the shape of future health services in Scotland. Achievements have included:

- Translation of information from users into standards of care in the national health service which has resulted in ASCS becoming regarded as an 'expert' in standard setting in all areas of children and young people's healthcare
- Influence on and input into Scottish Government and NHS policies, procedures and services
- Representing the voice of sick children, young people and families on groups such as the Scottish Government Children & Young People's Health Support Group; the National Steering Group for Specialist Children's Services in Scotland Age Appropriate Care Working Group; the Paediatric General Surgery Working Group; the NHS National Services Division (NSD) National Managed Clinical Network Review Group; the (NSD) Transition to Adult Care for Chronic Disease Working Group; the National Managed Clinical Network for Children with Exceptional Healthcare Needs
- Inclusion of the European Association for Children in Hospital (EACH) Charter in the Scottish Government's 'Delivering a Healthy Future: An Action Framework for Children and Young People' in 2007 as a benchmark against which NHS Boards should review their provision of children's hospital service
- ASCS's Campaign for the right of children and young people absent from school due to ill health to receive appropriate and equitable education provision which resulted in the Scottish Government's decision to set up a

- Stakeholder Group to review the Guidance on Education of Children Absent from School through Ill Health
- The only voluntary organisation represented on the Scottish Government Specialist Services for Children and Young People Monitoring Group.
  - Establishment of regional staff who work locally, identifying and responding to grass roots issues that impact on the health of children and young people

### 1.3 History of Funding Secured

From its inception ASCS has maintained a history of stable funding over more than 35 years, and has successfully applied for funds from various sources.

Core funding is provided by the Scottish Government, while individual projects and posts are currently funded from the following: the Scottish Government's Early Years Early Action Funding, NHS Board funding, Trusts and Foundations.<sup>1</sup>

ASCS is supported by a strong position with the professional healthcare providers in Scotland.

ASCS has developed into a well established organisation, with an annual gross income of £175,000<sup>2</sup> and a staff of seven.

## 2. Operating Principles

***As an over-arching principle, a belief in the healthcare rights of children and young people is at the centre of everything we do.***

### 2.1 Our Vision

ASCS's Vision is based on its original aims and has been agreed as follows:

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

### 2.2 Mission Statement

***Our Mission is to enable children and young people to understand their healthcare rights and to meet their individual healthcare needs in partnership with parents, carers and professionals. We do this through direct support and advice, influencing policy and campaigning for service improvement.***

### 2.3 Our Values

The work of Action for Sick Children Scotland is underpinned by the ten principles of the EACH Charter – the rights of children and young people in health care services - and their corresponding rights as set out in the United Nations Convention on the Rights of the Child (UNCRC). Our work has the wellbeing of children and young people as its central focus.

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<sup>1</sup> Position at November 2012

<sup>2</sup> As at 31 March 2012

The values which are important to ASCS's Board and staff are to:

***Believe in the rights of children and young people***

We believe in the rights of children and young people as enshrined in the UNCRC and in the EACH Charter and are committed to their promotion within the healthcare system

***Listen to children and young people to meet their needs***

Our work is focused on meeting the needs of children and young people in our health care system, ensuring that these are a central focus of those responsible for delivering child health policy, practice and service provision

***Empower children and young people***

We work to empower children and young people to identify and articulate their needs and we tailor our services accordingly

***Keep children and young people safe***

The safety of children and young people we work with is paramount

***Be supportive***

We are understanding and supportive of the needs of children, young people and their families

***Work in partnership***

We believe working in partnership with relevant statutory and voluntary agencies, putting the child at the centre, will achieve the best outcomes for sick children, young people and their families

***Be challenging***

We challenge the policies and procedures of healthcare and other providers, to ensure the services provided are appropriate to the changing needs of children and young people

***Be independent***

We are an independent, voluntary sector charity

***Be inclusive***

We are committed to non discriminatory practices and equality of opportunity in recruitment, work practices and provision of service

***Maintain confidentiality***

Our work is carried out with the highest regard for confidentiality

***Maintain integrity***

We conduct our business with integrity and respect for others

## **2.4 Core Business**

We fulfil our Mission through our core business which involves:

1. 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 equipped with appropriate ratios of trained staff.
2. Informing children and young people, parents and carers of their rights and responsibilities, where to access advice and support and what they should expect from health service providers - empowering them to participate in decisions about the treatment and care.
3. Raising awareness and representing children and young people's needs and concerns within government, healthcare committees and other non-governmental organisations.
4. Promoting the use of evidence based practice to provide high quality health care services at home and in hospital, while working to obtain equality of services and access across Scotland.
5. Surveying, at regular intervals parental access and facilities for sick children and young people in hospitals across Scotland through a questionnaire to health care staff.
6. Working to provide a network of ASC(S) staff across Scotland to ensure local implementation of policies for sick children and young people, providing a link to consult with parents and carers.
7. Working with colleagues within professional health education to influence the teaching, learning and practice of all staff who care for children and young people to ensure that they are effectively prepared to deliver high standards of practice consistently.
8. Working with health professionals at all levels to ensure that the specific needs of young people prior to and during their transition from paediatric, adolescent to adult services are addressed and that services to ensure a seamless process of transition are implemented across Scotland.

## **2.5 Strapline**

The strapline summarising our approach is:

***Helping sick children and young people meet their healthcare needs***

## **3. Our Services and Activities**

### **3.1. Projects**

ASCS currently delivers or has recently completed the following major projects.

#### **Parental Access and Family Facilities Survey**

Since 1985 ASCS has conducted regular surveys of all NHS hospitals in Scotland admitting paediatric patients to assess parental access and family facilities. The

findings of these surveys help inform the Scottish Government's children and young people's health policies and to inform families about what is available in their local hospitals. The most recent survey which will report in 2013 was supported by the Scottish Government.

### **Stay Well Lanarkshire Project**

Stay Well Lanarkshire assisted young people (11 to 18 years) with long term conditions to self manage their condition by taking part in our generic self management/peer support programme. The three year project developed a toolkit for young people with chronic illness and those working with them. ASCS aims to continue supporting children and young people to develop the skills and strategies to self manage their long term conditions.

### **Special Smiles Dental Project**

After the successful evaluation of the Tayside Special Smiles Dental pilot project in 2009, ASCS extended Special Smiles into new local authority areas. This project works in Additional Support for Learning schools training teaching staff to use dental play resources developed for children with complex and additional support needs. It helps children understand and practice good oral health and helps reduce child dental anxiety. It supports teachers, parents and carers to better contribute to these children's specific oral health needs. The Scottish Government's Early Years Early Action funding through Inspiring Scotland has enabled ASCS to continue in Glasgow.

### **Tayside Child Health Project**

This ASCS work focuses on vulnerable families, including young parents. The project developed a toolkit (DVD, booklet, workshop facilitator notes) to enable young parents and vulnerable families to learn about their healthcare rights and responsibilities when they or their child is ill. It delivered workshops on child health to parents with the aim of helping them to support their child at times of illness.

### **NHS Greater Glasgow & Clyde**

Our work in NHS Greater Glasgow and Clyde will continue to support sick children, young people and their families. It will ensure that their voices are represented to health care service providers and planners so that their healthcare rights and needs are reflected in policy, practice and service delivery.

The Glasgow Area Co-ordinator responds to enquiries from families with sick children in hospital or at home, providing information, advice and practical support. The Area Co-ordinator works closely with the Royal Hospital for Sick Children Glasgow, the children's ward at the Royal Alexandra Hospital and young people in adult hospitals. Work also includes raising awareness of the needs of sick children and their families through delivering talks to nursing students, schools and youth groups.

### **Children and Young People In and Leaving Care Health Project**

This project focuses on the healthcare needs of looked after children and young people. It has developed a resources toolkit for professionals working with this vulnerable group and piloted a support programme for LAC children and young people to help them manage challenging healthcare situations. The project will continue its focus on delivering workshops to support foster and kinship carers to look after the health care needs of those children and young people in their care.

### **Central Office Support Services**

These projects are co-ordinated through the central office which also has a major role in collaboration with the health services, social work, education and the voluntary sector to highlight any gaps in health services in order to provide joined up approaches and continuity of care for children and young people.

***Promoting universal recognition of the needs and rights of sick children and their families runs through all this work.***

## **4. Governance and Management Structure**

Action for Sick Children Scotland is a Scottish Charity SCO006016 and company limited by guarantee No. 100114. It operates in accordance with charitable and company legislation and is run by a voluntary Executive Committee whose members are also Directors of the Company.

The Committee provides strategic leadership and direction and its Office-bearers consist of Chair, Vice-Chair and Treasurer. Executive Committee members have a range of skills and experience in the area of child health and child care. The Committee also aims to include members with specialist business expertise and can also call on the services of a wide range of voluntary Professional Advisers for guidance. In addition to the voluntary Executive Committee ASCS also has the support of other volunteers who assist in a variety of roles.

The Committee is currently assisted by the following members of staff:

- National Co-ordinator
- Development Officer
- Area Co-ordinator (NHS Greater Glasgow & Clyde)
- Child Health Project Officer (Tayside)
- Dental Project Co-ordinator
- Dental Project Officers (2)

The National Co-ordinator and Development Officer are based in the national office in Edinburgh and other staff members work regionally from a home base.

Staff are accountable to the Executive Committee via the line management structure. Staff receive regular support and supervision and annual appraisals.

ASCS conducts an annual assessment of the risks facing the organisation and develops and implements a risk management plan to reduce or mitigate these risks.

ASCS is accountable to its funders, partners and the public in general and it strives to communicate clearly and transparently through our Annual Review and Accounts and in all other communications.

## **5. Current Position**

### **5.1 Our Client Group**

Action for Sick Children Scotland is unique in that it is the *only* Scottish charity which works for ALL sick children and young people (*irrespective of their illness and*

*condition*), and their families. This includes championing the rights of children and young people and working with vulnerable groups who may have specific needs arising out of a variety of factors which may be related to health conditions, social or other circumstances.

A list of the wide range of groups with whom ASC(S) is involved is in the separate Statistical Appendix.

## 5.2 The Need for the Services

- Children and young people have a right to the highest attainable standards of physical and mental health, access to suitable healthcare, and support in learning to make healthy and safe choices<sup>3</sup>.
- There remain gaps in the full implementation of children and young people's healthcare rights as described in the EACH Charter and underpinned by the UNCRC. ASCS's EACH Child and Young Person's Health Matters campaign has recently focused on the right for all children and young people absent from school due to illness to have equitable and appropriate education provision, regardless of their illness, condition or where they live.
- Children can suffer psychological trauma through illness and /or poor hospital or healthcare experiences. For some the impact can lead to a lifelong aversion to/fear of hospitals/medical treatment. ASCS uses structured play to help children deal with hospital, dental and medical treatment and there is a strong evidence base to support the effectiveness of structured play in allowing the child to come to terms with the threatening experience and alleviate anxiety.
- Most children admitted to hospital are between the ages of 0-8 years. Many children supported by ASCS are in this age group. Children from poor backgrounds are hospitalised more and supporting these children can result in a better outcome for those at risk from health inequalities.
- Centralisation of hospital services means more families travel outside their local areas to tertiary centres for specialist surgery. Increasing numbers of children may therefore be unable to access pre and post admission play opportunities, are treated without support and may suffer as a result.
- What happens to children in their early years, particularly pre birth to 3 years has a huge impact on their future and their outcomes in relation to emotional and physical wellbeing, wealth, educational attainment and employment prospects.
- Early intervention is needed to help children and young people at whatever age a problem arises or is first identified. This may be during the early years but may be later on in their childhood/adolescence.
- There is a clear link between areas of deprivation, unequal access to healthcare and ill health. A child brought up in deprived circumstances is very much more likely to suffer from not just one but several or all of infections, poor nutrition, mental health problems, poor educational attainment, unintentional injuries and substance misuse. They are more likely to experience physical and mental health problems in later life.

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<sup>3</sup> Scottish Government: Wellbeing Wheel: healthy

- The number of children looked after by Local Authorities (July 2011) is at its highest level (16,711) since 1981. Of these 34% were placed at home with parents, 33% were in foster care, 24% were formally in kinship care and 20% in residential accommodation. However experts believe the actual figure in kinship care across Scotland could be nearer 17,000.
- Looked after children have much poorer physical and mental health than their peers and use health services much less. Mental health issues are recognised as both a cause and a potential result of being looked after.
- Children in Scotland, aged 5-10, looked after at home or accommodated are six times more likely to have a mental *disorder* than those living with families in the community (52% compared with 8%). Recent studies show that the majority of looked after children have mental health problems. The Office of National Statistics reported in 2004 that 50% have mental health problems compared to 10-15% in general child population.
- Children and young people in care have often experienced the impact of multiple disadvantage before coming into care. An additional burden is placed on them and their carers if these children and young people also suffer from illness or chronic conditions.
- Supporting parents and carers, including vulnerable families and families caring for looked after children and young people will help their children achieve healthier outcomes.
- A child with a chronic condition can suffer from social isolation; poor preparation and support when moving to adult services; poor mental well-being; poor communication with peers, healthcare and other professionals and poor educational outcomes. These impacts may be compounded if they also live in a socially deprived area.
- Research shows the chronically ill need tools to manage their illness. ASC's Stay Well Lanarkshire self management project provided evidence of positive impact from young participants and their families.
- Children and young people with severe and complex additional support needs are at higher risk from dental disease and therefore dental procedures and surgery because of their conditions.
- During 2010-11 62,542 child patients had teeth extracted. 7573 (12%) had teeth extracted in a hospital dental setting. Tooth extraction remains the largest single reason for children receiving general anaesthesia in hospital, representing 20.7% of elective procedures.
- While children's dental health in Scotland has improved significantly over the last decade, the 2009-10 National Dental Inspection Programme (NDIP) Report of the oral health of 5 year old children in Scotland shows that 36% of children at age 5 had some dental decay. The 2011 NDIP Report on the oral health of Primary 7 children found that 31% of Primary 7 children had some dental decay.
- The 2010 Dental Inspection Programme also reported ongoing inequalities in the oral health of Primary 1 children with only 46.5% of children in the most deprived.

communities having no obvious dental decay compared to 78.7% in the least deprived.

### 5.3 The Demand for the Services

Detailed evidence of the demand for the work of ASCS is contained in the Statistical Appendix to this Strategic Plan.

Mid 2011 statistics show that there were over 1.1 million children and young people aged up to 18 years of age in Scotland, representing (20.9%) of the total population of 5.25 million. The 1.1 million children and young people under 18 years of age fall into the following age groups:

- Children aged <1-5 years: 354,187
- Children aged 6-11 years: 324,851
- Children aged 12-16 years: 294,716
- Young people aged 17-18: 128,487
- All children and young people in Scotland aged <1-18 years: 1,102,241

Although the number of children has fallen over recent decades as a result of a falling birth rate, this trend has reversed in the more recent past with the number of births in 2011 (58,592) higher than the 2002 figures of 51,270. The General Fertility Rate has also risen over this period, from 48.1 live births per 1,000 women in 2002 to 56.4 in 2011.

A summary of the totals in each NHS Board Area are shown below:

#### **Summary Table of Population Age by Area Health Board Area: 2011**

	<b>Population All Ages</b>	<b>Population &lt;1 to 18 + % of total population</b>
<b>ALL AREA BOARDS</b>	5254800	1102241 (21%)
Ayrshire & Arran	366890	76562 (21%)
Borders	113150	23716 (21%)
Dumfries & Galloway	148060	29518 (20%)
Fife	367292	78710 (21%)
Forth Valley	295541	65608 (22%)
Grampian	555280	1116510 (21%)
Greater Glasgow & Clyde	1210254	251328 (21%)
Highland	311960	63805 (20%)
Lanarkshire	563185	126222 (22%)
Lothian	848727	172478 (20%)
Orkney	20160	4118 (20%)
Shetland	22500	5100 (23%)
Tayside	405721	83327 (21%)
Western Isles	26080	5239 (20%)

<http://www.gro-scotland.gov.uk/statistics/theme/population/estimates/mid-year/time-series.html>

### 5.3.1 Hospital Admissions

Of the 1.43 million hospital admissions annually in Scotland (in-patients and day cases) just under 7 % (100,000) are for children aged 14 and under. This is a decrease on previous year (102,000 admissions).

Children may be admitted to an acute hospital for a number of reasons including: specialist diagnostic procedures; emergency treatment following accidents; and routine, complex and life saving surgery.

In children under 14 years of age, emergency admissions are more common than planned admissions (the reverse is true for adults). During 2011-12, the emergency admission rate for children under 14 years was 55,000 (55,402 in 2010-11) while the elective admission rate was 38,000 (39,398 2010-11). This represents 38% of total child admissions.

Children under four years of age have the highest admission rate, largely due to emergency admissions (54,000 in 2011-12 and 54% of total children under 14 admission rate).

In 2011-12 around 34,000 planned procedures/operations were carried out for children under 14 years or age.

### 5.3.2 Support Needs Services

The Support Needs System (SNS) records information about children (and young people) with additional support needs. Its aim is to monitor their progress and ensure they have access to services or support they require.

Currently, eleven NHS Boards use SNS and the numbers of children being assessed as at August 2010 is shown in the table below.

NHS Board	Number of children being assessed in SNS
Argyll & Clyde	3,029
Ayrshire & Arran	1,176
Borders	199
Dumfries and Galloway	----
Fife	----
Forth Valley	139
Grampian	4,434
Lanarkshire	1,795
Lothian	2,776
Shetland	32
Tayside	825
<b>ALL SNS Boards **</b>	<b>14,445</b>

Source: ISD Scotland

\*\* NHS Fife and NHS Dumfries & Galloway have very small numbers of children on SNS. Data for these children, and those registered under more than one NHS Board, are excluded.

### 5.3.3 Dental Services in Scotland

Dental services in Scotland are provided in various settings and include the General Dental Service (High Street dentists), the Community Dental Service and the NHS Hospital Dental Service (secondary care). This secondary care service accepts patients on referral from medical and dental practitioners. Consultants in other areas/specialties, including Emergency Dental Services, also make referrals.

General Dental Service (GDS) constitutes the main provision for family dental services for people in Scotland. The majority undertake a mixture of private and NHS treatment.

Hospital Dental Services (HDS) accept patient referrals from both dental and medical practitioners and from other hospital services. Through the HDS, patients can be treated in either an outpatient clinic, or depending on what treatment they require, can be admitted as either an inpatient or a day case.

HDS activity occurs not only in the two dental hospitals (Glasgow and Dundee), and the one dental institute (Edinburgh), but also in many general hospitals across Scotland. There are no in-patient beds in the dental hospitals/institute and therefore all inpatient activity occurs in the general hospitals.

Community Dental Service mainly targets populations (including children) who are disadvantaged groups and those with special needs, learning difficulties and the elderly in residential care.

They also provide a 'safety net' for those who are unable to access GDS and play a significant part in service delivery in remote areas. Their services are provided across Scotland in fixed or mobile clinics.

Childsmile, the Scottish Government child oral health programme which includes Core, Practice, Nursery, and School strands was introduced in 2006/07. It is designed to improve the oral health of children in Scotland and reduce inequalities in dental health and access to dental services.

86.1% of Scottish children were registered with an NHS GDS dentist as at 31 September 2011. This is an increase from 78.7% at 31st December 2008. Children are defined as those aged under 17.

The 6-12 age group had the highest percentage of population registered (97.9%) with a GDS dentist with 41.9% of the 0-2 age group registering.

Children from the most deprived areas are nearly twice as likely to have already had dental decay at the age of 5 years than children from the least deprived area. (2010 National Dental Inspection Programme)

#### **5.4 Benefits of our Work**

Through the work of ASCS, the rights and needs of sick children, young people and their families are widely protected and promoted.

Children and young people taking part in ASCS projects will benefit through:

- Increased self confidence, self esteem and resilience helping them to deal better with their experiences
- Enhanced social inclusion
- Improved ability to cope with their illness or condition through learning self management skills and greater understanding of living with a long term illness

- Improved communication skills, problem solving and team working skills
- Improved ability to make more informed decisions about how to manage their health conditions and how to access healthcare services
- More positive contact with dental health services with improvements in their long-term oral health
- Reduced anxiety associated with dental and or medical treatment
- Being better able to adapt to home and nursery/school life after hospital discharge or dental treatment
- Age appropriate information and specially designed resources, which by preparing them for medical procedures can reduce stress and anxiety.

Parents and carers will develop increased confidence in:

- Knowing their healthcare rights and responsibilities and their children's healthcare rights at times of illness
- Supporting their child/young person at times of illness
- Supporting their child during transition through childhood, adolescence and into adulthood
- Supporting their child to cope with experiences of hospitalisation, medical or dental treatment
- Their abilities to support the oral health needs of children with additional support needs
- Their abilities as a foster or kinship carer to support the healthcare needs of those in their care
- Making appropriate decisions about how to access and use healthcare services when their child is ill
- Their abilities to communicate with healthcare professionals
- Their improved parenting skills and abilities which will develop the confidence and self esteem needed to raise their children in a safe, secure and healthy environment
- Supporting one another through shared experiences
- Accessing and using specialist teams, general healthcare services, information resources and literature in the community
- Advocating for themselves and their children and being confident to engage directly with healthcare services.

Healthcare Professionals and Statutory agencies will benefit from:

- Greater awareness of the need for improved facilities in hospital for children, young people and their families and of the impact the quality of hospital facilities has on their experience of hospitalisation
- Greater awareness of the needs of children and young people with chronic illness and of the healthcare needs of looked after children and young people and a greater ability to provide a more appropriate service and response.
- Improved communication with children and young people with long term conditions
- Greater awareness of the needs of and improved communication with young and vulnerable parents.

Education Professionals will benefit from:

- Improved understanding of and communication with children and young people with long term conditions
- Improved understanding of the health rights of children and young people
- Greater awareness of oral health needs of children and young people with special needs and a greater ability to contribute to these children's oral health.

## 6. Monitoring and Evaluation

ASCS uses logic modelling as an evaluation tool and monitors and evaluates its work through internal reporting systems and via qualitative and quantitative methods including statistical recording, questionnaires, referrals, case studies and user feedback. Funders are provided with regular progress reports.

All staff submit regular written reports on their work to Executive Committee. In addition the Chairs of the Project Advisory Groups, who are also members of the Executive Committee, report back to Executive Committee.

## 7. Development Context

### 7.1 Key Influences on Development

A PEST analysis has been completed and the details are contained within the Strategic Plan's Statistical Appendix.

The principal political and legislative influences on our future development have been identified. Principal amongst them are:

- The European Association for the Welfare of Children in Hospital (EACH) Charter (1988)
- The Scottish Executive's 'National Framework for Service Change in the NHS in Scotland' (The Kerr Report) (2004), 'Delivering for Health' (2005); 'Delivering a Healthy Future: An Action Framework for Children and Young People's Health in Scotland' (2007)
- The Scottish Government's 'Better Health, Better Care Action Plan' (2007); 'Better Health, Better Care: National Delivery Plan for Children and Young People's Specialist Services in Scotland' (2009); Better Health, Better Care Hospital Services for Young People in Scotland (2009); Improving Health & Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan (2009); The Healthcare Quality Strategy for NHS Scotland (2010); The Scottish Patient Safety Paediatric Programme (2010)
- Early Years and Early Intervention Framework (2008), with its four key themes of: building parenting and family capacity pre and post birth; creating communities that provide a supportive environment for children and families; delivering integrated services that meet the holistic needs of children and families; developing a suitable workforce to support the framework.
- The Scottish Government's 'Looked After Children and Young People We Can And Must Do Better' (2007); These Are Our Bairns: A Guide for Community Planning Partnerships on being a good Corporate Parent: (2008).
- Scottish Government's National Performance Framework – Our Children Have the Best Start in Life and are Ready to Succeed' in particular Scottish Government National Outcome 5
- The Vision of Scotland's Ministers for all Scottish Children,' which outlines its hopes for children and young people to be fully supported as they grow and

develop into successful learners, confident individuals, effective contributors and responsible citizens.

- The Getting It Right for Every Child (GIRFEC) approach which puts the well being of children and young people at its heart and which describes the eight areas of wellbeing in which children and young people need to progress in order to do well now and in the future, namely Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included (SHANARRI).
- Scottish Government 's Children and Young People Bill which sets out a range of proposals to take forward ambitions for children's rights and services
- Royal College of Physicians of Edinburgh (RCPCE): Think Transition: Developing the essential link between paediatric and adult care (2007)
- The National Programme for Government and Single Outcome Agreements. Many of ASCS's priorities and projects are in line with Local Authority activities and priorities
- National Parenting Strategy: Making a positive difference to children and young people through parenting: Scottish Government 2012
- Referendum on Scottish Independence 2014: outcome of the referendum on independence may lead to changes in the Scottish Government's priorities.
- Election in 2015: any change of Government may lead to changes in Ministerial priorities with unpredictable outcomes
- Changes to and re-organisation of the NHS will impact on an NHS Board's ability to engage with ASCS.

The main economic considerations for the period of this Plan are:

- An economy which will continue to face a serious financial squeeze, which will impact on various forms of support for the voluntary sector
- Instability of funding, with statutory and Trust sources coming under pressure
- Concern over move towards formal "contracts" and a system of competitive tendering
- Pressure on resources resulting in moves towards more 'partnership' working.

Social considerations include:

- Scotland is more multi-cultural and therefore needs to be more inclusive
- Children are becoming less physically active
- Developments in the way people communicate (web sites, facebook, blogs / twitter) may encourage social involvement but less personal interaction
- An expectation in economic times of greater reliance on the voluntary sector although the resources may not be there
- Concerns about increasing regulation of the voluntary sector and the heavy burdens of monitoring, assessment and evaluation.

The advances in technology are welcome but the concern is whether ASCS will have the resources and capacity to take advantage of the opportunities they offer.

## **7.2 SWOT Analysis**

A formal SWOT analysis has been carried out and the detailed results contained separately. Actions required will be transferred to planning documents and individual action plans.

## **8. Strategic Development**

### **8.1 Long-term Aims**

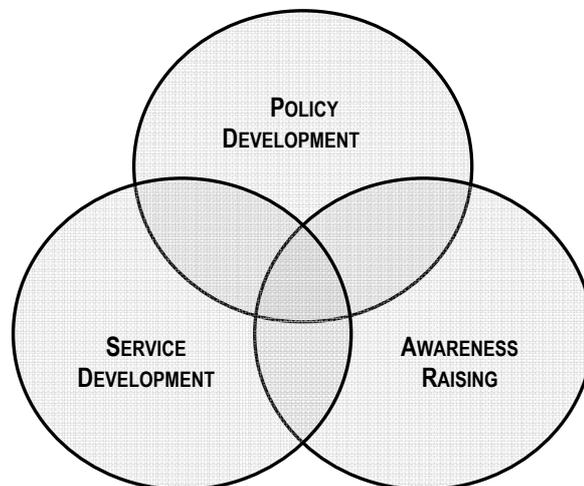
The overarching aims of ASCS are to:

1. Ensure that children, young people and families have appropriate information and equitable access to best quality services at times of illness
2. Promote universal recognition of the needs of and rights of sick children and young people and their families
3. Advise and work with parents/carers and professionals on the needs and rights of sick children and young people in hospital and in the community, specifically to empower parents/carers, children and young people to identify their needs during illness and access appropriate services
4. Ensure the best possible health services are provided for sick children and young people
5. Influence the service specification of health care provision for sick children and young people and their families.

## 8.2 Strategic Aims and Priority Areas for Development

ASCS's strategic aims were reviewed between September and November 2012.

Priority areas for development focus on a number of key areas as follows:



Priority Area for Development	Description
Policy Development	ASCS will undertake work to influence the development of policy at a national and local level in relation to the health of children and young people. A main focus over the next three years will include the review, development and implementation of the EACH Campaign. The results of the 2013 Parental Access and Family Facilities Survey will also influence policy development and awareness raising. ASCS will also engage with and respond to other policy initiatives at a national and local level as appropriate.
Service Development	ASCS will undertake a range of work to develop the quality and standard of services for children and young people across Scotland. This will include piloting the development of new services/practices in response to new and emerging needs, and working to support the mainstreaming of successful service initiatives. Work will also continue to ensure that the health needs of children and young people are listened to and taken account of in the planning and delivery of local services.
Awareness Raising	ASCS will undertake a range of work to raise awareness across Scotland on the needs and rights of children and young people. This will continue to include the provision of information through ASCS web site; newsletter; leaflets; workshops and briefing sessions. ASCS will develop use of social media as a way of raising awareness.

Some activities contribute under more than one heading.

**Strategic Aim 1:** Ensure that children, young people and families have appropriate information and equitable access to best quality services at times of illness

***Priority - Awareness Raising***

ASCS will further develop its marketing strategy and communications plan to include a range of work to raise awareness across Scotland on the needs and rights of children and young people. This will include:

***Campaigning Work***

- Review how far the EACH campaign has moved forward
- Launch in 2013 of Parental Access and Family Facilities Survey findings
- Conference planned for September 2014 which needs to be fully resourced
- Direct contact with opinion leaders and key groups.

***Information and Awareness***

- ASCS web site
- Newsletter and Annual Review
- Leaflets and Materials
- Seminars
- Briefing sessions
- Social Media.

**Strategic Aim 2:** Promote universal recognition of the needs of and rights of sick children and their families

***Priority – Policy Development***

The main policy focus over the next three years will be on the promotion and activity around the EACH Campaign (EACH Child and Young Person's Health Matters). Over the next three years, work will be undertaken to highlight a range of issues including education, children in and leaving care, disability and additional support needs, young mothers and their babies health care needs and play in hospital. Specific activities will include:

- Developing a detailed campaign programme to support the roll out of activity to promote EACH including: agreeing how this work should be taken forward; the priorities for ASCS to be pursued; and an action plan to take this forward
- Organising and hosting a conference in September 2014 for a range of professionals, policy advisors, and local practitioners
- Preparing and circulating promotional material covering key themes.

In addition to the main campaign focus, ASCS will also undertake a range of other work to influence the development of policy at a local and national level. This will include:

- Ongoing representation on a range of policy forums with a view to ensuring that the health needs of children and young people are fully considered
- Responding to consultation activity in relation to key policy areas as appropriate

- Using the findings from the Parental Access and Family Facilities Survey to inform future policy development.

**Strategic Aim 3:** Strengthen the infrastructure of the organisation to support staff and volunteers taking into account quality, efficiency and value for money

***Priority - Development of the National Office***

The National Office will continue to be part of direct support - both to projects and to user groups and the need for further resources will be kept under constant review.

A programme of work will be undertaken by ASCS with the aim of:

maintaining highest standards of governance; reviewing existing policies, procedures; increasing the level of volunteering; developing and implementing fundraising strategy to build on core and project funding from various sources.

**Strategic Aim 4:** Further develop existing and new projects, as exemplars of best practice and as candidates for inclusion in main stream healthcare services

***Priority 1 - Service Development***

ASCS has a track record in developing new and innovative health related services for children and young people across Scotland. A key feature of the work of the organisation is to develop and pilot new approaches in response to local needs. The service development approach of ASCS is based on the following:

- Ongoing programme of information gathering and analysis to identify new and emerging needs, and also to identify example of good practice from elsewhere
- Secure funding to undertake pilot work across Scotland to develop and demonstrate the value and impact of new service activity
- Evaluation of all pilot services and their appraisal in relation to the potential for wider application
- Work with NHS Scotland and Local NHS Boards, or the Scottish Government as appropriate with a view to mainstreaming new service developments as appropriate
- Consideration of providing ongoing training to support professionals in delivering the project.

***Priority 2 - Further Development of Existing Projects***

Over the next three years, existing ASCS projects will have the following objectives:

***Special Smiles Dental Project***

- A two year pilot project to develop a dental play resources for children with additional and complex needs in Tayside was evaluated as successful in 2009 by the Dental Health Services Research Unit at Dundee University
- The project continued in Renfrewshire then Glasgow from Jan 2010 to September 2011
- Scottish Government Early Years Early Action funding via Inspiring Scotland was awarded to enable further work in Glasgow and in South Lanarkshire between October 2011 – March 2013

- We will seek to secure further funding to extend in project into new local authority areas for period April 2013 to March 2015
- We will seek to secure mainstreaming agreement for this activity during 2014 for roll out across Scotland by 2016 and to explore continued involvement eg by providing additional support through delivery of training to professionals
- ASCS will work in partnership with the Childsmile Programme as appropriate.

#### *Self Management Project*

- Stay Well Lanarkshire worked for three years until May 2012 to help young people aged 11–18 years with a chronic condition to self manage
- A self management programme and a toolkit for young people with long term conditions and those working with them was developed.
- The project evaluation provided evidence of the positive impact of teaching self management skills to young people with long term conditions
- We will seek to secure funding to further develop work which will help children and young people to self manage their long term conditions
- The target is to enable professionals working with children aged 8 – 12 years and young people with long term conditions to provide better support to them during and beyond the lifetime of this work.

#### *Children and Young People In and Leaving Care*

- Between 2007 and 2012 the project has looked at the health care needs of looked after and accommodated children and young people and developed a toolkit for professionals working with this group. It piloted a support programme for LAC children and young people to help them manage challenging healthcare situations and developed workshops for foster and kinship carers to help them to look after the health care needs of the children in their care
- The project will continue in 2013-14 to deliver a workshop programme to kinship and foster carers
- The workshop programme will be externally evaluated with the target of achieving formal accreditation
- The target is to have this programme included in the mainstream training provided by foster care providers.

#### *Parental Access and Family Facilities Survey*

- Since 1985 ASCS has conducted regular surveys of all NHS hospitals in Scotland admitting paediatric patients to assess parental access and family facilities
- The findings of the most recent survey conducted in 2012 will inform recommendations on areas which require further attention and will inform how we take forward our EACH Campaign
- An event will be organised in Spring 2013 to launch the findings of the survey
- A plan to promote and disseminate the findings will be developed and implemented.

#### *Tayside Child Health Project*

- Since 2006 work has focussed on supporting vulnerable families and young mothers. A DVD, workshop facilitator notes and information raising awareness of the needs of young parents was developed and disseminated in Tayside during 2010.

- In 2011-12 child health workshops were delivered to parents to help them support their child at times of illness
- ASCS will review the focus of its work in Tayside in 2013 and beyond
- ASCS will review the possibility of continuing the work of this project into other NHS Board areas.

#### *Local Service Planning*

- ASCS is working with Greater Glasgow and Clyde NHS on informing children and young people's health service planning and provision
- Consideration will be given to the opportunity for this work to be increased in Greater Glasgow and Clyde NHS through additional funding
- Consideration will be given to the opportunity to expand this work in other NHS Board areas or to offer new and additional areas of focus – funding would be required to enable this.

### **Priority 3 - Development of New Service Initiatives**

#### *New Service Initiatives*

- Review by ASCS to be undertaken during 2013-14 to identify possible new service development areas taking into account findings of recent Parental Access & Family Facilities Survey
- Potential new projects will be assessed against criteria including: justification in terms of need/demand; opportunity for new service developments drawing on good practice from elsewhere; opportunity to secure funding; potential for mainstreaming any proposed project activity
- Funding submission for new Service Initiatives during 2013.

Potential project areas have been discussed and candidates include the following:

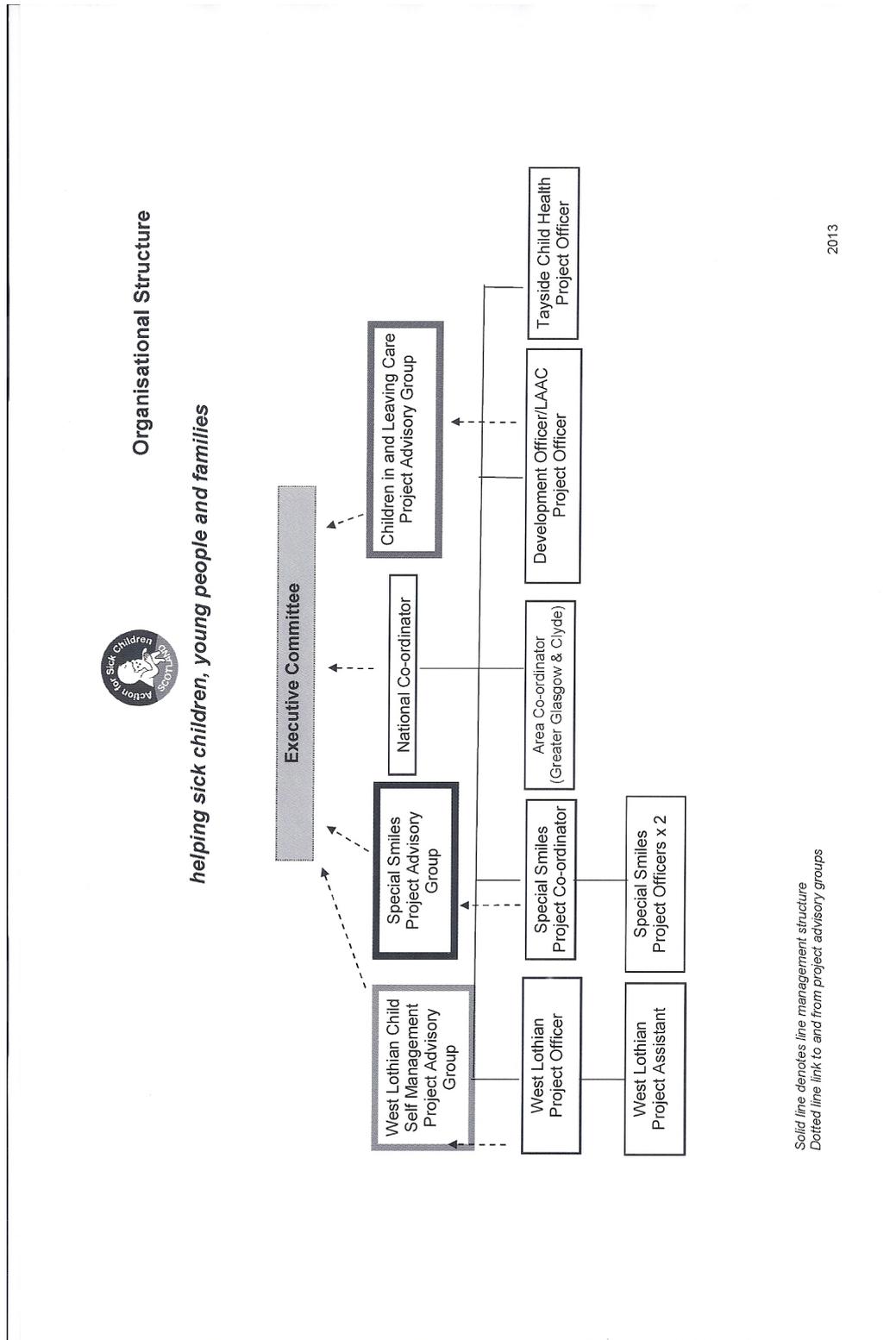
- Project/service development around mental health and wellbeing.
- Provision of facilities and support mechanisms for young people in transition
- Health Play project with parents and pre school children using playboxes
- Pain project.

## 9. Sources of Required Income

Potential funding sources to support the future development of ASCS are outlined below. They all have criteria which are consistent with the aims of ASCS's development priorities.

Source	Description
Charitable Trusts and Foundations	This work is ongoing work and will mainly be around project activity/short term funding. Full cost recovery is built in where possible.
Bequests / Donations	ASCS has had limited success in securing funding through bequests. Consideration should be given to increasing this form of funding Ways of receiving more funding via donations should also be explored.
NHS Scotland/NHS Boards	Limited funding currently secured from NHS. Need to be aware of opportunities from NHS Scotland and Local NHS Boards to fund ASCS activity.
Scottish Government	Ongoing work to secure funding from the Scottish Government which will focus on the impact of the work of ASCS.
Local Authorities/Local Community Planning Partnerships	Opportunity to link the work of ASCS to Local Authorities and Local CPP's. This will include aligning activity to key themes through the National Programme for Government and Single Outcome Agreements.
Private Sector Sponsorship/Philanthropic Funding	ASCS Funding Subgroup is looking at opportunities to develop private sector donations/sponsorship. There would also be value in seeking to secure some philanthropic investment.
The Big Lottery	The opportunity exists for ASCS to develop a major initiative through this source and look to secure 5 year funding programme.
Income Generation	Opportunity to develop income generation for ASCS including sale of play box; training materials; training courses and conferences; etc.

Appendix One: Organisation Chart



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Action for Sick Children (Scotland)  
Strategic Plan 2013 - 2016

Scottish charity No SC006016 and a company limited by guarantee, registered in Scotland.  
Company No. 100114  
Registered office is 22 Laurie Street, Edinburgh, EH6 7AB